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Norlander, Anna

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ANNA NORLANDER
DEPARTMENT OF HEALTH SCIENCES | FACULTY OF MEDICINE | LUND UNIVERSITY

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Anna Norlander

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Background and aim: As an increasing number of people are living and ageing with the consequences of stroke, the rehabilitation and support provided for this group needs to have a long-term perspective. Moreover, to prevent long-term activity limitations and participation restrictions after stroke, increased knowledge is needed regarding how engagement in different types of activities develops beyond the first years of recovery and adaptation. As such engagement is complex and multifaceted it needs to be studied from different perspectives and using well-defined methods of assessment. Thus, the overarching aim of this thesis was to contribute to an improved understanding of how activity and participation develops up to 15 years after stroke and of factors that may influence this process.

Participants and methods: The first two sub-studies of the thesis are based on longitudinal follow-up data from a sample of 145 stroke survivors consecutively included in the Lund Stroke Register during a one-year period and followed up after ten years with high retention rate. The second and third study builds on qualitative data from a sub-sample of the original participants, consisting of ten stroke survivors and four of their familiy members, all interviewed 15 years after stroke.

Methods include an ICF-oriented conceptual analyzis of the Barthel Index (BI) and the modified Frenchay Activities Index (mFAI), and descriptive analysis of activity performance ten years after stroke as assesd by these two instruments. In addition, long-term predictors of the frequency of performing social and lesiure activities ten years after stroke were identified through multiple regression analysis using follow-up data from 16 months after the stroke. Finally, the subjective experiences of social and lesiure participation long-term after stroke were explored using a grounded theory approch, focusing on personal and environmental conditions and individual strategies.

Main results and conclusions: The results show that the BI and the mFAI together cover 69 % of the 'activities and participation' component of the ICF core set for stroke and largely focus on different types of activities. Although most of the ten-year survivors were independent in self-care and basic mobility, performance of other types of activies varied substantially. In total, 23 % were rated as inactive, whereas the majority reported a high or moderate activity level ten years after stroke. The regression analyses resulted in a total of five significant predictors. A wide social network, ability to walk a few hundred meters, and driving a car at 16 months after the stroke was related to a higher frequency of social and leisure activities after ten years, whereas an age >75 years was related to a lower activity. The qualitative findings revealed that personal characteristics, access to activities, social networks, motivation, and perceived capacity are central to engagement in social and leisure activities after stroke. Furthermore, the strategies used to engage in such activities are based on individual goals and contexts, and result from balancing different priorities in life and evaluating costs and rewards of engagement. In conclusion, rehabilitation and support can be needed at different stages after stroke to meet the changing needs of long-term stroke survivors, and should focus on supporting stroke survivors and their families to understand and handle the long-term consequences of stroke in all areas of life, including social and leisure domains.

Key words: Assessment instruments, ICF, Leisure activities, Long-term, Participation, Predictors, Rehabilitation, Social activities, Stroke, Qualitative research
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Anna Norlander

LUND UNIVERSITY

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Persons with disabilities have the right to full and effective participation and inclusion in society, which includes taking part on an equal basis with others in cultural life, recreation, leisure and sport.

Convention on the Rights of Persons with Disabilities
(United Nations, 2006)

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Svensk sammanfattning (Summary in Swedish)

Bakgrund och syfte

Stroke är ett globalt hälsoproblem och den vanligaste orsaken till komplexa och långvariga funktionsnedsättningar bland vuxna. I Sverige drabbas ca 27 000 personer av stroke varje år, varav majoriteten är 75 år eller äldre. Tack vare bättre förebyggande vård och omhändertagande överlever idag de flesta som får en stroke. Många får dock kvarstående funktionsnedsättningar som nedsatt rörelseförmåga och styrka i ena sidan av kroppen, påverkan på tal och sinnesfunktioner, nedsatt balans och uthållighet samt mental trötthet och påverkade kognitiva funktioner (t ex koncentration och minne).

Efter en stroke är det vanligt att man upplever nedsatt förmåga att utföra tidigare vardagsaktiviteter vilket kan innebära att man blir beroende av andras hjälp. Många upplever också begränsad delaktighet i sociala och fritidsrelaterade sammanhang. Eftersom sådana aktiviteter är viktiga för vår hälsa och vårt välbefinnande genom hela livet är det viktigt att de som drabbats av en stroke får den hjälp och det stöd som de behöver för att kunna vara delaktiga.

Det saknas dock kunskap om hur sådana insatser bör vara utformade för att på bästa sätt främja ett aktivt och delaktigt liv på lång sikt efter stroke. Många studier har visat hur livet kan påverkas efter en stroke, men endast ett fåtal har fokuserat på den långsiktiga livssituationen. Det behövs därför kunskap om hur aktivitet och delaktighet utvecklas efter den initiala återhämtningsperioden och i takt med åldrandet, vilka faktorer som påverkar processen, och om vissa grupper löper högre risk än andra att drabbas av långvariga begränsningar.

Avhandlingens övergripande syfte var därför att bidra till en ökad kunskap om hur aktivitet och delaktighet utvecklas på lång sikt efter stroke och vilka faktorer som påverkar processen. Sådan kunskap skulle kunna ligga till grund för utveckling av rehabiliteringsinsatser som minskar risken för långvariga begränsningar i delaktighet efter stroke.

Metoder

Avhandlingen består av fyra delstudier som bygger på varandra. De två första studierna baserades på långtidsuppföljningar av 145 personer med stroke registrerade i Lunds strokeregister. I delstudie ett undersöktes i vilken utsträckning personer som fått stroke för tio år sedan utför olika typer av aktiviteter baserat på information insamlad med mätinstrumenten Barthel Index (BI) och en modifierad version av Frenchay Activities Index (mFAI). I samma studie länkades även de två

mätinstrumenten till det internationellt erkända ramverket ICF[1] för att tydliggöra vilken typ av aktiviteter som de omfattar.

I delstudie två gjordes statistiska sambandsanalyser för att undersöka om utförandet av sociala och fritidsrelaterade aktiviteter tio år efter stroke är kopplat till situationen under det första året, och i sådana fall vilka faktorer som bäst förutsäger det långsiktiga utfallet.

I den tredje och fjärde delstudien intervjuades ett mindre urval av de ursprungliga deltagarna och deras anhöriga för att få en bättre förståelse för deras upplevelser av deltagande i sociala och fritidsrelaterade aktiviteter. Intervjumaterialet analyserades kvalitativt med fokus på hur olika individuella förutsättningar och strategier för att delta i sociala och fritidsrelaterade aktiviteter påverkar delaktigheten bland personer som lever många år med konsekvenserna av en stroke.

Resultat och slutsatser

Resultaten visar att BI och mFAI kompletterar varandra då de innefattar olika typer av aktiviteter. mFAI fångar dock bättre variationer i aktivitetsutförande bland de som fått stroke för många år sedan eftersom instrumentet täcker in ett bredare spektrum av aktiviteter. Inget av instrumenten avslöjar upplevda aktivitetsbegränsningar eller delaktighetsinskränkningar eftersom de endast ger information om hur självständigt eller hur ofta olika aktiviteter utförs.

Tio år efter stroke var de flesta självständiga i aktiviteter relaterade till personlig vård och grundläggande förflyttningar, men variationen var stor gällande hur ofta man utförde mer komplexa aktiviteter. Det fanns också skillnader mellan olika åldersgrupper samt mellan män och kvinnor.

Att ha ett starkt socialt nätverk och att självständigt kunna ta sig omkring i samhället är sannolikt viktiga faktorer för det långsiktiga deltagandet i sociala och fritidsrelaterade aktiviteter efter stroke. Att drabbas av stroke i högre ålder är kopplat till en lägre grad av aktivitet.

Från intervjuerna med personer som levt med konsekvenserna av stroke under 15 år framgår det att tillgång till aktiviteter, social förankring, beroende av andra, motivation och upplevd förmåga utgör viktiga förutsättningar för deltagande i sociala och fritidsrelaterade aktiviteter. Förutsättningarna kan också förändras över tid och med åldrandet. De strategier som används för att kunna delta i olika aktiviteter baseras på individuella mål och livssituationer, och resulterar från avvägning mellan olika krav och prioriteringar i livet.

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[1] Klassifikation av funktionstillstånd, funktionshinder och hälsa.

För att främja delaktighet i sociala och fritidsrelaterade aktiviteter på lång sikt efter stroke kan upprepad rehabilitering och andra stödinsatser behövas i olika skeden. Sådana insatser bör inriktas på att stärka förmågan att hantera de långsiktiga konsekvenserna av stroke. De bör dessutom bygga på en medvetenhet om olika personers individuella mål och strategier, samt riktas både till individerna med stroke och personer i deras närhet.

Eftersom resultaten tyder på att svårigheter att transportera sig och vara social kvarstår många år efter stroke behöver insatser som fokuserar specifikt på sådana aspekter utvecklas och implementeras i samhället. Det är också viktigt att alla som har drabbats av stroke erbjuds möjligheter till rehabilitering utifrån individuella behov, och inte baserat på ålder eller grad av synliga funktionsnedsättningar.

Ytterligare forskning som undersöker större grupper av personer med stroke behövs för att bekräfta resultaten i denna avhandling. Upprepade djupintervjuer över flera års tid med personer som fått stroke skulle dessutom vara värdefulla för att till fullo förstå de anpassningsprocesser som människor som åldras med strokerelaterade funktionshinder går igenom.

List of papers

I.   Norlander A, Jönsson A, Ståhl A, Lindgren A, Iwarsson S. Activity among long-term stroke survivors. A study based on an ICF-oriented analysis of two established ADL and social activity instruments. Disability and Rehabilitation. 2016;38(20):2028-2037.

II.   Norlander A, Carlstedt E, Jönsson A, Lexell EM, Ståhl A, Lindgren A, Iwarsson S. Long-term predictors of social and leisure activity 10 years after stroke. PLoS ONE 2016; 11(2): e0149395.

III.   Norlander A, Iwarsson S, Jönsson A-C, Lindgren A, Månsson Lexell E. Living and ageing with stroke: an exploration of conditions influencing participation in social and leisure activities over 15 years. Brain Injury. 2018;32(7):858-866.

IV.   Norlander A, Iwarsson S, Jönsson A-C, Lindgren A, Månsson Lexell E. Understanding strategies for social and leisure participation long term after stroke. (In manuscript).

Abbreviations

ADL	Activities of daily living
BI	Barthel Index
CT-scanning	Computed Tomography imaging
FAI	Frenchay Activities Index
FAI-CSC	The 'community, social and civic life' sub-domain of the FAI.
GT	Grounded Theory
ICF	International Classification of Functioning, Disability and Health
LSR	Lund Stroke Register
mFAI	Swedish extended and modified Frenchay Activities Index
SL	Social and leisure
SOC	Sense of coherence
SUS	Skåne University Hospital
UN	United Nations
WHO	World Health Organization

Definitions

Activity	The execution of a task or action by an individual [1].
Activity limitations	Difficulties an individual may have in executing activities [1].
Body functions	The physiological functions of body systems [1].
Body structures	Anatomical parts of the body such as organs, limbs and their components [1].
Capacity	An individual's ability to execute a task or an action, indicating the highest probable level of functioning of a person in a given domain at a given moment [1].
Community, social and civic life	Organized social life outside the family, in community, social and civic areas of life [1].
Concept	An abstract idea or mental image which corresponds to some distinct entity or class of entities [2].
Conceptualization	The action or process of forming a concept or idea of something [2].
Disability	An umbrella term for impairments, activity limitations and participation restrictions [1].
Environmental factors	The physical, social and attitudinal environment in which people live and conduct their lives. These are either barriers to or facilitators of the person's functioning [1].
ICF components	Body functions, Body structures, Activities and participation, Environmental factors [1].
ICF domains	First level categories (chapters) within each ICF component [1].
ICF-linking	The identification of concepts within assessment instruments corresponding to the categories of the ICF [3].

Impairment	Problems in body function and structure such as significant deviation or loss [1].
Operationalization	The translation of the theoretical definition of a construct into measurement operations [4].
Participation	Involvement in a life situation [1].
Participation restrictions	Problems an individual may experience in involvement in life situations [1].
Performance	What an individual does in his or her current environment [1].
Personal factors	The particular background of an individual's life and living and features that are not part of a specific health condition [1].
Validity	The extent to which a measurement corresponds to what it is meant to measure [5].
Theoretical sensitivity	Theoretical concepts generated through the analysis comes from the data and are developed in relation to the data [6].
Transferability	The potential for research findings to be transferred to other settings or groups [7].

Preface

This thesis has developed over a period of six years, from early 2013 to 2019. During parts of this period, I have combined research with clinical practice as a physiotherapist at a stroke rehabilitation unit. I have also had one year of parental leave related to the birth of my first child. This has all influenced my perspectives and the course of the research.

When I was first assigned as a PhD student in 2013, I had been working as physiotherapist for a number of years and just received my master's degree in medical science. Even though I had not envision myself doing research, it felt like a natural progression when the opportunity appeared. Furthermore, I was offered to take part in a project that I found both interesting and of great concern for the patients I was working with. The project had an overarching aim, namely, to study different aspects related to the health and life situation among long-term stroke survivors, focusing on activity and participation. As a physiotherapist, I have tried to support my patients in regaining valued activities, but always wondered how their lives turn out in the long term, and whether the rehabilitation provide them with the tools they need. Thus, the research gave me an opportunity to shed light on some of these aspects.

Performing the research within the context of CASE, an interdisciplinary centre for research on ageing and health, provided invaluable experiences and perspectives, as well as support from experienced supervisors and colleagues. It also gave me the opportunity to use previously unpublished data collected by one of my supervisors as part of a comprehensive ten-year follow-up of stroke survivors in the Lund Stroke Register. This data formed the base for Study I and II of the thesis. Based on the first two studies, I saw a need to better understand the individual processes underlying our quantitative findings. Therefore, Study III and IV includes the subjective experiences of people living and ageing with stroke. In all four studies, I took a big part in planning the specific research questions and performing the analyses. For Study III and IV, I also independently performed the data collection.

I hope that the findings presented in this thesis contributes to discussions across disciplines on how to promote activity and participation in a long-term perspective after stroke, and ultimately to an improved life situation for those affected.

Introduction

Setting the scene

Stroke is a global health problem and one of the most common reasons for longstanding and complex disability among adults [8-10]. As an increasing number of people are surviving and ageing with the consequences of a stroke, awareness is growing regarding the need for strategies to reduce the risk of long-term activity limitations and participation restrictions in this group [11]. Activity limitations and participation restrictions are central components of disability, and can be understood as difficulties or problems experienced by an individual in relation to execution of tasks or involvement in life situations [1]. In this thesis, the term participation refers to involvement in defined activities (rather than in life at large). Moreover, it refers to the subjective experience of being part of a situation, whereas the term activity concerns the actual performance of tasks. Even though the profound impact of stroke on activity and participation has been described in many studies [12, 13], most of these focus on the first months and years after stroke, and knowledge is lacking regarding how engagement in different types of activities develops in a longer perspective and with ageing. Consequently, to be able to provide adequate rehabilitation and support for people who have experienced a stroke such knowledge needs to be developed. This thesis aims to contribute with some pieces to the puzzle.

