

Occupational engagement after stroke

a long-term perspective

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ABSTRACT

Introduction: In the literature it is recognized that stroke can have lifelong consequences and that these consequences become evident in the occupations that constitute everyday life. With an increase in prevalence and in the number of stroke survivors returning to independent living there is a need to understand the challenges that may face stroke survivors, not just in a short perspective, but also in the chronic phase of stroke where new or different challenges may present in many areas of life. Exploring occupational engagement after stroke and how it evolves over time can provide important aspects on recovery and adaptation to build understanding of the type of, and timing of support and rehabilitation needed

Aim: The overall aim of this thesis was to explore long-term performance and experiences of everyday life occupations for young and middle-aged stroke survivors and factors that may affect the ability to engage in occupation

Methods: All four studies are based on subsamples of the Sahlgrenska Academy Study on Ischaemic Stroke. Study I (n 237) and II (n 296) included participants with stroke before the age of 70 and used a quantitative design aimed at exploring occupational performance by studying the frequency of performance in Instrumental Activities of Daily Living seven years post stroke. Further, factors that independently predict (study I- prospective data) or explain (study II- cross- sectional data) long-term occupational performance were identified by using multivariable logistic regression. Study III and IV (n 9) used qualitative data collected by interviewing participants who had stroke between the ages of 45 and 60 years. The interviews took place 15-18 years after stroke onset and the interview guide was designed to address occupational engagement over a long-time perspective. Data were analysed using thematic analysis and focused on how engagement changed over time and across contexts (study III) and how views on and experiences of work affect life after stroke (study IV).

Results: The findings show reduced frequency of occupational performance, especially within more complex leisure and work activities. The lowest frequency was found for work where over 50% of those of working age at the seven-year follow-up reported not working. Regression analyses show that reduced frequency was related to gender, cohabitation status, global functional independence, stroke severity, cognitive dysfunction, emotional problems, and fatigue. Qualitative findings revealed that with time consequences of stroke were integrated into everyday life and participants described how they had moved on. Throughout this long process, occupational engagement was key for understanding, accepting and adapting to consequences of stroke. Work in particular was described as a central occupation affecting everyday life. Maintaining or replacing work with new occupations was challenging. The facilitators and barriers in the process surrounding return to work and at the workplace identified indicate a need for individual support.

Conclusion: The changes in occupational performance and experiences after stroke found in these studies indicate a need for long-term support and rehabilitation. Attention should be paid to supporting stroke survivors to engage in occupations that enable them to find ways of adapting to consequences that are in accordance with individual goals and context. For younger stroke survivors' particular attention should be paid to work and encompass a broader perspective than just initial return.

Keywords: ADL, Adaptation, Cohort study, Occupational engagement, Occupational performance, Occupational therapy, Participation, Rehabilitation, Return to work, Stroke, Qualitative research

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SAMMANFATTNING PÅ SVENSKA

Inledning: Stroke är en sjukdom som kan ha livslånga konsekvenser, vilka ofta framträder i de aktiviteter som tillsammans bygger vår vardag. Fler personer överlever stroke och lever idag längre med konsekvenser av stroke. Kunskapen om långsiktiga konsekvenser är dock begränsad. Inte minst saknas kunskap om vilka utmaningar i vardagen som uppstår över tid och vad som på sikt är viktigt utifrån den strokeöverlevandes perspektiv. I avhandlingen syftar begreppet aktivitetsengagemang till att innefatta både det faktiska utförandet av aktiviteter och den subjektiva upplevelsen. Att utforska både faktiskt utförande och upplevelse över tid kan tillföra viktig kunskap för förståelsen av långsiktiga utfall efter stroke. Kunskap som i sin tur också kan bidra med viktiga aspekter vid utformning av långsiktigt stöd och rehabilitering för strokeöverlevande och som också berör när i tiden olika typer av stöd och rehabilitering kan behövas.

Syfte: Det övergripande syftet med avhandlingen var att utforska långsiktigt utförande och upplevelse av vardagslivets aktiviteter bland yngre och medelålders strokeöverlevande samt faktorer som påverkar förmågan att vara engagerad i dessa aktiviteter.