Stroke

A stroke is caused by the interruption of the blood supply to the brain, usually because a blood vessel is blocked by a clot (infarction) or bursts (haemorrhage). This cuts off the supply of oxygen and nutrients, causing damage to the brain tissue. The most common symptom of a stroke is sudden weakness or numbness of the face, arm or leg, most often on one side of the body. Other symptoms include difficulty speaking or understanding speech and loss of balance or coordination. The effects of a stroke depend on which part of the brain is injured and how severely it is affected. A very severe stroke can cause sudden death. Stroke is uncommon in people under 40 years; when it does occur, the main cause is high blood pressure. The major risk factors for stroke are similar to those for coronary heart disease, with

high blood pressure and tobacco use being the most significant modifiable risks [14]. Other typical risk factors are diabetes mellitus, heart disease, and hypercholesterolemia [15].

Annually, approximately 15 million people worldwide experience a stroke. Of these, one third die and another third experience chronic disabilities. In 2013, the number of stroke survivors in the world were estimated to 25.7 million [8]. Although the incidence of stroke is declining in many developed countries, mainly as a result of better control of the major risk factors, the absolute number of strokes continues to increase because of the ageing population [9, 14]. In Sweden, stroke incidence during 2017 was 360 cases per 100 000 people. This means a total of 25 800 persons per year, with the majority (75 %) being 70 years or older [16]. Slightly more men than women sustain strokes, and the mean age is higher among women [17].

Thanks to advances in the acute care and rehabilitation and due to a higher incidence of stroke among young people [18], more people are living and ageing with the consequences of a stroke for a significant part of their lives. Recently, researchers studying epidemiological data from the South London Stroke Register concluded that one in five people live at least 15 years after a stroke. However, poor functional, cognitive and psychological outcomes affect a substantial proportion of these long-term survivors [19].

Common consequences of stroke include long-lasting impairments related to motor and sensory functions, mobility, balance, vision, speech, and cognitive functions [20, 21]. Often such impairments lead to dependence on others in activities of daily living (ADL), mobility limitations within the home and in the community, and participation restrictions [22-24]. "Hidden" impairments such as fatigue, aphasia, impaired memory or emotion regulation difficulties can cause substantial difficulties , not the least in social situations [25-28]. Furthermore, the consequences of stroke can have implications for family roles and responsibilities, as well as social and work roles and leisure activities [29, 30]. Depressive symptoms are commonly reported in the short and long-term perspective [11, 31].Thus, experiencing a stroke can be a life-changing event that affects all areas of life and challenges a persons identity [32-34]. On a societal level, stroke is related to substantial cost for acute and long-term care, rehabilitation, informal care and income loss [35]. Accordingly, care and rehabilitation that optimizes people's long-term functioning and participation in life after stroke not only benefit individuals, but also communities and national economies [36].

Stroke care and rehabilitation

Stroke care has developed during the last 10–15 years, with more effective examination and treatment methods and improved access to preventive and acute care [37]. In Sweden, most people with acute stroke undergo routine CT-scanning, and the proportion receiving thrombolysis is increasing, leading to improved functional outcomes. Furthermore, a majority (91 %) are treated at specialised stroke units. The median stay at the hospital is eight days. During this time, most patients are assessed by a physiotherapist or occupational therapist, and about one third by a speech therapist. About 75 % of the patients are discharged to their own homes. Almost half of these receive continued rehabilitation in their homes or in the outpatient care system [17]. Recent changes in care pathways, including shorter hospital stays and a reduction in residential care facilities for older people, means that more people who have had strokes are living in their own homes with home help services. There has also been an expansion of home rehabilitation at the expense of hospital-based rehabilitation [37].

Content and goals of rehabilitation

The WHO [36] defines rehabilitation as 'a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment'. Rehabilitations has also been described as an active process of change that involves acquiring the knowledge and skills needed to handle the consequences of a health condition [38]. Accordingly, it can include interventions aimed at regaining or improving body functions, capacity and skills (recovery), as well as support towards finding new ways of being active and/or experience participation despite impairments (adaptation). The latter involves providing education and tools for self-management, suggesting assistive devices or making changes to the individual's environment. Before planning or implementing any interventions, the rehabilitation process includes identification of a person's problems and needs, relating them to modifiable and limiting factors and defining rehabilitation goals. The rehabilitation plan can consist of single or multiple interventions delivered by a team of rehabilitation professionals. Even though rehabilitation typically occurs for a specific period of time, it can be needed at multiple occasions from the acute phase of a health condition and throughout life [39, 40].

Organisation of stroke rehabilitation

Most rehabilitation available to people with stroke is accomplished during the first months after the stroke. Based on current knowledge of critical time points in the biological recovery after stroke, the post stroke phases have been defined as acute (0-7 days), sub-acute (<6 months) and chronic (>6 months) [41]. As most recovery is believed to take place during the initial phases, concentrating rehabilitation interventions to these first months has been assumed most effective. However, awareness is increasing of stroke recovery as a longer process involving adaptation and psychological processes that extend beyond the first months or years [42]. Consequently, the need for a long-term perspective on stroke rehabilitation has been highlighted [11, 43]. Despite this, the Stroke Alliance for Europe recently reported that only 2 in 5 EU member countries' guidelines recommend (or it is usual practice) that patients are offered follow-up reviews, and called for national systems to ensure that stroke survivors' needs for ongoing long-term support are reviewed and followed up [44].

A study based on data from the Swedish National Stroke Register [45] shows that perceived unmet rehabilitation needs are common one year after stroke, and associated with dependency in activities of daily living. Last year, results of the first national 5-year follow-up of stroke survivors in Sweden were published [46]. These revealed that almost one third of the respondents perceived unmet rehabilitation needs 5 years after stroke, whereas little over half reported not being in need of rehabilitation. More than half experienced persisting impairments (e.g. balance, memory and communication), and only one third had fully resumed their pre-stroke activities. Thus, changes in the organisation and provision of rehabilitation may be needed to meet the needs of long-term stroke survivors.

Living and ageing with stroke

To understand what it means to live with stroke, several interview-studies with individuals who have experienced a stroke have been performed. A meta-synthesis (Salter 2008) showed that participants shared similar experiences in relation to five interacting themes: 'Change, transition and transformation', 'Loss', 'Uncertainty', 'Social isolation', and 'Adaptation and reconciliation'. The narratives of those affected portray stroke as an overwhelming disruption of life that requires re-interpretation of the self in relation to changed abilities and roles, and uncertainty concerning one's abilities and the future. Furthermore, as time passes, gradual and iterative processes of adaptation and reconciliation may take place.

Although this meta analysis includes studies performed at varying time points post stroke, none of these explicitly focuses on the experiences of long-term survivors.

However, since its publication, a few additional studies have emerged that explore the process of recovery and adaptation beyond the first years after stroke [42, 47, 48]. These all describe similar experiences of initial loss and disruption of the former self, but also struggles to reclaim activities and identity, and finding meaning through a new and changed life. Although the experience of stroke is individual and linked to each individual's reality and life situation [49], re-engagement in activities appears central to finding meaning and establishing a positive identity in the long-term perspective.

Activity and participation long-term after stroke

At the start of this research project, the few existing long-term studies [11, 50] highlighted the importance of meaningful activities for subjective well-being up to ten years after stroke, as well as the need for strategies to reduce the risk of long-term activity limitations among stroke survivors. In addition, long-term studies including outcomes of activity and participation were listed among the top ten priorities for stroke research [51]. Based on the results of more recent research [42], these needs remain.

Existing studies indicate that participation in daily and social activities increase during the first 12 months after a stroke, and then remain relatively stable [11, 23, 52], although at a lower level than pre-stroke [53]. How activity and participation develops in a longer perspective and what determines engagement in different types of activities long-term after stroke is not fully understood.

Social and leisure engagement

One of the principles of the UN 'Convention on the Rights of Persons with Disabilities' [54] is that people with disabilities have the right to full and effective participation and inclusion in society, which includes taking part on an equal basis with others in cultural life, recreation, leisure and sport. However, many stroke survivors report experiences of social isolation and reduced participation in community and leisure activities [13, 55], even among those with mild stroke [56]. Moreover, the few studies that have looked beyond the first year after stroke indicate that restrictions in social and leisure activities seem to persist over time [23, 29].

Those who manage to remain socially connected after the stroke report less depressive symptoms and higher subjective well-being [13, 55, 57, 58]. Engagement in social and leisure activities has also been related to improved functional recovery and survival after stroke [59, 60]. It is often assumed that recovery, in terms of restored or improved physical and mental functions, enables activity and participation. However, findings also indicate that engagement in meaningful activities could have a positive impact on function [61]. A plausible explanation is

that engagement in activities provide meaningful tasks that help maintain motor and cognitive functions and create incentives for physical activity and community integration [50]. Thus, an improved understanding of factors that promote or hinder social and leisure engagement after stroke are important to reduce the risks of long-term participation restrictions.

Factors positively related to engagement in social and leisure activities after stroke include walking ability, exercise, access to health services and rehabilitation, having a meaningful social position, and having social supportive networks [13, 62-66]. Depression, higher age, various stroke related impairments, and transportation difficulties are negatively related [22, 62, 67-72]. In addition, previous research indicates the central role of the individuals' attitudes and actions in the adaptation process towards reclaiming and finding new meaningful activities [13, 55], as well as the importance of appropriate coping strategies throughout the long-term recovery trajectory [48]. Hence, social and leisure participation after stroke appears as a dynamic, complex and individual process affected by several interacting factors related to the person as well as the environment. However, as most of the reported research focus on the first months and years after stroke, the possible long-term influence of these factors are not known. In addition, existing studies are often limited to patients treated at specific rehabilitation clinics or hospitals, or to people with particular characteristics (e.g. aphasia or working age). Consequently, there is a lack of knowledge on how activity engagement develops as people age with the consequences of stroke.

Ageing with disability

Considering the limited time perspective in most stroke studies, ageing research contributes with knowledge on how activity and participation develops as people age. With increasing age the type of activities engaged in may change [73]. Furthermore, engagement in leisure activities has been found to decrease with higher age [74]. A study comparing participation among people with stroke to a non-stroke control group [75] suggests that a part of the reduction in participation in daily activities and social roles after stroke is attributable to "normal" ageing and not entirely to the stroke itself. However, the overall lower participation reported among stroke survivors compared to age matched healthy people [22, 75] indicate that this group face greater challenges or have lower abilities to overcome them. There are also studies indicating that people who are ageing with a disability may experience accelerated physical and cognitive decline [76] as well as increased restrictions in community participation [77]. Considering the importance of community, social and leisure participation for health and well-being that has been demonstrated among people with other chronic conditions [78] and among older

people in general [79, 80], activity limitations and participation restrictions may pose serious threats to the health of people ageing with stroke.

According to the 'activity theory of ageing' [81] engagement in activities, especially those involving interpersonal interactions, benefits well-being among older people by strengthening social roles and identity. Accordingly, change and disruption of roles and activities can have a negative impact on identity and well-being. However, despite the empirical support for this theory [82, 83] it has also been criticised for being simplistic and not considering factors such as a person's previous lifestyle and personality. In contrast, the 'continuity theory of ageing' [84, 85] rather focuses on the endeavours of people to maintain earlier activity patterns through various adaptations. Changes in activities due to illness or disability does not necessarily mean perceived participation restrictions or poor well-being if a sense of coherence and meaningfulness is established [86]. Instead of as high an activity level as possible, the balance between the desired situation and the actual situation and between demands and capacity may be central. In addition, expectations of an active lifestyle can contribute to increased stress [87], and it should be considered what properties and qualities of activity are of most importance. For example, findings indicate that for social activities to have a positive effect on health they need to involve positive relationships and perceived support [88].

Defining and assessing activity and participation

The research much needed to reduce the knowledge-gaps concerning long-term activity and participation after stroke is challenging to undertake. Not the least because of inconsistent definitions of activity and participation and poor conceptualisation of the content of assessment instruments. That is, the terms activity and participation are often used interchangeably and their definitions varies between studies [89]. With regards to engagement in social and leisure activities, several overlapping terms can be found in the literature and agreed definitions are lacking [90, 91]. Depending on how constructs are defined, there are also different approaches to measuring them. In stroke research, common assessment instruments target different types of activities as well as quantify the outcome in different ways (e.g. frequency, independence, satisfaction) [92-94]. Considering that the benefits of activity on health and survival may differ in relation to the type of activity [81] and with regards to gender and age [74, 80] it is important that results are presented with sufficient detail. However, results are commonly reported in terms of total scores even though this may not be adequate for multidimensional scales (i.e., scales that includes different types of activities and reflect more than one underlying construct) [95].

Two examples of assessment instruments commonly used to assess activity after stroke are the Barthel Index (BI) [96] and the Frenchay Activities Index (FAI) [97]. Both instruments targets performance of a set of different types of activities. There have been previous attempts to group the items of the FAI using factor analysis, though no consensus exists regarding the number or composition of its domains [98]. The BI has on the other hand been regarded as a one-dimensional scale [99] even though the variety of its items suggests that it targets not only different activities but also body functions. The validity and interpretation of research findings are also challenged by the fact that the same instrument are used to assess widely different constructs. For example, the FAI has been used to assess 'social activity' [23, 58, 100], as well as 'functional status' [101], 'instrumental ADL' [43] and 'participation' [102], indicating issues with the definition and operationalization of its underlying constructs.

Hence, to enable comparisons and interpretation of research findings it is essential that the content of assessment instruments is clearly defined and that a common language is used. For this purpose, linking assessment instruments to the International Classification of Functioning, Disability and Health (ICF) has proved useful [103].

International Classification of Functioning, Disability and Health

The ICF [1] is the most widespread and internationally accepted conceptual framework used to describe the consequences of different health conditions on activity and participation. It was launched in 2001 by the WHO and provides a standard language for the definition and measurement of functioning, disability and health. In the ICF, functioning is used as an umbrella term for body functions, body structures, activities and participation. The functioning of an individual is thought of as an interaction between the health condition and the context (environmental and personal factors). The ICF recognises that there is a complex and dynamic relationship among these entities and that interactions work in both directions (Figure 1). Activity is defined as "the execution of a task or action by an individual" and participation as "involvement in a life situation". Difficulties or problems that an individual may experience in executing activities or being involved in life situations are consequently termed 'activity limitations' and 'participation restrictions'. In combination with impairments (of body functions and structures), this constitutes the construct disability.
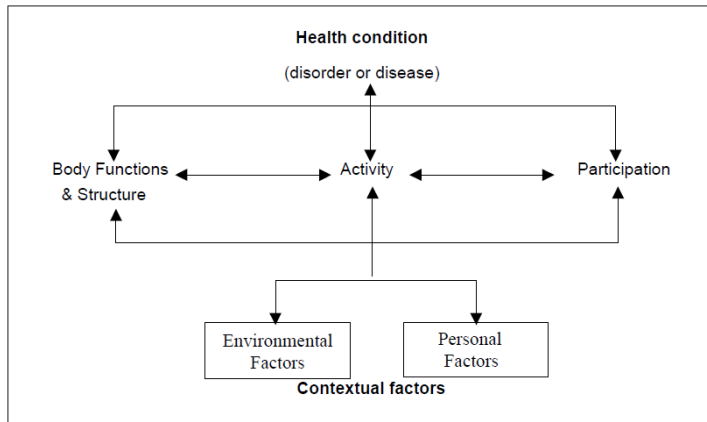
Figure 1
The model representing the conceptual framework of the International Classification of Functioning, Disability and Health (ICF)

The classification structure of the ICF is built on four main components; 'body functions', 'body structures', 'activities and participation', and 'environmental factors' (personal factors are not classified). Each of the four components comprises a number of health-related domains, organised into categories with four levels of detail. The 'activities and participation'-component consists of nine domains representing tasks or actions within different life areas; 'learning and applying knowledge', 'general tasks and demands', 'communication', 'mobility', 'self-care', 'domestic life', 'interpersonal interactions and relationships', 'major life areas', and 'community, social and civic life'. The same domains can be used to denote activities, participation, or both.

ICF core set for stroke
Even though the ICF conceptualises functioning and disability in the context of health and health-related states it is "aetiology-neutral", meaning that classifications are not dependent on specific diagnoses. However, a specific core set for stroke has been developed intended to reflect stroke-relevant aspects of functioning and disability [104]. It has been validated for stroke survivors of various ages and in different phases after stroke [105, 106] and is recommended for use in assessments after stroke to ensure that important aspects are addressed [105]. The 'activities and participation'-component of the core set for stroke consists of 51 second level categories representing its nine domains (Table 1). Currently, most of the instruments commonly used to assess activity and participation in stroke trials and clinical practice have not yet been linked to the ICF core set for stroke.

Table 1.
Categories of the 'activities and participation'-component of the ICF core set for stroke.

1. LEARNING AND APPLYING KNOWLEDGE d115 Listening d155 Acquiring skills d160 Focusing attention d166 Reading d170 Writing d172 Calculating d175 Solving problems **2. GENERAL TASKS AND DEMANDS** d210 Undertaking a single task d220 Undertaking multiple tasks d230 Carrying out daily routine d240 Handling stress and other psychological demands **3. COMMUNICATION** d310 Communicating with/receiving spoken messages d315 Communicating with/receiving nonverbal messages d325 Communicating with/receiving written messages d330 Speaking d335 Producing non-verbal messages d345 Writing messages d350 Conversation d360 Using communication devices and techniques **4. MOBILITY** d410 Changing basic body position d415 Maintaining a body position 420 Transferring oneself d430 Lifting and carrying objects d440 Fine hand use d445 Hand and arm use d450 Walking d455 Moving around	d460 Moving around in different locations d465 Moving around using equipment d470 Using transportation d475 Driving **5. SELF-CARE** d510 Washing oneself d520 Caring for body parts d530 Toileting d540 Dressing d550 Eating d570 Looking after one´s health **6. DOMESTIC LIFE** d620 Acquisition of goods and services d630 Preparing meals d640 Doing housework **7. INTERPERSONAL INTERACTIONS AND RELATIONSHIPS** d710 Basic interpersonal interactions d750 Informal social relationships d760 Family relationships d770 Intimate relationships **8. MAJOR LIFE AREAS** d845 Acquiring, keeping and terminating a job d850 Remunerative employment d855 Non-remunerative employment d860 Basic economic transactions d870 Economic self-sufficiency **9. COMMUNITY, SOCIAL AND CIVIC LIFE** d910 Community life d920 Recreation and leisure

A more comprehensive understanding of activity and participation

Since its introduction, the ICF has contributed to a broader view of disability and an increased awareness of, and focus on, the interplay between people's environment and their ability to engage in different activities. The ICF has also been criticized, foremost for the lack of development of personal factors, for poor definition of research strategies to measure the domains of disability, and for unclear distinctions between activity and participation [107, 108]. The blurring of these two constructs might reflect that activity is often considered a prerequisite for participation. In the ICF, it is in fact stated that performance of an activity in a societal context can also be understood as involvement in a life situation (i.e., participation)[1]. Attempts have been made to separate assessment instruments on the activity and participation level [92, 94]. Yet, the distinctions between the constructs and their measurement remains disputed.

By means of assessment instruments such as the FAI, a predefined set of activities are meant to provide a picture of a person's activity performance and lifestyle [97].

Using this type of standardized measures enables comparison between studies and assessment of change over time (e.g. before and after a rehabilitation intervention). The content of such assessment instruments is generally based on existing knowledge of common activities and problems experienced in certain patient groups. However, even though the content is valid on group level it may not apply to each individual. In addition, most instruments builds on a set of actions that a healthy person should be able to, and will, perform in the absence of disability. It is also assumed that some activities are necessary or central to the experience of participation. Hence, performance of those activities are equated with participation. However, it has been stressed that participation is largely a subjective experience that needs to be understood from the perspective of people with disabilities [109].

According to the ICF, disability is a function of physical impairments, activity limitations and participation restrictions. Considering disability as the opposite of ability, it refers to a situation where a person is unable to perform or be involved in an activity, and not to one where a person chooses not to take part in the activity for other reasons. Still, commonly used assessment instruments in stroke research builds on an assumption that not performing or being involved in certain activities or situations is equal to activity limitations or participation restrictions. Furthermore, the assessments might provide information about one or a few aspects of activity performance (e.g., frequency, independence) but does not contribute to an understanding of the underlying mechanisms to why performance differs between individuals.

To explain variations in activity and participation outcomes between individuals or groups of individuals, its association with personal and environmental factors are commonly examined. Whereas cross-sectional studies demonstrate associations between coexisting factors, longitudinal and prospective studies indicate a possible influence on the outcome variable over time. Although such associations do not prove causal relationship, knowledge of factors that are indicative of the long-term outcome can facilitate early identification of those with increased risks of long-term activity limitations or participation restrictions, and can point to areas that deserve further investigation.

Combining quantitative and qualitative research provides a more nuanced and insightful picture of a person's engagement in activities. Qualitative studies are usually grounded in the experiences of those affected and consider the individual as the 'expert' rather than the 'subject'. As qualitative studies may go beyond outcomes predefined by researchers or rehabilitation professionals, they are suitable for initial exploratory research phases or to deepen the understanding of complex phenomena [110]. As the impact of stroke on a person's life is multidimensional, it can likely not be understood from a single perspective or method. This is reflected by the expanded and more patient-centred range of assessment instruments used in

stroke rehabilitation [40, 111]. Furthermore, qualitative studies are increasingly contributing to an improved understanding of what it means to live with stroke [12].

Summing up

It is widely acknowledged that being able to take part in different activities and participate in society is important for our health and well-being throughout life. We also know that activity limitations and participation restrictions are common among people who have experienced a stroke, which consequently poses a risk to their long-term health and well-being. With an increasing number of people living and ageing with the consequences of a stroke, this is an important issue not only for the affected individuals and their families but for society as a whole. However, even though activity and participation are important goals in rehabilitation and the focus of many studies performed during the first years after stroke, not much is known about the long-term trajectory of activity and participation. Therefore, organisation of appropriate rehabilitation and support requires improved knowledge of the long-term situation and needs of people who are living and ageing with stroke. Such knowledge involves a deepened understanding of how activity and participation develops beyond the first years after stroke, of conditions influencing the process, and of strategies used by long-term stroke survivors to participate in different types of activities. This knowledge could potentially be used to identify those at risk for activity limitations and participation restrictions, and to target problem-areas at different stages of recovery and adaptation. As the effect of stroke on activity and participation is complex and profound, it cannot be understood from a single approach or point of view, but requires a combination of research methods, resting on a conceptually clear base.

Aims

The overarching aim of this thesis was to contribute to an improved understanding of how activity and participation develops up to 15 years after stroke and of factors that may influence this process. Such knowledge can aid the development of appropriate rehabilitation and support to reduce the risk of long-term activity limitations and participation restrictions among people living and ageing with the consequences of stroke.

Specific aims

To conceptualise the activity-specific content of two assessment instruments used to assess activity and participation among people who have experienced a stroke.

To describe to what extent stroke survivors perform different types of activities ten years after stroke, with special attention to gender- and age-related variations.

To identify long-term predictors of the frequency of social and leisure activities ten years after stroke.

To deepen the understanding of how individual conditions and strategies influence social and leisure participation up to 15 years after stroke.

Methods

Overall study design

The research reported in this thesis was developed in different steps, resulting in four separate studies where each was designed based on the findings from the preceding study.

The first step consisted of a conceptual analysis of two assessment instruments commonly used to assess activity among stroke survivors. Secondly, performance of different types of activities among ten-year stroke survivors were described based on the results of the conceptual analysis (Study I). The third step involved narrowing in on social and leisure activities and identifying long-term predictors of performance of such activities based on longitudinal data (Study II). Lastly, to enrich the quantitative findings and gain a deeper understanding of conditions (Study III) and individual strategies (Study IV) influencing social and leisure participation long term after stroke, in-depth interviews with those affected by stroke were performed and analysed using qualitative methodology. An overview of the different steps of the research process and the corresponding studies is presented in Figure 2.

The ICF is used as a conceptual framework throughout the thesis to create structure and clarity of content, but the studies go beyond predefined outcomes of activity and participation by incorporating the subjective experiences of people living and ageing with stroke.
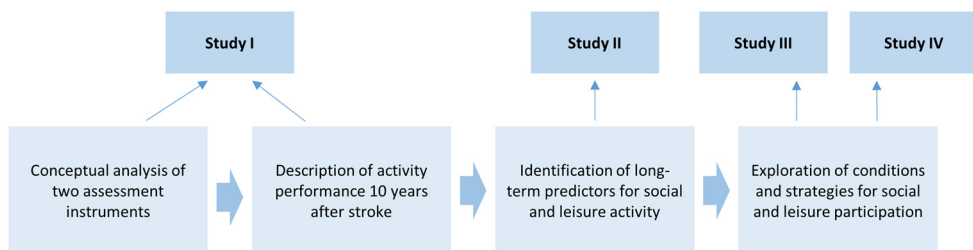
Figure 2
Overview of the research steps and studies included in this thesis.

Project context

Lund Stroke Register

The participants included in this thesis consist of long-term stroke survivors from the very first cohort of the Lund Stroke Register (LSR). The LSR is an ongoing population-based stroke register that started in 2001 with the purpose to include all people with first-ever stroke within the region. The LSR covers the population of eight municipalities with approximately 235,000 inhabitants (as of December 31, 2001) in the south of Sweden, consisting of both urban and rural areas and representing the local catchment area of Skåne University Hospital in Lund. Stroke was defined according to the established WHO criteria [112]. The register includes people with subarachnoid haemorrhage but not with traumatic or iatrogenic stroke. The major source of detection was the daily admission list at the Department of Neurology. The outpatient clinic, other hospital wards and the emergency unit were also screened for patients with stroke. In addition, inquiries were regularly made to residential care facilities in the uptake area. Further details on inclusion criteria and methods used to detect people with stroke, have been described in previous publications [31, 113].

During a one-year period (March 1, 2001 – Febr 28, 2002) a sample of 416 persons with first-ever stroke were registered in the LSR. All survivors who agreed to participate were assessed at baseline and followed up at four months, 16 months and ten years after the stroke incident. The 16-month follow-up included 310 participants (89 participants were deceased, 6 declined inclusion at baseline and 11 had dropped out for different personal reasons, such as severe illness or the death of a spouse. Beyond this point there were no additional dropouts, and all remaining survivors (n = 145) participated in the ten-year follow-up [114]. All follow-ups were performed by the same researcher (a skilled nurse experienced in stroke care) and included comprehensive assessments targeting stroke characteristics, living situation, functional abilities, health and well-being. The ten-year follow-up also included assessment of activity performance using the Barthel Index and a Swedish modified and extended version of the Frenchay Activities Index [115]. The majority of the participants were followed-up at a hospital outpatient clinic, and the remaining at other care facilities, at home visits, or by telephone. If participants had difficulties replying to the questions because of cognitive or communicative problems they were assisted by a relative or caregiver.

Participants

Sampling procedure

Study I and II of this thesis include all the stroke survivors from the first cohort of the LSR who participated in the ten-year follow-up (n=145) described in the preceding section.

Based on the results of these first two studies, a smaller sub-sample (n=10) of the participants were selected for in-depth interviews 15 years after stroke (Studies III & IV). In line with grounded theory methodology [6], data collection and analysis were performed in parallel to determine the need for additional sampling. Initially, 15 potential participants were selected among the remaining survivors (n= 108, as of March 2016). The purposeful sampling strategy [110] aimed for variation regarding age, gender, functional status, living situation and frequency of social and leisure activities, and was based on quantitative data collected at stroke onset and at follow-ups 16 months and ten years after the stroke [31, 114]. When eight participants had consented and been interviewed, two additional participants were recruited to ensure that the study included the perspectives of those with severe disabilities and a wider age span. In addition, four family members (two adult children and two spouses) were interviewed to further develop the emerging findings. Theoretical saturation [6] was employed to determine the final sample size.
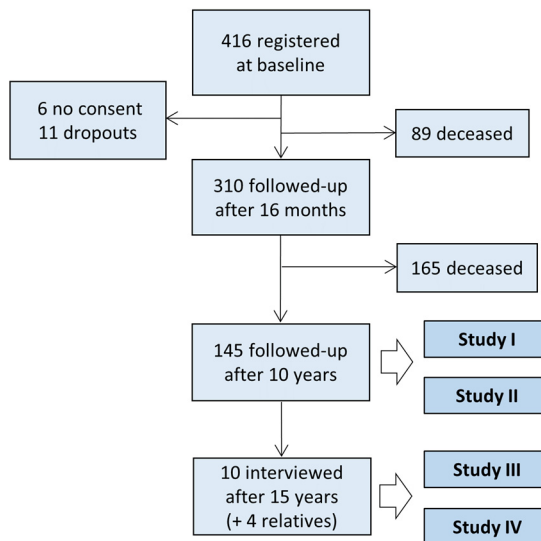
Figure 3
Participant flow chart from inclusion in the Lund Stroke Register to 15 years post stroke

Participant characteristics

The ten-year survivors (n=145) represented a population based sample with high follow-up rate, and consisted of 59 women and 86 men. The median age at stroke onset was 68 years (min-max 17–87). Before the stroke, the majority had been age-retired (59 %) or working (29 %), and lived in ordinary housing without home care (97 %). Most of them (75 %) lived with a spouse or other person, and the remaining (25 %) lived alone. Demographic data for the participants at the ten-year follow-up are outlined in Table 2.

The sub-sample of stroke survivors who were interviewed 15 years after stroke onset (n=10) (Table 3) consisted of five women and five men, with ages ranging from 33 to 88 years (median 76) at the time of the interviews. All but two lived with a spouse, and in ordinary housing (except for one who had moved to a residential care facility). One participant was working full time and the remaining were retired or on sick leave. Two had had a recurrent stroke. Two were dependent on others for personal ADL and used a wheelchair for ambulation, whereas the majority were independent but experienced some mobility limitations outside of the home, especially regarding longer distances. Four participants experienced difficulties in their everyday life related to cognitive impairments and one had verbal communication problems. The four interviewed family members consisted of two adult children and two spouses (related to separate participants).

Table 2.

Demographic data for the participants with stroke at the ten-year follow-up (N=145).

	Men n = 86 (59%)	Women n = 59 (41%)
Median age, yrs (Q₁-Q₃)	78 (69-83)	79 (71-87)
Education level, n (%)		
Low (≤9 yrs)	51 (59)	35 (59)
Medium (10-12 yrs)	13 (15)	14 (24)
High (>12 yrs/university)	22 (26)	10 (17)
Stroke type, n (%)		
Cerebral infarction	74 (86)	52 (88)
Intracerebral hemorrhage	9 (11)	1 (2)
Subarachnoid hemorrhage	3 (3)	5 (8)
Undefined	0 (0)	1 (2)
Stroke severity (NIHSS)		
Mild neurological impairment (0-4)	58 (67)	43 (73)
Moderate impairment (5-14)	24 (28)	12 (20)
Severe impairment (15-24)	4 (5)	3 (5)
Very severe impairment (25-42)	0 (0)	1 (2)
Disability level (mRS), n (%)		
No disability (0-1)	53 (62)	25 (42)
Slight to moderate disability (2-3)	20 (23)	25 (42)
Mod. severe to severe disability (4-5)	13 (15)	9 (15)
Mobility devices, n (%)		
None	55 (64)	26 (44)
Walking device	16 (18)	22 (37)
Walking device and wheelchair	4 (5)	3 (5)
Wheelchair	11 (13)	8 (14)
Cognitive impairment (MMSE ≤ 24)*, n (%)	15 (20)	19 (35)
Housing and care situation, n (%)		
Ordinary housing, no home care	65 (76)	34 (58)
Ordinary housing, with homecare	12 (14)	19 (32)
Special housing	9 (10)	6 (10)
Living alone, n (%)	30 (35)	32 (54)
Occupation, n (%)		
Working	10 (11)	2 (3)
Sick leave	4 (5)	6 (10)
Retired	72 (84)	51 (87)
Comorbidity, n (%)		
Diabetes mellitus diagnosis	23 (27)	10 (17)
Atrial fibrillation	21 (24)	15 (25)
Other heart disease	29 (34)	17 (29)

* 18 missing (13 men, 5 women). Percentage calculated based on participants with complete data.