Metoder: Samtliga fyra delstudier har inkluderat personer som deltagit i en större studie i Västsverige, benämnd the Sahlgrenska Academy Study on Ischaemic Stroke (SAHLSIS). I delstudie I och II deltog 237 respektive 296 personer som insjuknat i stroke före 70 års ålder och som deltog i en långtidsuppföljning sju år senare. Dessa studier hade en kvantitativ design och syftade till att utforska hur ofta deltagare utförde vanligt förekommande aktiviteter i vardagen, såsom matlagning, inköp, fritidsaktiviteter och förvärvsarbete, sju år efter sitt insjuknande. Vidare utforskades i delstudie I om faktorer i den akuta fasen, såsom strokegrad, ålder, kön och boendesituation vid insjuknandet hade samband med aktivitetsutförande och därmed kan bidra till att tidigt identifiera personer som riskerar nedsatt aktivitetsutförande på längre sikt. I delstudie II utforskades sambanden mellan faktiskt utförande och så kallade dolda nedsättningar efter stroke, såsom kognitiv påverkan, depression, ångest och mental trötthet, för att undersöka om dessa kan bidra till att förklara nedsatt aktivitetsutförande sju år efter insjuknande. I delstudie III och IV deltog 9 personer som insjuknat i stroke innan 60 års ålder. Studierna hade en kvalitativ design och tematisk analys användes som metod. Deltagarna intervjuades 15–18 år efter sitt insjuknande för att få en fördjupad förståelse för hur de upplevt vardagens aktiviteter och de erfarenheter de bär med sig efter de år som passerat. Delstudie III

fokuserade på hur utförande och upplevelse har förändrats över tid och i olika sammanhang. Delstudie IV fokuserade på deltagarnas upplevelser kring arbete och hur det påverkade deras vardag efter stroke.

Resultat: Resultaten visar att deltagare är mindre aktiva inom vanligt förekommande aktiviteter i vardagen. Minst aktiva var deltagare inom arbete och fritidsaktiviteter. Av de som fortfarande var i förvärvsarbetande ålder vid sjuårsuppföljningen var det mer än 50% som inte arbetade. Analyserna i delstudie I visade att det fanns samband mellan nedsatt aktivitetsutförande och kön, boendesituation (med annan vuxen eller ensam), hur allvarlig stroke man haft (Scandinavian Stroke Scale), samt mer övergripande nivå av självständighet (modified Ranking Scale). Resultat av studie II visar att kognitiva nedsättningar, depressiva symtom och mental trötthet kan kvarstå lång tid efter stroke och har samband med nedsatt aktivitetsutförande sju år efter insjuknande i stroke. Av intervjuerna framkom att även om konsekvenserna av stroke kan kvarstå så blir de över tid en del av vardagen och deltagarna beskrev hur de gått vidare i livet mot en tillvaro där stroke inte längre var i fokus. Detta var för många en lång process där både faktiskt utförande och upplevelser av olika aktiviteter var av stort vikt för att förstå, acceptera och anpassa sig till konsekvenser av stroke. Arbete beskrevs som en aktivitet som i hög grad påverkade vardagen både för de deltagare som återgick till sitt arbete och de som inte gjorde det. Att bibehålla sitt arbete eller ersätta arbete med nya aktiviteter när man inte kunde arbeta beskrevs som en utmaning och studien belyser både hinder och möjligheter i processen kring arbetsåtergång.

Slutsatser: De förändringar i utförande och upplevelse av vardagens aktiviteter efter stroke som framkommit i denna avhandling visar att det finns ett behov av långsiktigt stöd och rehabilitering. Uppmärksamhet bör riktas mot att stödja strokeöverlevande i att engagera sig i aktiviteter som erbjuder möjlighet för personerna att upptäcka och anpassa sig till konsekvenser av stroke vilket på sikt ökar personens möjligheter till en meningsfull vardag. Aktiviteterna bör utgå från personens egna målsättningar och de sammanhang personen befinner sig i. För yngre strokeöverlevande bör särskild uppmärksamhet riktas mot arbete och då innefatta inte bara tidig återgång utan också insatser i ett längre perspektiv för att bibehålla sitt arbete eller att hitta andra aktiviteter i vardagen när arbete inte är möjligt.

LIST OF PAPERS

This thesis is based on the following studies, referred to in the text by their Roman numerals. The published papers are reprinted with permission from Scandinavian Journal of Occupational Therapy (Study I) and PLoS ONE (Study II). Study III has been submitted to Scandinavian Journal of Occupational Therapy. Study IV is in manuscript form.

- I. Blomgren C, Jood K, Jern C, Holmegaard L, Redfors P, Blomstrand C, Claesson L. Long-term performance of instrumental activities of daily living (IADL) in young and middle-aged stroke survivors: Results from SAHLSIS outcome. *Scandinavian Journal of Occupational Therapy*. 2018;25(2): 119-126.
- II. Blomgren C, Samuelsson H, Blomstrand C, Jern C, Jood K, Claesson L. Long-term performance of instrumental activities of daily living in young and middle-aged stroke survivors - Impact of cognitive dysfunction, emotional problems and fatigue. *PLoS One*. 2019;14(5): e0216822.
- III. Wassenius C, Claesson L, Blomstrand C, Jood K, Carlsson G. Integrating consequences of stroke into everyday life – experiences from a long-term perspective. Manuscript submitted
- IV. Wassenius C, Claesson L, Blomstrand C, Jood K, Carlsson G. The centrality of work in the life of long-term stroke survivors. In manuscript