NHISS: National Institutes of Health Stroke Scale [116].

mRS: Modified Ranking Scale [117].

MMSE: Mini Mental State Examination [118].

Table 3.
Characteristics of the sub-sample of participants interviewed 15 years after stroke (n=10).

Participant no.	1	2	3	4	5	6	7	8	9	10
Education*	Average	Average	Low	High	High	Low	Low	Low	Average	Low
Occupation before stroke	Studying	Working	Sick leave	Working part time	Retired	Retired	Working	Working	Sick leave	Retired
Living situation before stroke	Co-habiting	Co-habiting	Co-habiting	Co-habiting	Co-habiting	Co-habiting	Alone	Co-habiting	Co-habiting	Alone
Stroke severity (acute NIHSS)	Severe	Moderate	Mild	Mild	Mild	Severe	Mild	Mild	Mild	Moderate
Cognitive impairment after 16 months	No	No	No	No	No	Yes	Yes	No	No	No
Self-rated motor impairment after 16 months	Upper extr.	Upper & lower extr.	Upper extr.	No	No	Upper & lower extr.	Upper & lower extr.	No	Upper & lower extr.	Lower extr.
Disability after ten years (MRS, 0-5)	1	2	0	2	0	5	0	4	2	1
Social and leisure activity after ten years (FAI-CSC, 0-9)	5	9	9	8	9	3	3	3	0	8

* Low ≤ 9 years, Average = 10-12 years, High > 12 years/univ.

NIHSS: The National Institutes of Health Stroke Scale. Mild = 0-4, moderate = 5-14, severe = 15-24, very severe = 25-42 [116].

MMSE: Mini Mental State Examination [118].

MRS: Modified Ranking Scale. 0=no symptoms, 1 = no significant disability despite symptoms, 2 = slight disability, 3= moderate disability, 4 = moderately severe disability, 5= severe disability [117].

FAI-CSC: Frenchay Activities Index-Community Social and Civic life domain. Graded 0-9, from never to at least once per week (see Study I).

Note: Age and gender not included in the table to limit identification

Data collection

Activity performance ten years after stroke

Activity performance ten years after stroke was studied using data collected as part of the LSR ten-year follow-up (see 'Project context'). The assessments were made using two standardized assessment instruments, the Barthel Index and a Swedish modified and extended version of the Frenchay Activities Index.

Barthel Index

The Barthel Index (BI) is one of the most commonly used assessment instruments in stroke trials and clinical practice [103, 119]. It was designed to enable quick assessment of dependence level in activities of daily living (ADL), and includes ten items concerning feeding, bathing, grooming, dressing, bowel control, bladder control, toilet use, transfers bed to chair, mobility on level surface and stair climbing. The amount of support an individual needs to perform each activity is rated on weighted ordinal scales ranging from 0-15, with the highest score indicating independence. The instrument has good reliability and validity for stroke populations [119, 120]. Though some slightly modified versions exits, for this thesis the original version with a maximum score of 100 [96] was used (a copy of the instrument can be reviewed in Appendix 1).

Extended and modified Frenchay Activities Index

The Frenchay Activities Index (FAI) has been recommended as a complement to the BI in order to capture a wider range of activities [121, 122]. It is a 15-item questionnaire used to gather self-reported information about performance of daily and social activities within and outside the home [97]. Activity performance during the preceding 3-6 months are rated on ordinal scales ranging from 0 to 3, with the higher grade indicating a more frequent performance. The reliability, validity and sensitivity of the FAI have been established for stroke populations [123, 124]. This instrument has been criticized for not recognizing some common activities of older people [125]. Therefore, a Swedish extended version was developed that includes an additional item related to telephone use and an extension of the mobility items. It has been tested with acceptable reliability [115] and has been used in a previous study involving stroke survivors [126]. At the LSR ten-year follow-up, the 16 items of the extended FAI were used. A minor change to the response options of items 12 and 13 improved conformity by allowing all item scores to be based on frequency of performance. A copy of the extended and modified instrument (hereinafter referred to as mFAI) can be reviewed in Appendix 2.

Long-term predictors of social and leisure activity

A selection of variables, to be analysed as potential long-term predictors of social and leisure activity, were selected from the extensive data collected at the LSR 16-month follow-up. At this follow-up, different aspects of stroke outcome were obtained using well-established assessment instruments as well as study-specific questions. Assessment instruments included the BI, Mini Mental State Examination (MMSE) [118], Geriatric Depression Scale (GDS-20) [127] and the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36) [128]. The study-specific questions covered lifestyle related risk factors, social network resources, satisfaction with stroke services and rehabilitation, stroke related functional disabilities, pain, housing situation, activities of daily living (ADL), indoor and outdoor mobility and general health. A majority of these questions were based on the items included in a Swedish national 2-year follow-up survey of people with stroke [129].

As engagement in social and leisure activities is complex and likely influenced by many different factors over time, it was relevant to include a broad range of independent variables representing different aspects of functioning, disability and health. An initial literature search and repeated discussions within the interdisciplinary research team resulted in a selection of 22 independent variables, covering the four ICF domains 'body functions' (8 variables), 'activities and participation' (6 variables), 'personal factors' (2 variables) and 'environmental factors' (6 variables).

Conditions and strategies for social and leisure participation

Subjective experiences of social and leisure participation over a period of 15 years after a first-ever stroke were explored through in-depth interviews with stroke survivors and some of their family members. The participants were initially contacted by telephone and asked to participate. At this time, all were offered to have someone close with them during the interview. Thus, one participant with communicative difficulties was supported by her spouse, and another opted for his adult son to be present. All interviews were conducted by the author of this thesis in the participants' homes (in one case a residential care facility) and lasted 1-1½ hours. Interviews focused on social and leisure participation, defined as involvement in social or solitary activities engaged in for pleasure, relaxation, or other emotional satisfaction (in contrast to demands or necessities of daily living). A semi-structured interview guide was used to cover central topics related to the aim of the studies but the interviews allowed the participants to speak freely and for additional topics to emerge. The interviewer also individualised the content of each interview based on existing follow-up data.

The family members were interviewed to explore if their perception of the situation differed from that of the person with stroke, and to further understand their supportive role. Accordingly, the separate interview guide constructed for these interviews, focused on the stroke survivors participation in social and leisure activities from the perspective of the family member.

Data analysis

Conceptual analysis of two assessment instruments

The first and necessary step of the research process was to create a conceptually clear base for analysis and presentation of the data collected by means of the BI and the mFAI. To clarify what specific types of activities that were covered by the two assessment instruments, all content of the BI and the mFAI was linked to the categories included in the 'activities and participation' component of the ICF core set for stroke [104]. The linking followed the methodology described in the most recent ICF linking rules [3] and was validated in three steps by the members of the research team. First, two researchers, including the author, independently linked all items of the two instruments to one or several of the 51 'activities and participation' categories of the core set (table 1). This step was followed by discussion, and any disagreements that remained were settled with the aid of a third researcher experienced with instrument development and knowledgeable with the ICF.

After this, the items of the two instruments were grouped into activity-specific domains. The grouping of items was done in accordance with the nine chapters of the 'activities and participation' component of the ICF (i.e., Learning and applying knowledge, General tasks and demands, Communication, Mobility, Self-care, Domestic life, Interpersonal interactions and relationships, Major life areas, Community, social and civic life). The activity-specific domains that were identified within the BI and the mFAI were named using the terminology of the corresponding ICF chapters. Since both instruments contained items linked to 'Mobility', to avoid confusion, these domains were given unique names (BI: 'Basic mobility', mFAI: 'Outdoor mobility'). Any items of the two instruments that did not concern activities and participation were excluded.

Activity performance ten years after stroke

Based on the initial conceptual analysis of the assessment instruments, data concerning performance of activities, as assessed by the BI and the mFAI ten years after stroke, was analysed and presented using descriptive statistics, with special

respect to age and gender differences. Total scores as well as activity-specific domain scores (relating to the nine chapters of the activities and participation component of the ICF) were calculated. Using the principle established for the original FAI [130], total score cut-off levels were used to differentiate between participants who were inactive (total score = 0-16), moderately active (total score = 17-32) or highly active (total score = 33-48). For the BI, the maximum score in each of its domains was considered independence.

Since the data was ordinal, analysis of sub-group differences according to gender and age were performed using non-parametric statistical methods. The Mann-Whitney U test was used to study differences between men and women and the Kruskal-Wallis test to study differences between age groups. To determine where such differences occurred when more than two groups were compared, post-hoc analyses using the Mann–Whitney U test with Bonferroni correction for multiple comparisons were applied. The correction for multiple comparisons involved adjusting the statistical significance level to $p \leq 0.017$ to reduce the risk of type I errors.

Long-term predictors of social and leisure activity

To identify long-term predictors of the frequency of social and leisure activity, selected variables from 16-months after the stroke were included in linear regression analysis with the 'community, social and civic life' sub-domain of the mFAI as the dependent variable. This sub-domain, hereinafter referred to as FAI-CSC, was created as part of the conceptual analysis of the mFAI (Study 1) and consist of three items; 'social outings', 'pursuing active interest in hobby' and 'outings/car rides'.

The independent variables (i.e., potential predictors) were first tested individually for their association with the FAI-CSC, using the Spearman rho correlation analysis for ordinal data and the Kruskal-Wallis test for nominal data. The variables that qualified for further investigation ($p \leq 0.25$) consisted of eight variables related to 'body functions', five related to 'activities and participation', two related to 'personal factors', and five to 'environmental factors'. In order to fit reasonable regression models all independent variables were dichotomized (table 4). One regression model was created for each ICF domain, all with the FAI-CSC as the dependent variable. The models were then reduced manually using a stepwise backward method until only statistically significant ($p < 0.05$) variables remained. Finally, the remaining variables in each of the four separate regression models were included in a combined model, using the same method. This final model was controlled for potential confounders in terms of stroke severity, stroke type, cardiac disease, recurrent stroke and pre-stroke education level.

Table 4
The dichotomized independent variables included in the multiple regression analyses.

Body functions	Activities and participation	Personal factors	Environmental factors
Indication of cognitive impairment (MMSE) 0) No (≥25) 1) Yes (<25) **Indication of depressive mood (GDS-20)** 0) No (≤5) 1) Yes (>5) **Impaired motor function** 0) No impairment, or only upper or lower extremity 1) Impaired function in both upper and lower extremities **Speaking difficulties** 0) No 1) Yes **Anger** 0) Almost never or sometimes 1) Often or constantly **Pain** 0) Almost never or sometimes 1) Often or constantly **Tiredness** 0) Almost never or sometimes 1) Often or constantly **Urinary incontinence** 0) Continent or occasional accident 1) Incontinent	**Driving a car** 0) No 1) Yes **Exercise frequency** 0) ≤ 1/week 1) >1/week **Mobility** 0) Independent indoors and outdoors 1) Dependent outdoors or both indoors/outdoors **Ability to carry out pre-stroke interests** 0) No, hardly or never 1) Yes, as before or almost as before **Ability to walk a few hundred meters** 0) Very or slightly limited 1) Not at all limited	**Age** 0) < 75 years 1) ≥ 75 years **Gender** 0) Women 1) Men	**Living situation** 0) Lives alone 1) Lives with partner or other person(s) **Main occupation** 0) Does not work/study 1) Works/studies fulltime or part time **Rehabilitation/training** 0) Unmet perceived need 1) Perceived need met **Social contact frequency** 0) Less than daily 1) Daily **Extent of social network** 0) 0-3 sources of contact 1) 4-5 sources of contact

MMSE: Mini Mental State Examination [118]. GDS-20: Geriatric Depression Scale [127].

Conditions and strategies for social and leisure participation

The interview material was analysed using a grounded theory approach [6]. The analysis was an iterative process consisting of several steps, including open coding, identification of concepts, development of concepts in terms of their properties and dimensions, development of categories and sub-categories, and integration of categories into a central theme. Constant comparison was used as an analytical tool throughout the process. The narratives told by the participants with stroke comprised the foundation of the analysis, and experiences shared by the family members complemented and enriched the data. The grounded theory methodology aims to create a theoretical framework grounded in the collected data and takes into consideration the context in which something happens, causal conditions, actions (strategies) and consequences [6, 131]. For this thesis, the analysis was divided into

two steps presented in individual papers, the first focusing on conditions for participation in social and leisure activities (Study III) and the other on strategies used by the persons with stroke (Study IV).

The author of this thesis performed all initial coding and created preliminary categories, and after this worked in close co-operation with the supervisors to further develop the analysis. The emerging findings were validated several times through discussions including all co-authors (Studies III & IV) and through input from interdisciplinary research seminars. In addition to the transcribed interviews, field notes and memos were essential for the analysis and important to increase the researchers insights and awareness of self during the analysis. Even though the analysis allowed for interpretation of meaning by the researchers, all emerging concepts and categories were constantly checked against the interview data to be verified, rejected or further developed and refined.

Table 5.
Overview of the aims, participants, main outcome variables and data analysis in the four studies included in this thesis.

Aim	Participants	Time since stroke	Main outcome variables	Data analysis	Study
To conceptualize the activity-specific content of the BI and the mFAI.	Not applicable	Not applicable	The BI and the mFAI	ICF-linking	I
To describe to what extent stroke survivors perform different types of activities ten years after stroke.	145 stroke survivors	10 years	Independence and frequency of activity performance, as assessed by the BI and the mFAI.	Non-parametric descriptive statistics	I
To identify long-term predictors of the frequency of social and leisure activities ten years after stroke.	145 stroke survivors	10 years	Dependent variable: Frequency of social and leisure activity, assessed by means of the FAI-CSC.	Linear regression analysis	II
		16 months	Independent variables: 22 variables covering body functions, activities & participation, environmental factors and personal factors.		
To deepen the understanding of how individual conditions and strategies influence social and leisure participation up to 15 years after stroke.	10 stroke survivors 4 relatives	15 years	Qualitative interviews focusing on participation in social and leisure activity long-term after stroke.	Grounded theory qualitative analysis	III & IV

Ethical considerations

Lund Stroke Register follow-ups

The LSR follow-ups have received ethical approval several times related to different studies. The ten-year follow-up was approved by the Regional Ethical Review Board in Lund in 2011 (no. 2011/278). Written informed consent was obtained from each participant or next of kin before baseline data collection and follow-ups. Participants were given the opportunity to ask questions and for medical concerns to be addressed. There was also a predefined plan for how health-related issues should be addressed if they emerged. In some cases this lead to referral to the primary care and adjustment of medication. To perform the studies included in this thesis, the author received only selected data relevant for the studies. All data was handled confidentially and was securely stored separate from any personal contact information. Results were presented on group level and in a manner that prevented identification of individuals.

In-depth interviews

The in-depth interviews were approved by the Regional Ethical Review Board in Lund in 2016 (no. 2016/179). Before any participants were contacted, medical records were checked to see that they were still alive. The participants were then contacted by phone. This direct form of contact could mean that the participants feel more pressured to accept compared to a request by mail. However, it also enabled the participants to immediately ask questions, and for the researcher to provide additional information. If needed, time were given for consideration.

Several steps were taken to protect the participants' integrity and free will. Verbal and written information was provided well in advance before the interviews. Participants were allowed to ask questions and discuss any matters of uncertainty before giving their written consent. They were also repeatedly informed about their right to refrain from answering any questions or to withdraw from the study at any time. All data was handled confidentially, and results were presented in a way that minimized the risk of identifying individuals. All interviews were, by choice of the participants, performed in the safe and comfortable environment of their own homes. If participants had not chosen to have someone with them during the interviews, as much privacy as possible was ensured during the interview situation. Participants were informed that they could contact the researcher if they wanted to discuss any thoughts or questions evoked by the interviews. They also received contact information to the principle investigators of the research project.

Results

Conceptual content of two assessment instruments

Linking the BI and the mFAI to the ICF demonstrated that the two instruments complement each other and largely target performance of different types of activities. The content of the BI was linked to 14 unique categories within the 'activities and participation' component of the ICF core set for stroke (27 % coverage), all representing the ICF chapters 'Mobility' or 'Self-care'. The content of the mFAI was linked to 26 unique categories (51 % coverage), representing 'Learning and applying knowledge', 'General tasks and demands', 'Communication', 'Mobility', 'Domestic life', 'Major life areas', or 'Community, social and civic life'. With a slight overlap between the BI and the mFAI related to mobility, the two instruments together covered 69 % of the 'activities and participation' component of the core set. Whereas they together fully covered the chapters 'Mobility', 'Domestic life', and 'Community, social and civic life', no links were made to 'Interpersonal interactions and relationships'.

The items of the BI were grouped into two activity-specific domains; Basic mobility (3 items) and Self-care (5 items). Two items, targeting bowel and bladder control, were excluded since they were related to body functions rather than to activities and participation (resulting in a maximum total score of 80 for the remaining eight items). The items of the mFAI were grouped into six activity-specific domains; Learning and applying knowledge (1 item); Communication (1 item); Outdoor mobility (8 items); Domestic life (8 items); Major life areas (1 item); and Community, social and civic life (3 items) (Table 6).

Table 6
BI and mFAI items grouped based on activity type, in accordance with the chapters of ICF Activity and participation.

	ICF chapters						
	Learning and applying knowledge	Communication	Mobility*	Self-care	Domestic life	Major life areas	Community social and civic life
BI items (n=8)[1]			8. Transfers 9. Mobility 10. Stairs	1. Feeding 2. Bathing 3. Grooming 4. Dressing 7. Toilet use			
mFAI items (n=22)[2]	14. Reading books	16. Using the telephone	8 A. Walking outside > 15 min 8 B. Manual wheelchair outside > 15 min 10 A. Driving a car/motorbike 10 B. Going by bus or train 10 C. Going by bicycle or moped 10 D. Powered wheelchair 10 E. Passenger private car/taxi 10 F. Special transport service		1. Preparing main meals 2. Washing up after meals 3. Washing clothes 4. Light housework 5. Heavy housework 6. Local shopping 12. Gardening outside 13. Household maintenance	15. Gainful work	7. Social occasions outside the home 8. Actively pursuing hobby 11. Travel outing/car ride

BI: Barthel Index. mFAI: Swedish extended and modified version of the Frenchay Activities Index. ICF: International Classification of Functioning, Disability and Health.

[1] Two items of the BI were excluded (bowel and bladder function) as they were not linked to ICF Activity and participation.

[2] Includes an additional item (item 16) and an extension of the mobility items (items 8 A-B and 10 A-F) compared to the original FAI, based on Wendel et al. [115].

*As both instruments contained items related to ICF Mobility, the instrument domains were given unique names (BI: Basic mobility, mFAI: Outdoor mobility).

Activity performance ten years after stroke

Ten years after stroke, most of the participants were independent in self-care (72 %) and basic mobility (75 %). More than two thirds (69 %) obtained the maximum score for both domains of the BI. Those 80 years or older had significantly lower scores (i.e., higher dependence) in self-care as well as basic mobility compared to the younger age groups. There were no significant gender differences.

The individual variation was large regarding activity frequency based on the mFAI total score, with scores ranging from 0 to 46 (median = 32). Close to half (48 %) of the participants were classified as highly active, 29 % as moderately active and 23% as inactive. There were no statistically significant differences between men and women regarding overall activity frequency, nor for the activity-specific domains. Individual item scores, however, revealed gender differences for specific activities. For example, women more often prepared main meals, washed clothes and carried out light housework compared to men. Men and women also used different modes of transport. That is, women more often travelled as passengers in private car or taxi, and men more frequently drove cars and rode bicycles. Between age groups, there were significant differences in overall activity level, with inactivity being most common among those ≥80 years. Participants aged ≥80 years reported lower frequencies of activity within the domains 'domestic life', 'community, social and civic life' and 'communication'. Those younger than 65 years more often participated in activities related to 'outdoor mobility' and 'major life areas' (i.e. paid work) compared to the older age groups. Analysis on item level also revealed age related differences regarding mode of transportation. For example, those ≥80 years used special transport services and powered wheelchairs to a greater extent than the younger age groups (table 7).

Hence, several participants reported high levels of overall activity performance ten years after stroke in terms of independence and frequency of a predefined set of activities. Even though the majority were independent in activities related to self-care and basic mobility, the individual variation was considerable for more complex activities. In the 'social, community and civic life'-domain of the mFAI, the reported activity frequencies spanned the entire score range of 0-9 (median = 4.9).

Table 7
BI and mFAI activity-specific domain scores and total scores (median values) for all participants and according to gender and age.

Instrument domains (n items)	Max. score	All N=145	Men n=86	Women n=59	p-value*	< 65 yrs n=20	65-79 yrs n=66	≥ 80 yrs n=59	p-value†
		Md (Q1-Q3)				Md (Q1-Q3)			
The BI									
Basic mobility (3)	40	40 (35-40)	40 (40-40)	40 (35-40)	0.516	40 (40-40)	40 (40-40)	40 (25-40)	<0.001 b,c
Self care (5)	40	40 (35-40)	40 (35-40)	40 (35-40)	0.738	40 (40-40)	40 (40-40)	40 (20-40)	<0.001 b,c
Total score (8)[1]	80	80 (70-80)	80 (74-80)	80 (70-80)	0.554	80 (80-80)	80 (80-80)	75 (45-80)	<0.001 b,c
The mFAI									
Domestic life (8)	24	17 (8-21)	16 (7-20)	19 (11-21)	0.052	18 (14-23)	20 (13-22)	12 (0-19)	<0.001 b,c
Community social and civic life (3)	9	5 (3-7)	6 (3-8)	4 (1-7)	0.052	6 (4-8)	6 (4-8)	4 (1-6)	0.001 b,c
Outdoor mobility (2)[2]	6	6 (3-6)	6 (4-6)	5 (3-6)	0.101	6 (4-6)	6 (5-6)	5 (2-6)	0.006 a,b
Learning and applying knowledge (1)	3	1 (0-2)	1 (0-2)	1 (0-2)	0.871	1 (2-0)	1 (2-0)	0 (2-0)	0.370
Major life areas (1)	3	0 (0-0)	0 (0-0)	0 (0-0)	0.173	2 (0-3)	0 (0-0)	0 (0-0)	<0.001 a,b
Communication (1)	3	3 (2-3)	3 (2-3)	3 (2-3)	0.087	3 (3-3)	3 (2-3)	2 (2-3)	0.018 c
Total score (16)[2]	48	32 (20-38)	31 (19-37)	34 (21-39)	0.345	36 (27-40)	35 (27-39)	23 (8-34)	<0.001 b,c

BI: Barthel Index. mFAI: Swedish extended and modified Frenchay Activities Index. Q1-Q3: First-third quartile.

* The Mann-Whitney U test for differences between two groups (statistical significance: p<0.05).

† The Kruskal-Wallis test for differences between three groups (statistical significance: p<0.05).

[1] Two items of the BI (bowel and bladder function) were excluded as they were not linked to ICF Activity and participation.

[2] The single highest rating within each of the extended items (8 A-B and 10 A-F) was used when calculating the Outdoor mobility domain score and the total mFAI score.

Post-hoc analysis: Letters denote significant difference between age groups using Bonferroni corrected p-value <0.017.

a <65 yrs vs. 65-79 yrs.

b <65 yrs vs. ≥80 yrs.

c 65-79 yrs vs. ≥80 yrs.

Long-term predictors of social and leisure activity

The four separate regression models, one for each of the four ICF components, resulted in a total of five statistically significant predictor variables (one representing body functions, two representing activities and participation, one representing personal factors, and one representing environmental factors) (table 8).

Table 8
ICF-component specific predictors of social and leisure activity frequency ten years after stroke (N=145).

ICF components	Predictors*	B	95% CI	p	R2 (%)
Body functions	Impaired motor function	-2.351	-3.439; -1.263	<0.001	11.4
Activities and participation	Driving a car	1.602	0.724; 2.479	<0.001	27.3
	Ability to walk a few hundred meters	2.295	1.310; 3.280	<0.001	
Personal factors	Age (≥ 75 yrs)	-2.585	-3.556; -1.615	<0.001	16.2
Environmental factors	Extent of social network	2.161	1.251; 3.070	<0.001	13.4

* Independent predictors identified by multiple regression analyses for each ICF-component.

When these variables were combined into a final multiple linear regression model, four variables remained significant. Driving a car, having the ability to walk a few hundred meters, and having a wide social network at 16 months after the stroke were related to a higher frequency of social and leisure activity after ten years, whereas an age ≥ 75 years was related to a lower activity. The final model explained 36.9 % of the variance in the FAI-CSC score (table 9). When tested for potential confounders no significant change was detected.

Table 9
Independent predictors of social and leisure activity frequency ten years after stroke (N=145).
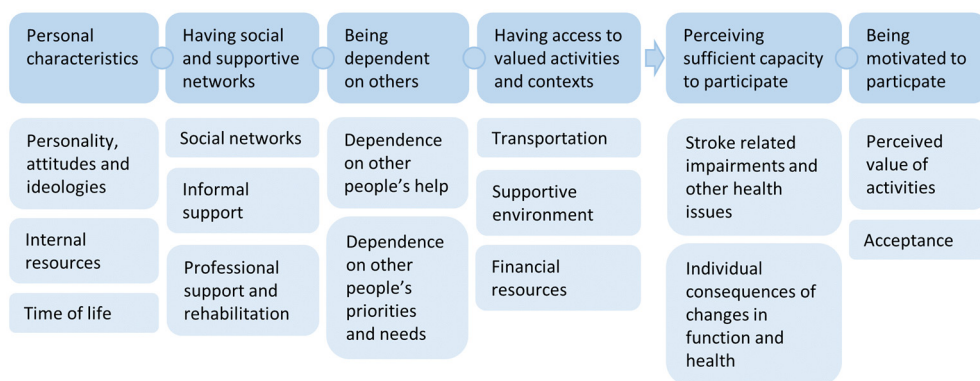
Predictors*	B	95% CI	p
Driving a car	0.999	0.135; 1.863	0.024
Ability to walk a few hundred meters	1.698	0.738; 2.658	0.001
Extent of social network	1.235	0.396; 2.074	0.004
Age (≥75 yrs)	-1.657	-2.576; -0.738	<0.001

*Based on the combined regression model including all four ICF-components. Explanatory power (R^2) = 36.9 %.

Conditions and strategies for social and leisure participation

The interviews revealed that for most participants, experiencing a stroke had meant fundamental changes to their life situation. Over time, the consequences of the stroke had gradually become integrated into their lives. Participation in social and leisure activities varied over time resulting from recovery and adaptation and in relation to the current life situation. Hence, changes in participation were not only related to the stroke but also to ageing and to changing life conditions (e.g. illness, relocation, retirement, family situation, etc.).

The findings of the first part of the qualitative analysis, which focused on conditions for social and leisure participation (Study III), formed the theme: '*A dynamic transaction of personal and contextual conditions changing with time and ageing*', emphasising that the conditions for participation in social and leisure activities were interconnected and changeable. The six main categories of conditions that emerged from the analysis, each with a set of sub-categories representing different dimensions of the conditions, are outlined in Figure 3. Conditions of the same category could promote and/or hinder engagement in social and leisure activities depending on the context. For a full description of all conditions and their influence on social and leisure engagement, see attached Study III.

Personal characteristics	Having social and supportive networks	Being dependent on others	Having access to valued activities and contexts	Perceiving sufficient capacity to participate	Being motivated to particpate
Personality, attitudes and ideologies	Social networks	Dependence on other people's help	Transportation	Stroke related impairments and other health issues	Perceived value of activities
Internal resources	Informal support	Dependence on other people's priorities and needs	Supportive environment		Acceptance
Time of life	Professional support and rehabilitation		Financial resources	Individual consequences of changes in function and health	

Figure 3
Main categories and sub-categories of conditions for participation in social and leisure activities (Study III).

The findings of the subsequent analysis, focusing on individual strategies (Study IV), formed the theme: '*Employing different strategies to promote well-being through prioritizing and balancing costs and rewards of engagement in activities*', showing that the participants' strategies involved balancing engagement in social and leisure activities with other demands and priorities in life. Even though the

participants used different strategies, the analysis revealed a set of common underlying purposes. These purposes formed the main categories outlined in Figure 4. The subcategories represent the strategies used. For a full description of how the different strategies were used, see attached Study IV.

Building identity and meaning through SL engagement	Overcoming difficulties in SL activity performance	Balancing SL engagement with the demands of daily life	Managing risks of negative consequences of SL engagement	Coping with change in SL participation
Choosing SL activities that strengthens identity and meaning	Compensating and adapting activity performance	Prioritizing responsibilities	Avoiding high-risk activities	Accepting change
Avoiding SL activities that are not meaningful or conflicts with self-image	Optimizing capacity	Reducing responsibilities	Taking precautionary measures	Waiting for improvement
	Being persistent			
	Replacing activities			

Figure 4
Strategies for participation in social and leisure (SL) activities long-term after stroke, categorized according to their underlying purposes (study IV).

Synthesizing the findings of both studies (Figure 5), social and leisure participation emerged as an ongoing process determined by the interaction of personal and environmental conditions and individual strategies. The interviews revealed that the strategies were linked to personal goals and contexts and resulted from prioritizing and balancing different goals, evaluating personal and environmental resources and barriers, and weighing expected rewards and costs of engagement in activities. Taken together, this made up the participants' perceived capacity and motivation to engage in social and leisure activities. The process resulted in holding on to activities, giving up activities and finding new ones.

To promote their well-being, the participants prioritized holding on to or finding new social and leisure activities that were perceived as meaningful and strengthened their identity. This could be accomplished through various means of compensation and through adaptation of the activity performance. Furthermore, the participants' strategies involved being persistent and optimizing capacity. Reducing everyday responsibilities, and taking precautionary measures to minimize risks of negative consequences, further enabled social and leisure participation. Reasons for giving up social and leisure activities included that activities were not perceived as meaningful, that other activities and responsibilities were prioritized, that the

expected costs of participation outweighed the rewards, or that the participants did not perceive that they had the required capacity to participate. The participants also gave up activities to avoid negative consequences or to protect their perceived identity and competence.