CONTENT

ABBREVIATIONS	v
INTRODUCTION	1
THEORETICAL PERSPECTIVES	2
An occupational perspective	2
What is occupation	2
Occupational engagement	3
Participation	6
Occupational adaptation	7
STROKE	9
Rehabilitation	10
Stroke care and rehabilitation in Sweden	11
LIFE AFTER STROKE	12
OCCUPATIONAL ENGAGEMENT AFTER STROKE	12
Return to work after stroke	14
RATIONALE	16
AIM	17
PARTICIPANTS AND METHODS	19
STUDY DESIGN	19
PARTICIPANTS AND SAMPLING PROCEDURE	21
The Sahlgrenska Academy Study on Ischaemic Stroke (SAHLSIS)	21
Study I and II	23
Study III and IV	23
DATA COLLECTION	24
Instruments	24
Interviews	26
DATA ANALYSIS	28
Statistical analysis	28
Thematic analysis	29
Theoretical and epistemological positions	30
ETHICAL CONSIDERATIONS	32
RESULTS	33
PARTICIPANTS	33
OCCUPATIONAL PERFORMANCE	35
THE EXPERIENCE OF OCCUPATION	37

FACTORS AFFECTING OCCUPATIONAL ENGAGEMENT	39
DISCUSSION	42
OCCUPATIONAL PERFORMANCE	42
THE EXPERIENCE OF OCCUPATION	44
Occupational changes	44
It takes time	45
Occupational engagement as means	46
Making priorities and the importance of value	46
FACTORS AFFECTING OCCUPATIONAL ENGAGEMENT	48
Physical and cognitive	48
Personal	51
Physical, social and cultural environment	52
METHODOLOGICAL CONSIDERATIONS	54
SAMPLING	54
DATA COLLECTION	56
DATA ANALYSIS	57
Statistical analysis	57
Thematic analysis	58
CONCLUSION	61
FUTURE PERSPECTIVES	63
ACKNOWLEDGEMENTS	64
REFERENCES	67

ABBREVIATIONS

ADL	Activity of Daily Living
AOTA	American Occupational Therapy Association
BADL	Basic Activity of Daily Living
BI	Barthel Index
BNIS	Barrow Neurological Institute Screen for higher cerebral functions
CMOP-E	Canadian Model of Occupational Performance and Engagement
FAI	Frenchay Activities Index
FIS	Fatigue Impact Scale
HAD	Hospital Anxiety and Depression scale
IADL	Instrumental Activity of Daily Living
ICF	International Classification of Functioning, Disability and Health
IS	Ischaemic Stroke
MoHO	Model of Human Occupation
mRS	modified Rankin Scale
NIHSS	National Institutes of Health Stroke Scale
RTW	Return to work
SAHLSIS	Sahlgrenska Academy Study on Ischemic Stroke
SSS	Scandinavian Stroke Scale
SU/S	Sahlgrenska University Hospital/ Sahlgrenska
WFOT	World Federation of Occupational Therapist
WHO	World Health Organization

INTRODUCTION

It is through participation in everyday occupations that people develop, connect with others and find meaning and structure in life (1-3). Occupational therapists focus on helping individuals achieve health, well-being, and participation in life through engagement in occupations (AOTA, 2014). Hence, occupational engagement has been stated as a core principle for the practice of occupational therapy (4, 5).

Numerous studies report on how stroke, leading cause of acquired disability (6), can have impact on, and cause disruption to the lives of stroke survivors (7). The negative impact on occupation can persist over time (8-10) and many stroke survivors are reported to struggle with loss of valued activities (11). Recovery after stroke has been described to relate to recovery of function, finding practical ways of dealing with impairment and psychosocial recovery despite impairment. The latter two can be described as ways of adjustment (7). Occupational engagement can play an important role in recovery and has been identified as a key part for occupational adaptation (7, 12). Engagement in personally valued occupations is a significant predictor of emotional well-being post stroke (13) and the perceived value of activities contribute to the reasons why people with stroke prioritise certain activities over others (14).

Current rehabilitation outcome measures are often focused on objective measures of function rather than the stroke survivors previously valued social activities and meaningful roles (14). Thus, the performance of occupation has received more attention than the subjective experience of occupation. Focusing on physical functioning or functional ability represent a restricted view on the impact of stroke and recovery. A view that does not provide knowledge of what the impact means to the stroke survivor (11).

This thesis assumes the view that occupational engagement, encompassing both the performance and experience of occupation, is central to the understanding of life after stroke. That is, if we are to understand the impact of stroke we need to understand not only what a person does, but also why.

A significant health event can cause a sudden and significant change in occupational ability (15). Although the change in occupational ability may be sudden, work on this thesis is guided by the assumption that adapting to such a change is a complex and non-linear process that can continue and evolve over

a long period of time. During this process, occupational, environmental and personal factors interact (16).

This thesis focuses on young and middle-aged stroke survivors. These are people that often lived active lives prior to stroke and for whom the responsibilities of family life, work, and demands from society differ from that of an older population (17). With an increasing prevalence (18, 19) and more people returning to independent living (8), there is need of more knowledge about the long-term consequences and prognosis for younger populations.

THEORETICAL PERSPECTIVES

AN OCCUPATIONAL PERSPECTIVE

In the following section I will address the occupational perspective and constructs that have guided work on this thesis. As many concepts lack definitions that are consistent within the profession of occupational therapy and occupational science I will at times introduce different views on some of the concepts central to this thesis, followed by clarifications on how they have been used in this thesis.

Applying an occupational perspective, is applying a specific way of looking at or thinking about human doing (20). Occupational science has developed as a result of a need to develop occupation-based theory to understand why people do the things they do (21, 22) and was aimed at exploring the nature, meaning and sociocultural structure of occupation (3). As an occupational therapist I have used theories and constructs that origin from both occupational therapy and occupational science literature to study both the how and why people engage in the occupations that they do.

WHAT IS OCCUPATION

The World Federation of Occupational Therapist (WFOT) define occupations as referring to the everyday activities that people do as individuals, in families and within communities to occupy time and bring meaning and purpose to life. Occupations include things that people need to, want to and are expected to do (WFOT 2010). Occupation is a concept central to the profession of occupational therapy and occupational engagement can be both the means and end of an occupational therapists work (23). An occupation is a subjective event in perceived temporal, spatial and sociocultural conditions that are

unique to that one-time occurrence. A person interprets his or her occupations before, during and after they happen (24). From this perspective an occupation is best understood by departing from the experience a person has when taking part in an occupation. According to Pierce (24), an occupation can be observed, but the interpretation of the meaning or emotional content of an occupation by anyone other than the person experiencing it is necessarily inexact. Within a profession focused on occupation it is therefore important to address how we within research and practice approach occupation.

The occupations of everyday life are often categorized into a limited number of categories. The literature provides guidance as to which categories should be used and there is a commonly held belief that occupations can be divided into three categories (25). The most common categories are; self-care, productivity and leisure (26) or ADL, play and productivity (27). Other categorizations, common in stroke research and praxis, are basic ADL (BADL) and instrumental ADL (IADL). Whilst BADL refer to activities such as feeding, dressing and managing personal hygiene, IADL refer to more complex activities, such as domestic chores, social activities and gainful work (28). These are all examples of how occupations are typically categorized by type. Another way of categorizing occupations is by experience rather than type. Such ways of categorizing occupations in relation to how they are experienced by people engaged in the occupations themselves have been outlined in works by Hammel (25) and Jonsson (29) but are to my knowledge not explicitly addressed within stroke research.

In this thesis the term IADL is used along with the term occupation. Though it may at times confuse, it reflects the challenges of combining theory with clinical praxis, within occupational therapy and also within stroke research and praxis. The larger project (SAHLSIS), on which this thesis is based, focused on the categories of basic and instrumental ADL and initial work on this thesis used these categories and was focused towards IADL. This thesis also includes qualitative studies focused on the subjective experiences of occupations.

OCCUPATIONAL ENGAGEMENT

Occupational engagement is a common construct in occupational therapy literature. It is stated as an important factor for health and well-being (26, 30) influencing quality of life (30). Although expressed as a core principle for the practice of occupational therapy (4, 5) it has until recently been used as a basic

assumption without further clarification and definition (5, 31). Amongst those studies that do provide a definition, a range of different sources are to be found (5) and the construct of occupational engagement still lacks clarity amongst occupational therapists' (32). In a recent scoping review on how occupational engagement is both defined and evaluated within the current body of occupational therapy literature Black et al. (5) conclude that there is no commonly used definition and that the necessary components of occupational engagement differ between different definitions of the construct. Further they report that although a number of theoretical definitions of occupational engagement are provided these are not applied within the clinical and research based literature (5). This highlights a highly relevant challenge for both researchers and clinicians as the lack of a clarity about what the construct holds will affect not just the understanding, but also operationalization and communication about occupational engagement. Needless to say, this has been a major challenge also in this thesis and in the following section I will address how the construct of occupational engagement has been used throughout this thesis. In doing so I will also address different perspectives on the construct and how it can relate to, or sometimes even be used interchangeably, with other concepts common to occupational therapy and the field of rehabilitation.