The outcomes, in terms of participation, depended on the interaction between the employed strategies and the conditions. For example, the decision to move from a villa to a smaller apartment (to reduce the household workload) resulted in improved opportunities to engage in social and leisure activities for one participant, and in the opposite for another. This was related to the different properties of the environments to which they had moved in combination with their personal interest. The outcome of the strategies used could also lead to revaluation of strategies and of perceived capacity or goals. In addition, it could entail changing conditions. For example, engaging in an activity that involved interaction with others, such as joining a choir, could lead to an expanded social network and opportunities for additional activities.

Overall, the interviews confirmed that stroke recovery can be a long-term process with possible need for different kinds of support during different phases of recovery and adaptation. It appeared that not only current conditions, but also the participants' previous life situation and experiences, including support and guidance received in the early phases after the stroke, influenced their long-term engagement in social and leisure activities.
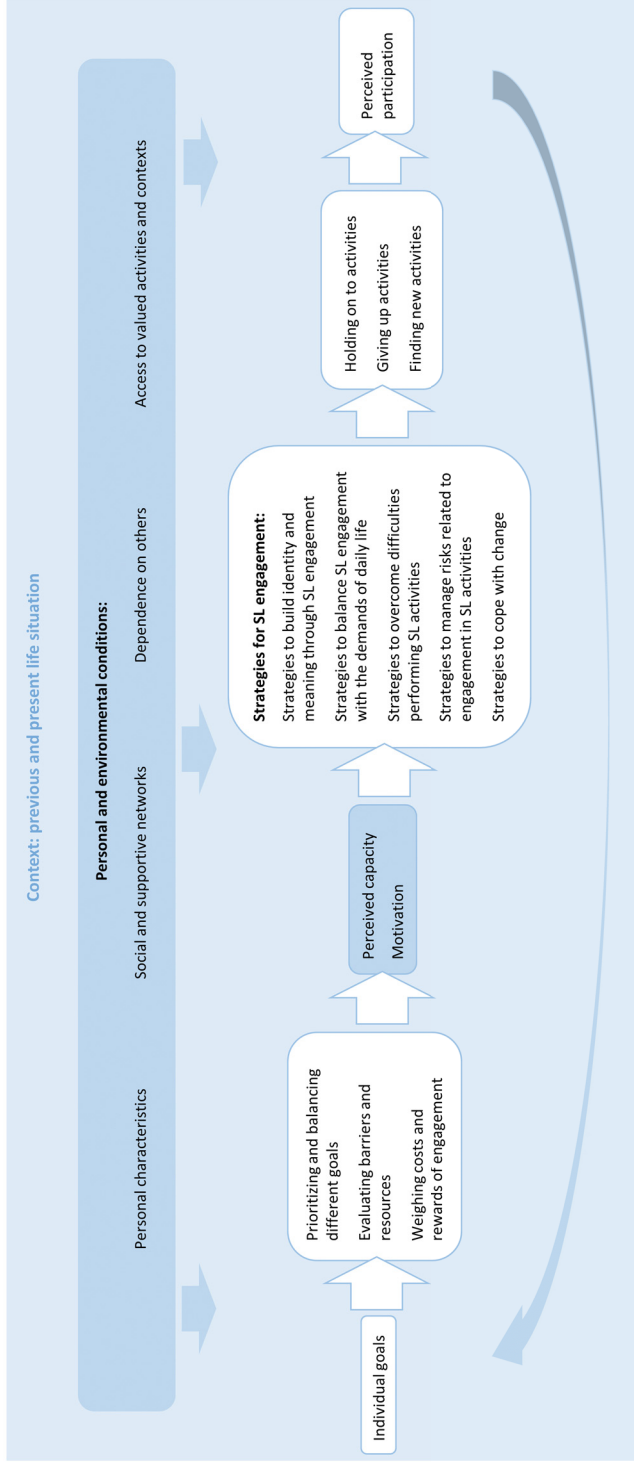
Figure 5
A model illustrating conditions and strategies for participation in social and leisure (SL) activities long-term after stroke as part of an ongoing proces

Discussion

Through quantitative as well as qualitative findings, targeting different aspects of activity and participation up to 15 years after stroke, this thesis contributes to a deepened understanding of activity and participation among long-term stroke survivors. The initial conceptualization of two assessment instruments formed a necessary base for the forthcoming studies of the thesis, and might provide an example for future research. In addition, the variation in activity performance identified between different activity domains highlight the relevance of studying these separately. The findings also shed light on factors of special importance for social and leisure participation that could be targeted in rehabilitation. Furthermore, the qualitative findings contribute to an improved understanding of how people's different living conditions and strategies to engage in social and leisure activities affect their long-term participation. In the following sections, I discuss and interpret the combined results of all four studies in more detail.

What aspects of activity are captured by the BI and the mFAI among long-term stroke survivors?

Based on the results of Study I, assessments using the BI and the mFAI complement each other as they focus on different types of activities. Even though both instruments have a mobility domain, they capture different modes of transportation. However, our results indicate a ceiling effect in assessments using the BI among long-term survivors. As the mFAI covers a broader range of activities within different areas of life, it may be more suitable for activity assessments in this population. Even though the BI and the mFAI together cover a major proportion of the categories included in the 'activities and participation' component of the ICF core set for stroke, none of the instruments were linked to the domain 'interpersonal interactions and relationships'. This is an important area to asses considering that participation restrictions related to changed social roles and relationships seem to persist, and even increase, long-term after stroke, which is also in line with previous research [56].

The BI as well as the mFAI capture 'performance' of activities. As defined in the ICF, performance refers to what a person actually does in his or her current (or usual) environment, and is separated from 'capacity' which refers to what an individual can do under optimal conditions. The gap between these constructs points to how the context (in which the assessment has taken place) affects a person's activity performance. It should be noted that the BI captures the level of dependence and does not consider the effort or time needed to perform the activities. Hence, even though the majority of the ten-year survivors were independent in self-care and basic mobility, performance of such activities might still require a lot of their energy. The qualitative findings indicate that this was in fact the case for some of the participants. Concerning the mFAI, the assessments provide information on the frequency of performing a predefined set of activities, and do not consider why certain activities are not performed or how the respondents experience their performance. That is, a low score may not necessarily indicate activity limitations or participation restrictions. For example, a low frequency of performing activities such as cooking and cleaning might reflect that such chores are managed by someone else in the household, rather than an inability to perform them. As a matter of fact, living with a partner has been related to a lower score on the domestic domain of the FAI [75, 100].

To what extent do stroke survivors take part in different types of activities more than ten years after stroke?

The results of Study I show that people who have experienced a stroke ten years previously can have a high activity performance in daily life. However, considering that one third reported some level of dependence related to basic mobility and self-care, and almost one fourth were rated as inactive based on the mFAI total score, a non-negligible number of people might experience long-term activity limitations. These findings warrant further attention to the perceived possibility of stroke survivors to engage in different types of activities in a long-term perspective, and to factors that determine such engagement.

When Study I was performed, no Swedish population-based long-term follow-up of stroke survivors that included activity assessments had previously been reported. The few European long-term follow-ups that could be considered for comparison [11, 132, 133] all had high loss to follow-up. In addition, different versions of the BI and the FAI were used. More recently, two follow-up studies of stroke survivors in Sweden, performed six years [53] and seven years [43] after stroke was published. Both studies reported high scores for the BI, and similar mean values for the FAI total score. Moreover, seven years after stroke the proportion of highly active

participants was found to be lower within the domain of work/leisure compared to domestic chores. Approximately one third and one fifth of the survivors were lost to follow-up in the respective studies. In addition, the seven-year follow-up was limited to persons with stroke onset before the age of 70 and with no recurrent stroke. Accordingly, keeping the methodological differences between studies in mind, our findings regarding overall activity level are within the range of those of other studies.

The differences found related to age and gender in our sample (Study I) are consistent with those seen among stroke survivors at earlier time points post stroke [95, 125], and in the general population [134]. In a previous follow-up of long-term stroke survivors, inactivity was found to increase with age and was higher among men throughout the study period [11]. In a study of young and middle aged stroke survivors, female gender was independently related to better outcomes for the FAI total score and for domestic chores [43]. A similar trend for women to have higher scores for 'domestic life' whereas men more often performed activities within 'community, social and civic life', was found in our sample but did not reach statistical significance. As previous studies have demonstrated that men and women may benefit from different types of activities, even in terms of survival [80], these variations should be further explored. However, it should be noted that the differences in activity performance between sub-groups cannot with certainty be explained by age or gender as such, but may be secondary to other factors such as socioeconomic, housing or health situation. Moreover, the gender distribution was not the same in the three age groups in Study I, with a higher percentage of women among those ≥ 80 years. Women also had more disabilities and more often lived alone compared to men, which is in line with Swedish national data [17].

The results of Study I, as well as those of other follow-ups [43, 53], imply that long-term stroke survivors are more active compared to stroke survivors assessed one year after stroke onset [95, 125]. A plausible explanation may be that ten years after stroke, the oldest and those with the most severe disability were deceased [114]. More favourable outcomes with longer follow-up intervals have previously been demonstrated, and appear to be mediated by lower age at stroke and better discharge functioning rather than the time since stroke [29]. Considering that previous activity patterns predict activity later in life [53, 74] and are related to long-term health and survival [80, 135], it is possible that a high pre-stroke activity level contributed to the survival of those remaining. Unfortunately, as detailed data on activity performance was not available for this sample prior to the ten-year follow-up it was not possible to explore such explanations empirically. Another explanation is that ten years after stroke, people may have adapted to the consequences of the stroke and developed compensatory strategies that allow them to be active despite functional limitations, as found by Brunborg et al. [50].

In line with other recent studies involving long-term stroke survivors [42, 47, 48] our qualitative findings (Studies III & IV) revealed that most participants had experienced an initial period of disruption during which they had withdrawn from previous activities to some extent. It appeared that during the first years of recovery and adaptation, engagement in social and leisure activities gradually increased. With time and ageing, adaptation could also entail giving up activities. At the time of the interviews, that is 15 years after the first stroke, a few participants perceived their social and leisure participation as unchanged or increased compared to before the stroke, but most described that they were less active. Whereas several were mostly satisfied with their participation in social and leisure activities, others described substantial participation restrictions and dissatisfaction with their situation. These varying experiences, point to the relevance of assessing participation in relation to individual expectations and previous activity levels. Satisfaction with activity performance has previously been found to be an important aspect of subjective participation [136]. Furthermore, Singam et al. [53] reported that although 84% of their sample were active according to the established cut-off for FAI, only 35% had returned to their pre-stroke level.

What determines participation in social and leisure activities long term after stroke?

The first step of this thesis towards understanding what determines the long-term activity levels was to identify factors from the first year after the stroke that were indicative of the ten-year outcome (Study II). Whereas the identified predictors do not prove causality, they point to factors that deserve additional investigation. The qualitative findings (Studies III & IV) were important for an enhanced understanding of the underlying mechanisms. Combining the results of all four studies, social and leisure participation emerge as a dynamic process influenced by contextual conditions as well as individual behaviours. Furthermore, the results highlight that the adaptive processes occurring after stroke are individual and not necessarily linear. However, throughout these long-term processes, some factors appear to be of particular importance for engagement in social and leisure activities.

Access to activities

The fact that two of the predictors identified in Study II represent outdoor mobility ('driving a car', 'ability to walk a few hundred meters') is logical considering that the dependent variable largely consists of out-of-home activities. The qualitative findings helps explain the underlying mechanisms by revealing that difficulties

getting to and from activities was a major barrier for social and leisure participation. Noteworthy, not only the availability, but also the perceived efficiency of different modes of transport appears to be important for the perceived access to activities. For example, unreliability of special transport services or perceived barriers related to use of public transportation could lead to social and leisure activities being given up or replaced with activities within the home or in the nearby surroundings. The complexity of community mobility [137] indicate that interventions targeting mobility needs to consider the multiplicity of real-life situations and settings.

The association between outdoor mobility and social and leisure engagement is in line with other research. Several studies have shown the profound implications of not being able to drive after stroke, including restricted community participation and social isolation [71, 138]. Difficulties using public transportation after stroke has also been described [139]. Walking distance has been found central for activity engagement both within home and in the community [140]. Adding to previous studies, the results of this thesis suggest that mobility limitations experienced initially after the stroke are insufficiently compensated for over time. Considering that among stroke survivors in Sweden, more than one third of those aged 75+ report dependence on others in outdoor mobility one year after stroke [141], community accessibility is an important issue to address to avoid long-term participation restrictions.

The long-term consequences of gender differences in access to out-of-home activities should also be considered. Based on the results of Study I, men and women appeared to travel out of home to the same extent ten years after stroke, but used different modes of transport. Whereas men more often were drivers, women more often travelled as passengers. Accordingly, women might be more dependent on other people for transportation, and thus, more vulnerable to changes in the support provided over time and with ageing. The qualitative interviews revealed that for some of the women, their participation in out-of-home activities had changed after their husbands had stopped driving (because of illness or old age). Men, on the other hand, might be more affected by the long-term consequences of driving cessation after stroke.

Whereas supportive environments allowed participation despite mobility limitations, environmental barriers could lead to giving up activities. To overcome barriers such as long distances to activities, stairs, or lack of parking spaces, participants employed different strategies such as using assistive devices, applying for a special parking permit or moving. Seeing how relocation affected the participants' possibilities to engage in social and leisure activities in both positive and negative ways, it should be considered how the properties of a new housing environment could influence social and leisure participation. This is an important

issue concerning that people are often advised to move to more functional dwellings as they grow older or because of disabilities.

As access to activities was also influenced by the participants' financial situation, another factor to consider is the long-term effects of stroke on people's economy. Our findings are in line with other studies demonstrating that a low income negatively influences return to participation after stroke [142]. As many stroke survivors do not resume any gainful work after their stroke [28, 43], the financial situation is an important issue to address. Depending on the social welfare systems in different countries, changes at policy level may be needed to appropriately support long-term stroke survivors. Furthermore, basic financial guidance could be provided in the clinical setting for those in working age.

Social and supportive networks

Another factor associated with activity performance ten years after stroke, was the participants' reported social network at 16-months (Study II). Out of the three variables representing social support included in our analyses, the size of the network was the only significant predictor. Considering that difficulties maintaining and acquiring new social relationships are commonly experienced after stroke [13, 55], a wide social network may have acted as a buffer against social isolation over time. The results of this thesis show that the vulnerability of social networks after stroke seems to persist and even increase over time and with ageing, leading to reduced opportunities for social activities. The association might also be a reflection of the social activity levels the participants had before their stroke, which is supported by ageing research demonstrating that previous activity levels are indicative of activity later in life [74].

Regardless, ability to hold on to previous social contacts or make new ones seems to be a key factor for strong social networks long-term after stroke. Our findings indicate that contacts with family and relatives are more stable than work-related or friend-based social networks, which was also found by Northcott et al. [143]. Based on the findings of this thesis, having a sense of contributing to the relationship (i.e., reciprocity) helps sustain social as well as spousal relationships over time. This points to the long-term impact of role changes after stroke on social participation. Furthermore, those who successfully made new relationships actively engaged in organisations, neighbourhood communities and leisure activities, which highlights the importance of enabling such engagement, as well the central role of personality.