Though sharing basic assumptions on the role of occupation I find that there are at least two distinctly different views on occupational engagement present in the literature. Most definitions acknowledge that occupational engagement is multidimensional, extend beyond performance and to various extents include both objective and subjective aspects (4, 5, 30, 32). The understanding that engagement extends beyond performance of occupation to include subjective experiences is recognized in core models of occupational therapy (5). However, the view on performance as part of occupational engagement or as a separate concept distinguish between definitions. Two of the most common models of practice in occupational therapy in Sweden are the Model of Human Occupation (MoHO) and the Canadian Model of Occupational Performance and Engagement (CMOP-E) (33) and I will briefly address how the view on what occupational engagement holds differ. The MoHO defines occupational engagement as a clients' doing, thinking and feeling under certain environmental conditions in the midst of or as a planned consequence of therapy (p 171) (34) acknowledging the cognitive and emotional aspects of engaging in occupation alongside the physical completion of activity (5). The subjective experience can be seen as in addition to, and associated with the

performance (32). Kielhofner thereby includes both the actual performance and the experience as within the construct of occupational engagement. As perhaps evident from the adaptation of the CMOP into the CMOP-E in 2007, where engagement was added, performance is in this model viewed as separate from engagement (26). The reason for adapting the model was to highlight that performance and engagement are two different modes of occupation (33) and seen as distinct from each other (5, 26). In this model performance refer to the active participation in occupation whilst engagement refer to broader emotional and cognitive factors that may be associated with occupation (26). So far the wording is similar to that of the MoHO but the distinctly different view on the role of performance becomes clear in the view that performance can provide means to engagement, but is not necessary for engagement as a person can be engaged without performing (5). That is, while the MoHO view occupational performance as part of occupational engagement, the CMOP-E view performance as one way for occupational engagement but not necessary to experience engagement.

A major aim for occupational therapists and other rehabilitation professionals is to enable clients to engage in meaningful and purposeful occupations (34). This statement introduces another aspect that further complicates the clarity of the construct of occupational engagement, namely that of meaning and purpose. The majority of studies using occupational engagement acknowledge the inclusion of meaning (5, 32), although some discuss it as part of the definition, whilst others consider it a means to obtain meaning (5). In dimensions of meaning in the occupations of daily life Hammel (35) argue that in a way all occupations are to be considered meaningful in that they have some value for the individual engaged in them. By this statement she highlights the question of addressing meaning as a positive term when it can be argued to also evoke other feelings, such as humiliation. Here in lies the difference between perspectives on occupational engagement in relation to meaning. Some definitions either do not refer to positive or negative meaning of occupational engagement or encompass all experiences of meaning and purpose (5), whilst others position the construct as a positive value of occupation (31).

In this thesis the construct of occupational engagement is used as it is defined in most studies, to encompass both objective and subjective aspects on occupation. Thus requiring the inclusion of both objectively observable and

subjectively experienced outcomes (5) and bringing them together as co-dependent components within the same construct. Observable, or as termed by Black et al. (5), physical aspects of occupational engagement are in the literature described using terms such as performance, participation, doing or being active (5). In this thesis the term occupational performance is used to refer to the actual and observable performance or doing of an occupation. The subjective aspect of occupational engagement is understood as the subjective experience of being involved in occupation. This thesis assumes the view that occupational engagement encompasses performance and experience across a wide range of occupations, that are not necessarily ascribed a positive value by those performing them. Thus, acknowledging that occupational engagement can evoke both positive and negative experiences of meaning.

PARTICIPATION

In this thesis I have chosen to use the word engagement. As the term engagement is used interchangeably with participation in the literature (33) the perspective on and use of occupational engagement in relation to the commonly used definition of participation provided by the International Classification of Functioning, Disability and Health (ICF) (36) will be addressed briefly. The ICF was introduced in 2001 with the aims to provide a scientific basis for understanding and studying health and health-related domains, their consequences and impact factors and to provide a framework for measuring health and disability at both individual and population levels. It has since become the most dominant and widely accepted theoretical framework in rehabilitation praxis and research (14). By providing a common language to describe how people live with a health condition the ICF has had important implications for occupational therapy and the term participation has been incorporated into occupational therapy literature and theoretical models guiding the profession (33, 37). In the ICF participation is defined as involvement in life situations. Although this definition of participation may provide opportunity to include subjective experiences of occupation, the operationalisation of participation within the ICF as a persons observed performance has received critique for excluding the subjective experience (37, 38). Hemmingsson and Jonsson (37) distinguish between the concept of occupation as used within occupational therapy and participation as defined by the ICF. Addressing the relevancy of acknowledging the differences in incorporating subjective experiences when assessing participation, they argue

that if adhering to the ICF there is a risk of measurement and evaluations becoming too objectively focused. Thereby missing out on the subjective aspect that is important for occupation and thus may not adequately reflect the experiences of people with stroke (39). In a review on social participation after stroke Woodman et al. (14) address the concern that the ICF fails to reflect the continuous changing nature of participation after stroke. By not including the subjective and unique experiences of a person Woodman et al. (14) argue the ICF does not emphasise the value of engaging in activities.

OCCUPATIONAL ADAPTATION

Occupational adaptation is a construct used within occupational therapy to describe the process and/or outcome of the interaction between the person, occupation and environment in response to occupational challenge (16). The construct of occupational adaptation was first described by Schkade and Schultz (40), who integrated occupation and adaptation into a single phenomenon within the patient. A basic assumption is that “Occupation provides the means by which human beings adapt to changing needs and conditions, and the desire to participate in occupation is the intrinsic motivational force leading to adaptation“ (p 829)(40). This assumption indicates a reciprocal relationship between occupation and adaptation, and occupational engagement has been identified as a key part for occupational adaptation (7, 12).

Recent studies on the construct of occupational adaptation report that there is a lack of consensus in the literature as to whether occupational adaptation is an outcome, a process or both (12, 16). Schkade and Schultz (40) described occupational adaptation as an internal normative process in which occupation serve as means. Other studies have described how occupational adaptation can be both an outcome of occupational engagement and a process of the ability to find meaning and satisfaction in occupations (16). Kielhofner (15), defined occupational adaptation as the construction of a positive occupational identity and achieving occupational competence over time in the context of one’s environment. Thereby acknowledging the impact of temporal and contextual aspects on ability to adapt.

The majority of studies on occupational adaptation have identified occupational challenge as preceding occupational adaptation (12). Though it may be argued that all people make occupational adaptations as part of life, a

significant health event can cause a sudden and significant change in occupational ability (41) thereby presenting more abrupt challenges. This thesis focuses on stroke survivors. Stroke is a life-long disease, presenting both acute and long-term challenges that require occupational adaptation. In a systematic review, Sarre et al. (7), reported on how adjustment after stroke is non-linear, marked by both setbacks and successes and vary in relation to time and context. Though not using the construct of occupational adaptation the findings of this review is in line with other studies reporting occupational adaptation as a non-linear, dynamic and ongoing process (12, 42, 43). The three most frequent outcomes of occupational adaptation reported in the literature are preserving participation in meaningful occupations, relative mastery and occupational competence (12). However, it should be recognized that adaptation may not necessarily increase occupational performance and there are studies that also address potentially negative consequences. By performing daily occupations stroke survivors have been reported to gradually discover both strengths and weaknesses (44). For some this can result in the above-mentioned outcomes. For others the challenge of occupational adaptation can be overwhelming, resulting in negative feelings and the loss of occupations (41, 42).

Here the construct of occupational adaptation is used to explore and increase understanding of the occupational changes that may take place as stroke survivors engage in occupation. In this thesis, focused on the long-term perspective, the construct of occupational adaptation provides a theoretical base for exploring how occupational engagement evolves over time and across contexts. Thereby, in this thesis, occupational adaptation is viewed as a process in which occupational engagement can serve as both means and goal of adaptation.

STROKE

The World Health Organization (WHO) defines stroke as rapidly developing clinical signs of focal, and at times global, loss of cerebral function, with symptoms lasting more than 24 hours or leading to death, with no apparent cause other than of vascular origin (45). Stroke is classified as ischaemic or haemorrhagic based on the underlying pathology. This thesis focuses on ischaemic stroke. Ischaemic stroke is caused by interruption of the blood supply to a part of the brain resulting in sudden loss of function (46). It is the most common cause of stroke and globally accounts for just under 70% of strokes (47). In Sweden ischaemic stroke accounts for just over 85% of strokes (48, 49).

In a Global Burden of Stroke study published in 2019 it was reported that the stroke incidence, mortality, and disability-adjusted life-years rates tend to decline from 1990 to 2016 (50). However, the overall stroke burden in terms of absolute number of people affected by, or remaining disabled from stroke has increased across the globe in both men and women of all ages.(51). Advances in the acute treatment of stroke, such as thrombolysis and the implementation of stroke units have increased post stroke survival rates (49, 52) and the prevalence is increasing (18, 19). Particularly in high income countries (47). The global prevalence of stroke was reported to be around 80 million people in 2016 (50). Between 1990 and 2013, there were significant increases in absolute numbers and prevalence rates of both haemorrhagic stroke and ischaemic stroke for younger adults (20-64 years) (51).