The qualitative findings shed light on how social networks promote long-term participation by creating incentives and arenas for social and leisure activities, as well as through providing practical and emotional support. The relation between social support and participation was further investigated in a recent systematic

review, including Study II of this thesis [144]. This review concluded that high levels of social support have a positive influence on participation, social and leisure activities, as well as returning to work post-stroke, and that the quality and quantity of social support are important. For several of our participants, the support provided by family members enabled participation in valued activities. Even though most of them only required limited assistance, some experienced participation through another person despite not being able to perform the activity themselves. These findings indicate the importance of not only targeting 'performance' of activities when assessing participation, but also including the subjective experience.

Furthermore, our results indicate that being supported by others might also mean being dependent on others. Being dependent was perceived to limit the frequency and flexibility of social and leisure activities, and meant a vulnerability to any changes in the provided support. To promote independence and well-being, research findings suggests that members of the social network should be encouraged to strengthen autonomy, self-efficacy and a positive identity of the person with stroke [55, 145]. However, despite their central role, families rarely receive any education in how they can promote participation. The possible long-term strain on family caregivers also needs to be considered, seeing how family members of people with stroke report signs of stress and reduced quality of life [31, 146].

Not to forget, social and supportive networks not only consist of friends and family, but can also be formal (e.g., health care and rehabilitation professionals). Our findings indicate that the professional support and guidance received in the early phases after the stroke influenced the participants' attitudes, understanding and actions towards engagement in various activities. It is important that rehabilitation professionals are aware of the potential long-term impact of their interaction with patients. In line with other studies [32, 48], this suggests an empowering approach to post stroke care, facilitating clients to identify and utilise individually appropriate coping strategies to enable long-term participation. Furthermore, our findings highlight the lack of community support targeting social and leisure participation, and call for the development of such services.

Ageing

The findings of all four studies of this thesis indicate that the long-term consequences of a stroke on social and leisure engagement is related to the person's age at the time of the stroke. Other studies [29, 53] point in the same direction by demonstrating more favourable outcomes in social and leisure domains with younger age at stroke onset. An explanation could be that older people generally engage in such activities to a lower extent compared to younger people [74]. Furthermore, some of the interviewed participants (Study IV) expressed being satisfied with lower activity levels at they got older, indicating that people might

change their expectations on activity and participation as they age. However, the lower levels of community and leisure participation demonstrated among people with stroke compared to age-matched healthy persons [75] warrants specific attention.

People with stroke might experience an accelerated ageing and an increased vulnerability to age-related physical and cognitive decline due to lower reserve capacity. That is, elderly stroke survivors might be at increased risk for activity limitations and participation restrictions because of the combined effects of ageing and stroke related impairments. Adding to this, older people with stroke in general have lower access to specialized stroke care compared to younger ones [17]. Older people are also less satisfied with their access to rehabilitation after stroke [45]. Furthermore, our findings (Study III) indicate that with increasing age, social and supportive networks may decrease, limiting access to support as well as to social activities.

The conditions and strategies for social and leisure participation identified in Studies III and IV may not be specific to people with stroke, but can also be understood in the light of theories generated within ageing research. It has been suggested that as physical function declines with age, older individuals turn to activities that are more sedentary, boosting participation in the cognitive/sedentary domain [73]. This is consistent with our finding that a higher age was related to lower frequency of activities within most assessed activity domains, with the exception of the frequency of reading books (Study I). This general process of adaptation that individuals are likely to engage in throughout life is also the focus of the 'selective optimization with compensation' theory [147]. The key concepts of this theory aims to explain strategies used to maintain a higher level of functioning in the face off loss or decline. Selection means focusing attention on fewer, more important goals or rescaling/reconstructing goals. Optimization involves persistence, acquisition of new skills/resources, practice of skills, and investing time and energy into goal-directed means. Compensation maintains a given level of functioning despite impairments through compensatory means such as assistive devices and help from others. Several of these strategies relate to those reported in this thesis (Study IV). The 'selective optimization with compensation' model has also been suggested as a framework to include ageing considerations in stroke rehabilitation [148].

In accordance with theories such as the 'life thread model' [49], 'life course theory' [149] and 'continuity theory of ageing' [84, 85], the impact of stroke should be seen from a life course perspective. This means that a person's background, previous life events, perceived social reality and plans for the future are significant for how the stroke is experienced and how it influences activity and participation. The basic assumptions of these theories are in line with our findings that personal characteristics (including personal history, family values and time of life) are

important conditions for social and leisure participation (Study III). A life course perspective also support that experiences and actions in the early phases after the stroke could influence the long-term trajectory of activity and participation.

Body functions and perceived capacity

An interesting finding of Study III was that even though stroke related impairments and other health issues clearly affected the participants' perceived capacity to engage in activities, the consequences on social and leisure participation were highly individual. To some extent, this could be linked to environmental factors, to different priorities, and to how people handled their difficulties (Studies III and IV). Perceived capacity also seemed to be related to the knowledge and understanding of different stroke symptoms. Taken together, this indicates that objectively assessed impairment level is not the most important factor explaining a person's capacity to engage in social and leisure participation long-term after stroke. The fact that no independent variables representing body functions remained significant in the final regression model of Study II, and that controlling for initial stroke severity did not change the results, corroborates this.

The seemingly low significance of body functions for social and leisure engagement may be characteristic for long-term stroke survivors. As long as 10-15 years after the stroke, most recovery and functional improvements has plateaued. Accordingly, at this stage, activity and participation may be determined by other factors to a greater extent. In addition, it may be that impaired body functions are more indicative of reduced activity performance in other activity domains. For example, Singam et al. [53] found that better recovery was related to higher scores for the outdoor activities domain. It should also be acknowledged that the results might have been different in a sample with a higher proportion of severe strokes, or among younger stroke survivors as demonstrated by Blomgren et al. [43].

Motivation to participate

The finding that engagement in social and leisure activities requires a certain amount of motivation (Study III) corresponds to the generally accepted belief that motivation is central to people's behaviour [150]. Moreover, our findings reveal that a combination of personal and environmental conditions influenced the participants' motivation. Even though motivation could be considered an internal personality trait, our findings are in line with the notion of motivation as a function of personal, social and contextual factors [151]. In addition, the participants' narratives support that lack of motivation can result from not valuing an activity, not feeling competent to do it, or not believing it will yield a desired outcome, as proposed in the 'Self-

determination theory' [152]. Accordingly, how people with stroke perceive their own capacity might influence their motivation to engage in activities.

Figure 5 demonstrate how processes that involve weighing expected costs and rewards influence motivation to engage in social and leisure activities. Similar processes of weighing costs and benefits have previously been described. For example, a cost-benefit model was proposed by Studer et al. [153] in relation to engagement in physical activities. In this model, expected benefits comprise anticipated positive feelings and other gains achieved during or through the activity. The expected costs entails effort, time, unwanted outcomes, and missing out on other activities. It is assumed that motivation to perform a given activity will be high if the expected benefits outweighs the expected costs, but low if benefits and costs are of similar magnitude. Furthermore, costs and benefits are considered specific for the individual and bound to a certain context.

Our findings also reveal that the participants were more motivated to engage in activities that were perceived as meaningful (Study IV). The experience of meaning seemed to stem from the perceived value of the activities, as described in the 'ValMO-model' [154]. According to the ValMO-model, the value is generated in the interaction of the person, the task and the environment, and is composed of three value dimensions; concrete, symbolic and self-reward value. Concrete value may be a product, improved capacities and skills, or avoidance of negative consequences. The symbolic value dimension is characterized by what an activity signifies for a person, for example through strengthening his or her identity. Self-reward value comes from performing activities that are perceived as enjoyable in themselves. Hence, the findings of this thesis link to existing theories and models on motivation, and can be understood in the light of these.

Individual behaviours

Study IV revealed a close connection between strategies and personal characteristics. Personal characteristics emerged as driving forces for social and leisure engagement as well as determinants for the strategies used, not the least with regards to how the participants coped with change. Coping can be defined as specific efforts, both behavioural and psychological, that people employ to master, tolerate, reduce, or minimize stressful events [155]. Whereas behavioural strategies consist of taking action, such as modifying one's own behaviour or seeking support, psychological strategies involve cognitive processes such as accepting the situation [156].

The relevance of coping strategies for social and leisure participation are corroborated by other studies concluding that the ability of the person to accept their stroke-related problems and adapt their behaviour and attitude are central factors to

social participation post stroke [13, 66]. The two types of psychological strategies identified among our participants; 'accepting change' and 'waiting for improvement', can be understood in the light of the findings of Wallenbert and Jonsson [157] who described the inner conflict that can occur about whether or not to develop new daily habits after a stroke. They propose that although adaptation and change of activities would be beneficial for participation, it also represents giving up possible improvements, and a sense of compromising future recovery and independence. This dilemma can lead to a state of waiting to get better or waiting for the situation to change. As a result, few new activities are established.

The long-term coping strategies used by people with stroke can also be related to Antonovsky's [158] theory of sense of coherence (SOC). SOC is defined as "the extent to which one has a pervasive, enduring though dynamic, feeling of confidence that one's environment is predictable and that things will work out as well as can reasonably be expected". It builds on the concepts comprehensibility, manageability and meaningfulness. It is hypothesised that a person with a strong SOC is more likely to believe that he or she can meet demands and will feel less stress and tension. Hence, a person's SOC might influence the strategies used to participate in social and leisure activities, and conversely, the strategies could serve to maintain a sense of coherence in life after stroke. Moreover, SOC might be a mediator between impairments and participation restrictions [159].

Thus, in the light of existing theories, the findings of this thesis contributes to an improved understanding of why, and how, people manage to hold on to social and leisure activities in the long term after experiencing a stroke, as well as what makes them give up activities, and what drives the search for new ones.

Methodological considerations

Epistemological perspective

All research is based on underlying ontological and epistemological views, that is, different perspectives on reality and on the creation of knowledge. Whereas 'objectivism' builds on the existence of a true and objective reality that can be discovered through research, 'relativism' presumes that there is no absolute truth, but rather several different and subjective realities that are all equally true, meaning that everyone creates their own reality. Even though qualitative research commonly builds on the subjective experiences of people, nor the qualitative or the quantitative methods of this thesis can be fully justified as from a strictly relativistic perspective. Nor do they pertain to a truly objectivistic perspective. As I see it, the epistemological perspective forming the base of this thesis is closer to that of social

constructivism [160]. Social constructivism distances itself from the relativistic perspective by recognizing that there is a true reality. This truth can, for example, consist of existing knowledge of a particular disease, or an idea shared by the whole society and therefore taken for granted as an objective truth. At the same time, the meaning of this reality is believed to be socially constructed. As proposed by Andrews [160]: "One can believe that concepts are constructed rather than discovered, yet maintain that they correspond to something real in the world".

The ICF as a conceptual framework

For conceptual consistency, and to promote sound interpretation of findings, I chose to use the ICF as a conceptual framework throughout the whole thesis. Since its launch, the ICF has contributed to an increased awareness of health and disability as multidimensional constructs, as well as of the varying content of assessment instruments. The ICF can also be a valuable tool in the stroke rehabilitation process by providing a common language and a structure for rehabilitation plans shared by team members, patients and their family [161]. This said, there are challenges with using the ICF, not the least regarding the definition and operationalisation of activity and participation. This issue has been addressed by several researchers (e.g., [107, 162]) suggesting that the two concepts might be better evaluated separately.

In the context of this thesis, activity and participation are considered interrelated but separate constructs in accordance with their different definitions in the ICF [1]. It should be clear that the studies included in the thesis only address some aspects of activity and participation, and focus on participation in specific activities rather than participation in a more general sense. Even though the BI as well as the FAI traditionally have been considered measures on the activity level [94], the FAI has also been used as a measure of participation [102]. Aware of this challenge regarding definitions, this thesis rests on the belief that even though performance of an activity implies some degree of participation, the subjective experience of participation is not captured by any of the two instruments. Thus, the results of Studies I and II are described solely in terms of activity.

Incorporating the subjective experiences of people living with stroke (Studies III & IV) enabled an in-depth exploration of participation in social and leisure activities. For the qualitative studies of this thesis, social and leisure participation was defined as involvement in social or solitary activities engaged in for pleasure, relaxation, or other emotional satisfaction. Thus, this definition incorporates aspects of 'community, social and civic life' as well as 'interpersonal interactions and relationships' as defined in the ICF [1].

ICF-based and activity-specific subdomains

Grouping the items of the BI and mFAI into activity-specific domains using the ICF as a conceptual framework is a novel approach as far as I know. At the start of this research project, I searched widely for established sub-domains for the original FAI, but realised that there were none. Previous studies were the items of the FAI have been grouped using factor analysis show different results [98]. Moreover, the content of the domains identified through factor analysis are not conceptually logic. Consequently, a varying number of subdomains (if any) are used in different studies, even in the most recent ones (e.g., [43, 53]), sometimes without specifying which items are included in each domain. Due to this confusion, grouping the items of the mFAI in accordance with the ICF contributed to a conceptually clear foundation for the forthcoming studies of the thesis. The activity specific domains can be used for more fine-tuned descriptions of a person's activity performance within different areas of life. The total score might, on the other hand, be a better representation of a person's overall activity level, although this builds on an assumption that a low activity in one domain can be compensated for by high activity in another. It should be noted that the BI and mFAI sub-domains only reflect some aspects of the corresponding ICF chapters.

ICF-linking

Although the BI and the FAI have previously been linked to the ICF [93, 163], most studies have not applied the ICF core set for stroke. The mFAI has not previously been linked to the ICF. The fact that existing studies, including our own, report similar but not identical results suggest that there may be validation issues in the ICF-linking procedure. Our efforts to ensure the quality of the linking included using the most recent linking rules [3] as well as the competence of a multidisciplinary team of researchers. In addition, the procedure was described in a transparent way (Study I).

Sampling of participants

One-year cohort of the LSR

Whereas follow-ups of people with stroke are often based on patients enrolled at a certain rehabilitation clinic or limited to sub-groups of people with certain characteristics (e.g., aphasia or younger age), a notable strength of Studies I and II is that the sampling was based on a population-based cohort including all people with first ever stroke in a defined area. It also includes people with cognitive and communicative difficulties and those living in residential care, that is, groups often excluded in stroke research. Moreover, the loss to follow-up was remarkably low, contributing to a high representativeness of the cohort. An explanation for the strong

retention of participants could be the great efforts put into localizing and contacting the survivors, as well as the participants' previously established contact with the researcher who performed all follow-ups from baseline to ten years after stroke. In addition, the follow-ups benefited the participants by allowing them to discuss their situation and ask questions and for medical concerns to be addressed. To avoid exclusion of survivors with cognitive or communicative difficulties, proxy respondents were used, which may have influenced the results. Previous studies have demonstrated adequate agreement between patients and proxy respondents in assessment of risk factors as well as activity measures after stroke, and support the use of proxies to reduce sample selection bias [164, 165]. When needed, the presence of spouses or caregivers who knew the participants likely contributed to more accurate reports. Limitations include the relatively small sample, and more long-term studies in different regions and countries are needed to confirm the results.

Interviewed sub-sample of participants

In line with the principles of grounded theory [6], purposeful and theoretical sampling was employed to select a sub-sample of participants for in-depth interviews. Compared to advertising for participants, the purposeful sampling likely benefited variation and reduced selection bias. Rather than using a random sampling procedure, the participants were selected based on variables of relevance for the research question, in order to gain different perspectives and rich data. Among those contacted, only three persons declined. The decision to interview a few relatives was based on remaining gaps in the understanding of the emerging findings. Although interviewing relatives of all the stroke survivors might have yielded additional findings, the perspective of family members was not the main focus of the studies.

Transferability of findings

It should be considered whether the findings of this thesis are transferable to people who experience a stroke today. It is possible that changes in stroke care and rehabilitation, as well as in society, means that people who sustain a stroke today experience their activity and participation differently. The differences in activity performance between men and women identified in Study I might not be valid in the future due to changes in norms and traditional gender roles. This said, our sample of long-term stroke survivors share similar characteristics with current stroke cohorts. A recent epidemiological study were the first one-year cohort of the LSR (year 2001-2002) were compared with the corresponding cohort for 2015-2016 showed no statistically significant differences with regards to gender, age and stroke severity [166]. Comparing the 145 ten-year survivors included in this thesis with all those with first ever stroke registered in the Swedish National Stroke Register during 2017 [17] show similar proportions of men and women, stroke types and average stroke severity (acute NHISS). The lower age as stroke onset in our sample is not

surprising considering that these represent long-term survivors. Lower age at longer follow-up intervals has previously been reported [29]. The similarities could reflect recent trends in stroke incidence, with less severe strokes, lower age at stroke onset and increased life expectancy [9, 18].

With regards to the qualitative findings, these types of explorative studies do not aim to be representative in the same manner as quantitative studies, but rather strive for rich data that contributes to a deeper understanding of the studied phenomenon [6, 167]. Moreover, the analysis procedure aims to abstract the findings, making them more generally applicable. Optimally, that should account for variations that occur over time and across different contexts. Even though our findings are in line with those of other Scandinavian studies [42, 47], additional research performed in different contexts are needed to validate them. Accordingly, the findings presented in this thesis should be interpreted as specific for the context in which the research was performed.

Data collection

LSR follow-up data

All quantitative data used for Study I and II of this thesis was collected as part of the LSR follow-ups before the start of this research project. Some reflexions can be made regarding the mFAI. Using a modified and not widely used version of the FAI, limited the possibility to compare the results with those of other studies. However, as the results show that many of our participants frequently used other modes of transport than those included in the original FAI (driving a car/travel on bus) the extended version might more accurately capture performance of transport-related activities, particularly among women and those ≥ 80 years (Study I). A limitation is that only the highest score for item 8 A-B and 10 A-F (see Appendix 2) were used to calculate the domain score for 'outdoor mobility'. Therefore, it might not adequately reflect the activity performance among those who used more than one mode of transportation. With regards to the added item 'using the telephone', including this seems relevant for the assessed population as this item obtained the highest score of all individual items. Moreover, the ICF-linking demonstrated that this item improved the coverage of the 'activities and participation' component of the ICF core set for stroke by means of links related to communication. It can be mentioned that even though the version of FAI adapted by Wendel et al. [115] includes additional response options regarding frequency changes, cause for change and satisfaction with activity performance, this information was not included in the studies of this thesis due to methodological issues.

FAI-CSC as a measure of social and leisure activity

Study II narrowed in on one particular type of activities, that is, social and leisure activities as assessed by the FAI-CSC. Even though the three items included in this sub-domain are relatively broad, they do not cover the full range of possible social and leisure activities. In particular, social interactions within the home are not included. As the interviews revealed that a strategy used by long-term stroke survivors is to relocate social activities to the home (Study IV), such activities are relevant to assess. Furthermore, several of the participants referred to gardening and reading as meaningful leisure activities. Even though the mFAI comprises two items related to gardening and reading books, these were not linked to 'community, social and civic life' as defined in the ICF, and thus, not included in the FAI-CSC. Acknowledging these limitations, using a specific subdomain as the dependent variable in our analyses, facilitated more meaningful interpretation of the results compared to using the FAI total-score that comprises several different types of activities.

Selection of independent variables

The selection of independent variables to include in the regression analyses was guided by an initial review of existing qualitative and quantitative research findings within the stroke field, as well as the professional experiences of the interdisciplinary team of co-authors, representing physiotherapy (AN), gerontology (SI), nursing (EC, A-CJ), neurology (AL), occupational therapy (EML, SI) and public health (EC). We also made sure to include variables representing all four components of the ICF. In the light of the qualitative findings of this thesis, as well as other recent research indicating that engagement in social and leisure activities is a complex process likely influenced by many different factors over time [13, 66], the inclusion of such a broad range of variables seems relevant. In addition, information on the participants' previous social and leisure activity might have contributed interesting findings.

Richness of the qualitative data

In the qualitative data collection, measures to promote rich data included open interviews guided by semi-structured interview guides. In the initial stages of the research process, pilot interviews were performed to improve and develop the interview guide. Throughout the data collection, the recorded interviews were reviewed by another researcher experienced in qualitative research, and discussed to identify possibilities of improvement. Limitations include the retrospective data collection with potential risk of recall bias. Multiple occasions of data collection over time after stroke would likely have been beneficial to understand the processes of change and adaptation occurring over time, though this was not possible within the context of this thesis. In addition, repeated interviews with the included

participants to follow-up any thoughts that was evoked by the first interviews might have contributed with additional data.

Data analysis

Statistical analyses

To ensure rigor of the analyses, all statistical analyses included in this thesis (Studies I & II) were undertaken in close collaboration with a statistician. Nevertheless, the specific methods chosen, and how the data was treated, naturally influenced the results. For example, the manner in which the independent variables used in regression analyses (Study II) were dichotomized likely contributed to our findings. Several measures were taken to improve reliability of findings, including correcting significance levels for multiple comparisons (Study I). For additional details, see the attached papers.

Qualitative analyses

For the qualitative part of the research, I chose to employ a grounded theory (GT) approach [6]. This method was chosen as it is suitable for analysis of processes and considers people's behaviour in interaction with the context. Furthermore, it encourages parallel data collection and analysis, which enables inclusion of additional participants and development of research questions based on the emerging findings. Advantages of this approach is that it allows the researcher to further develop the understanding of the explored processes. The constant comparative and interpretive method of analysis proposed within GT makes it possible to go beyond purely thematic categorization and also consider the relation between categories. Dividing the analysis into two steps (i.e., Studies III & IV) could be considered an alternative approach. However, the data as a whole, including the context in which something happened, causal conditions, actions/interactions (strategies) and consequences, was kept in mind throughout the analysis. In the final stages, findings were merged to describe the process of engagement in social and leisure activities (Figure 5).

Among the different approaches within GT, I have taken inspiration from that of Charmaz [131]. However, with regards to the structure of the analysis, I employed the method as described by Corbin and Strauss [6]. Charmaz, who have taken a constructivist approach, acknowledges that the researcher constructs the findings through interpreting data in the light of previous knowledge. This differs from the approach described by Glaser [168] who believes that the researcher should free herself from all previous knowledge. Although most GT researchers acknowledge that one to some extent has studied theory and literature before (and during) the analysis, the main part of the literature review should wait until the final stages and

primarily focus on the findings that have emerged from the data [169]. However, while Corbin and Struss express that an "objective" truth exists in the data and that one should avoid letting the literature contaminate the analysis, Charmaz suggests using existing theory to find the most reasonable or most probable explanation that best matches the data.

To strengthen trustworthiness, the qualitative analysis of this thesis strived for sensitivity to what the data told (rather than objectivity). Emerging concepts were constantly checked against the data for confirmation, rejection or development. As described by Ramalho [169], reflexivity is a key element in ensuring the groundedness of findings, meaning that the researcher should be aware of one's own influence in the research process. Therefore, analytic memos, reflexive thinking and discussions within the research team were central to promoting reflexivity as well as theoretical sensitivity [6, 131]. In addition, the members of the research team supported each other in remaining open to new ideas and emerging findings. The representation of different clinical and research backgrounds in the team also contributed to an interdisciplinary and more nuanced understanding of the findings.

Implications for research and practice

Implications for stroke care and rehabilitation

- To promote long-term social and leisure participation after stroke, interventions aimed specifically at supporting engagement in such activities needs to be developed and implemented in the clinical as well as community settings.

- Interventions should target the social anchorage of stroke survivors as well as their access to activities, which includes finding well-functioning and efficient modes of transportation in the community.

- Additional attention may be needed to those who sustain a stroke above the age of 75 years, as elderly stroke survivors might be particularly vulnerable to activity limitations and participation restrictions.

- Considering that even a "mild" stroke can have significant consequences on participation, organisational changes in stroke care is needed to ensure equal access to rehabilitation based on individual needs rather than on age or objectively assessed stroke severity.

- Rehabilitation should have an increased focus on psychosocial factors and on supporting stroke survivors in understanding and dealing with the long-term consequences of stroke.

- Furthermore, successful rehabilitations interventions needs to be based on an awareness of each patient's personal characteristics and individual goals.

- It is also important for rehabilitation professionals to understand the subjective values and meaning attributed to different activities, and to guide people who have experienced a stroke in finding activities that are meaningful to them.

- To be able to adequately capture and address the changing needs of stroke survivors over time and with ageing, and throughout different stages of recovery and adaptation, routine long-term follow-ups should be implemented.

Implications for future research

- Encouragingly, since the start of this research project, a few additional studies including aspects of activity and participation among long-term stroke survivors have been published, although none stretching over as long as 15 years. The fact that a large proportion of these studies represent Swedish research projects might partially be related to the extensive national and local systems for registering incident strokes in Sweden.

- Studies including stroke survivors from other regions and countries are needed to confirm and develop the findings of this thesis.

- Furthermore, longitudinal, prospective research following stroke survivors over time is needed to fully understand the long-term trajectory of activity and participation after stroke.

- Research should include exploration of how stroke survivors' motivation and perceived capacity to engage in different activities are influenced by the rehabilitation process and interactions with health care professionals and other members of the social network in a long-term perspective.

- There still appears to be some confusion and overlap regarding the definition and measurement of activity and participation. The studies reported in this thesis could possibly provide an example of how the content of assessment instruments can be conceptualized in order to promote sound interpretation of research findings.

Conclusions

The findings reported in this thesis adds to the current knowledge of activity and participation after stroke by incorporating a long-term perspective. By using longitudinal follow-up data from a population based sample as well as the subjective experiences of people living and ageing with the consequences of stroke, the findings show that:

- Linking the BI and the mFAI to the ICF enables more fine-tuned descriptions of activity and promotes sound interpretation of results. It also shows that the two instruments are complementary for assessment of activity performance long-term after stroke and together represent several activity domains, but does not cover subjective participation.

- Although most long-term stroke survivors can be expected to be independent in self-care and basic mobility ten years after stroke, they might experience limitations in other activity domains, such as engagement in community, social and civic life.

- Out of home mobility, social network resources and age are likely important factors for the long-term frequency of social and leisure activities after stroke. Noteworthy, limitations related to outdoor mobility and reduced social networks appear to be poorly compensated for over time and with ageing.

- Over a period of 15 years after a first-ever stroke, several interrelated personal and contextual conditions that change over time and with ageing, continuously influence peoples perceived ability and motivation to engage in social and leisure activities. The strategies used by stroke survivors are linked to individual goals and contexts and involve balancing social and leisure engagement with other demands and priorities in life. These findings contributes to an improved understanding of why, and how, people manage to hold on to activities in the long term after experiencing a stroke, as well as what makes them give up activities, and what drives the search for new ones.

- In the long-term trajectory after stroke, rehabilitation and support can be needed at several occasions during different phases of recovery and adaptation and throughout the ageing process. Successful rehabilitation needs to build on an awareness of the individuals own goals and strategies. In addition, to promote long-term participation, an empowering approach that teaches people with stroke and their families to understand and handle the varying consequences of stroke is likely beneficial. Moreover, support especially aimed at enabling social and leisure participation needs to be developed in the clinical as well as community settings.

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Appendix 1 – Barthel Index

THE	**Patient Name**:	_____
BARTHEL	**Rater Name**:	_____
INDEX	**Date**:	_____

Activity	Score

FEEDING
    0 = unable
    5 = needs help cutting, spreading butter, etc., or requires modified diet
    10 = independent   _____

BATHING
    0 = dependent
    5 = independent (or in shower)   _____

GROOMING
    0 = needs to help with personal care
    5 = independent face/hair/teeth/shaving (implements provided)   _____

DRESSING
    0 = dependent
    5 = needs help but can do about half unaided
    10 = independent (including buttons, zips, laces, etc.)   _____

BOWELS
    0 = incontinent (or needs to be given enemas)
    5 = occasional accident
    10 = continent   _____

BLADDER
    0 = incontinent, or catheterized and unable to manage alone
    5 = occasional accident
    10 = continent   _____

TOILET USE
    0 = dependent
    5 = needs some help, but can do something alone
    10 = independent (on and off, dressing, wiping)   _____

TRANSFERS (BED TO CHAIR AND BACK)
    0 = unable, no sitting balance
    5 = major help (one or two people, physical), can sit
    10 = minor help (verbal or physical)
    15 = independent   _____

MOBILITY (ON LEVEL SURFACES)
    0 = immobile or < 50 yards
    5 = wheelchair independent, including corners, > 50 yards
    10 = walks with help of one person (verbal or physical) > 50 yards
    15 = independent (but may use any aid; for example, stick) > 50 yards   _____

STAIRS
    0 = unable
    5 = needs help (verbal, physical, carrying aid)
    10 = independent   _____

TOTAL (0–100):   _____

The Barthel ADL Index: Guidelines

1. The index should be used as a record of what a patient does, not as a record of what a patient could do.
2. The main aim is to establish degree of independence from any help, physical or verbal, however minor and for whatever reason.
3. The need for supervision renders the patient not independent.
4. A patient's performance should be established using the best available evidence. Asking the patient, friends/relatives and nurses are the usual sources, but direct observation and common sense are also important. However direct testing is not needed.
5. Usually the patient's performance over the preceding 24-48 hours is important, but occasionally longer periods will be relevant.
6. Middle categories imply that the patient supplies over 50 per cent of the effort.
7. Use of aids to be independent is allowed.

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Appendix 2 – Extended and modified Frenchay Activities Index

In the last **3** months how often have you undertaken:	
1. Preparing main meals 2. Washing up	0 = Never 1 = Less than once a week 2 = 1-2 times per week 3 = Most days
3. Washing clothes 4. Light housework 5. Heavy housework 6. Local shopping 7. Social outings 8A. Walking outdoors > 15 min 8B. Wheelchair outdoors > 15 min 9. Pursing active interest in hobby 10A. Driving a car/motorbike 10B. Going by bus or train 10C. Going by bicycle or moped 10D. Powered wheelchair 10E. Passenger private car/taxi 10F. Special transport service	0 = Never 1 = 1-2 times in 3 months 2 = 3-12 times in 3 months 3 = At least weekly
In the last **6** months how often have you undertaken:	
11. Outings/car rides 12. Gardening* 13. Household/car maintenance*	0 = Never 1 = 1-2 times in 6 months 2 = 3-12 times in 6 months 3 = At least weekly
14. Reading books	0 = None 1 = 1 in 6 months 2 = Less than 1 in 2 weeks 3 = More than 1 every 2 weeks
15. Gainful work	0 = None 1 = Up to 10 hours/week 2 = 10-30 hours/week 3 = Over 30 hours/week
16. Using the telephone/text-phone[2]	0 = Never 1 = Less than once a week 2 = 1-2 times per week 3 = Most days

*Modified response options compared to Wendel et al, 2013.

Activity and participation long term after stroke

This thesis focuses on different aspects of activity and participation up to 15 years after stroke. It builds on follow-up data collected over a period of ten years, as well as in-depth interviews with people living and ageing with the consequences of stroke. Special attention is given to engagement in social and leisure activities and to factors influencing participation in this area.

Anna Norlander is a registered physiotherapist with a master in Medical Science. She has several years of experience working as a physiotherapist in stroke rehabilitation, and is currently involved in research and teaching at the Institution of Health Sciences at Lund University.

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