Globally, and in Sweden, stroke remains as one of the leading causes of disability in the adult population (47, 49, 53) and the global burden of stroke is high (50). With increasing prevalence of stroke and ageing populations the burden of stroke is also likely to increase (53-55). Stroke is a chronic disease where the societal costs and effects for those affected stretch beyond the acute phase (55, 56). Long-term needs of stroke survivors place ongoing demands on resources (54) and there is a need effective treatments in the acute phase with effective secondary prevention as well as rehabilitation and long-term follow-up to reduce the burden of stroke (51). An increasing incidence of ischaemic stroke in the younger population (18, 51, 57) adds to the large number of survivors who will live many years with their stroke related disabilities. Compared with stroke in older adults, stroke in the young has a disproportionately large economic impact (58). One aspect is the longer life expectancy. Another is the loss of productivity (59, 60). Indirect costs for productivity losses are reported to account for 21% of the costs attributable to stroke in Sweden (56).

In Sweden around 25 500 people suffered a stroke in 2018 (61). The prevalence of people living with disability as a consequence of stroke has been estimated to at least 140 000 people (62). The mean age at stroke onset in Sweden is 75 years, however, 1 out of 5 strokes affect people under 65 years (49). Around 37 % of ischaemic strokes occur in those under the age of 70 years (57). Whilst Feigin et al. (51) report an increased incidence in adults up to an age of 65 a Swedish study found an increase among young people aged 18 to 44 years but a slow decrease in the incidence of IS among people aged 45–64 years since the mid-1990s (57). Mortality is reported to decrease in all age groups in Sweden (49, 57) and thus more people can be expected to live many years with ongoing consequences of stroke.

The severity and type of disability caused by stroke varies greatly (49). Based on current knowledge of critical timepoints in the biological recovery after stroke, post stroke phases have been defined as acute (0-7 days), sub-acute (<6 months) and chronic (>6 months) (63). The long-term consequences are determined by site and size of the initial stroke lesion and by the extent of subsequent recovery (55). Motor impairments are most widely recognized but other impairments within speech and language, swallowing, vision, sensation, and cognition are also common (55). Impaired balance, transfer ability, walking and reduced upper extremity functions are reported in 50-85%. Memory problems, reduced attention, executive dysfunction and spatial neglect are reported in around half and aphasia in one third of stroke survivors (53). Even in patients with good functional outcome cognitive dysfunction, depression or other emotional problems and fatigue are reported as common after stroke (17, 64-69). Many consequences persist over time, with a high prevalence of cognitive dysfunction (8, 66, 70), depression (8, 71) and fatigue (8) being reported many years after stroke.

REHABILITATION

Recovery after stroke is a complex process, and most likely the result of a combination of spontaneous and learning-dependent processes (55). In this process rehabilitation plays an important part and the majority of people with stroke will be in need of rehabilitation (55). The World Health Organisation (WHO) defines rehabilitation as “a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment.” Further it is stated that rehabilitation is an integral component of health services and that investment in rehabilitation allows people to achieve and maintain optimal functioning, by improving their health and by increasing their participation in life, such as in education and work. Thereby it is also an investment in increasing their economic

productivity (72). Thus, rehabilitation has the potential to positively affect at both an individual and societal level. The Swedish National Board of Health and Welfare includes in the concept of rehabilitation efforts aimed at creating opportunities for an independent life and active participation in society (SOSFS 2007:10).

STROKE CARE AND REHABILITATION IN SWEDEN

In Sweden, stroke care and rehabilitation is guided by National Guidelines (49). The guidelines are provided by The National Board of Health and Welfare and the goal of these guidelines is to contribute towards patients and clients receiving a high standard of medical care and social services (73). A major revision was published in 2018, followed by most recent updates and minor revisions in 2020. According to these guidelines the acute care and initial rehabilitation after stroke should take place at a stroke unit, which is an organized in-hospital facility that entirely (or next to entirely) is devoted to care for patients with stroke as there is evidence to support positive effect of organised inpatient care in such units (74). Stroke units are staffed by a multidisciplinary team with special knowledge in stroke care. After the initial phase, rehabilitation can continue in the home environment or different in- or outpatient settings. Rehabilitation should continue for as long as required, be individualized, goal-oriented and multidisciplinary.

All cases registered as a first-time stroke are to be included in the national quality register Riksstroke, which serve as an instrument for follow-ups of the guidelines and as a tool for continuous quality improvement of stroke care. For the 2018 report (75), the coverage rate was 89% and according to these data around 75 % of patients diagnosed with stroke received stroke care and rehabilitation directly at a stroke unit, and 92% at some time during their initial hospitalisation. The median stay was seven days. During this time 85% were assessed by an occupational therapist and a physiotherapist. The majority (77%) of patients were discharged to independent housing. A number that has been reported to increase also in other countries (8).

The national guidelines recognize that people with stroke often have a long-lasting need of rehabilitation that may stretch for many years after stroke onset (49). However, evaluation has shown that follow-up and rehabilitation after stroke is lacking (76). In a follow-up five and three years after stroke, it was reported that in a longer perspective around 60% still experienced

consequences of stroke (77). The same follow-up found that by five years, 31% reported that they had not returned to previous life and activities and a further 34% reported that they had returned but not quite as before. Regarding rehabilitation, 25% reported that they needed rehabilitation but did not receive this. Of those previously employed 12% had returned to their work at five and three years after stroke.

LIFE AFTER STROKE

With the recognition of stroke as a both acute and chronic disease the long-term outcomes have gained increased interest in recent years. As prevalence increase, estimates of long-term outcomes and evaluation of prognostic factors are becoming increasingly important in order to make best use of resources and provide evidence-based rehabilitation beyond the acute-care settings (9, 78, 79). In the Action Plan for Stroke in Europe 2018–2030 four overarching targets were identified. One of these targets was to have national plans for stroke encompassing the entire chain of care from primary prevention to life after stroke by 2030 (53). According to this plan, health issues including both specific and hidden post stroke deficits, activity issues such as meaningful activities and vocational support, adjustment and wellbeing issues and information and support issues are all to be considered in life after stroke (53). However, research into outcomes beyond the first year is sparse (9, 78, 79) and few research studies cover the entire lifespan after stroke (53). Consequently, there is limited evidence to guide the provision of long-term support and rehabilitation after stroke to address these issues. In 2015 The World Stroke Organization (WSO) identified evaluating the best ways to address and improve life after stroke as a stated priority (80) and the Action Plan for Stroke in Europe 2018-2030 list research into the experiences and needs of stroke survivors at different times during their lifespan as a prioritized area (53).

OCCUPATIONAL ENGAGEMENT AFTER STROKE

Among adults, stroke is the most common cause of new disability leading to more than one impairment that could affect daily activities (53). A stroke can make survivors unable to carry out a wide range of activities and meaningful roles, thereby having profound impact on many areas of life (14). Common consequences of stroke include changes in independence and autonomy (14) and a decrease in leisure activities (81) and work (7). Many stroke survivors report an impact on social life (14, 82-84), where they become more socially isolated and engage in fewer activities outside their home environment (85).

Diminished activity level and social isolation can result in further negative health events (86)

Research often focuses on short-term outcomes (87) and assessments of mobility and independence in basic activities of daily living (B-ADL) are the most frequently employed measures in rehabilitation studies (88). These outcome measures are useful in planning discharge from in-patient care, but for those returning to the demands of everyday life these measures are likely to be insufficient. In a synthesis on patients' views on the impact of stroke on their roles and self it was reported that stroke survivors wanted more attention to be paid to aspects such as psychosocial needs, regaining roles, return to work, adapting to life situations and discussing the transition to independence (89). These are areas that require a longer time perspective, in which it is important to include not only basic needs, but also the more complex occupations that constitute a persons' social environment and everyday life. Cott et al (39) pointed to the need for, what they term "real world" outcomes, meaning the inclusion of areas relevant and meaningful for everyday life. One way of addressing these in research has been through the inclusion of instrumental activities of daily living (IADL). Results from previous research highlight the need to address IADL as they are strongly correlated to well-being (13, 14). In particular, social (90, 91), leisure (92, 93) and work (93) activities are often related to well-being and satisfaction with life. When IADL is used in research it most often refers to the performance of occupations.

Though IADL have rarely been the main focus of long-term outcome studies, there are studies with follow-up times up to 10 years which indicated that stroke can have a negative impact on the ability to perform IADL (8-10). Investigating pre- and post-stroke participation in IADL, Singham et al. (94) reported that after six years only 35% of survivors were as active as they were before their stroke. Long-term consequences include restricted participation and autonomy (71) and higher number of occupational gaps compared to age matched controls (95). Both Teasdale [31] and Walsh [11] reported changes and restrictions in leisure activities in 60% of their samples. Restrictions in social and leisure activities seem to persist over time (68, 91) and social loss compared with before stroke has been found for as long as 11-13 years after stroke (96). Many stroke survivors have residual impairments leading to exclusion from paid employment (97) and inability to sustain employment (8, 98).

Physical, communicative or cognitive sequels limit participation in work and other valued activities (7). IADL is a category of occupations that generally require higher cognitive and social skills (92, 99). Consequently, associations

with cognitive dysfunction (99-101), emotional problems (99, 102), and fatigue (64, 103-105) have been reported. Even people with mild stroke can experience consequences within the more complex occupations of everyday life and a significantly restricted lifestyle (106) and decreased participation (107) has been reported. By one year after stroke, Carlsson et al. (83) found that all participants in their study on of the consequences of 'hidden dysfunctions' after a mild stroke in person < 75 years have had to make new priorities in life and give up activities. Re-engagement in valued occupations after stroke has been described as an ongoing interaction between the stroke survivor, the physical and social environment that together determine whether valued occupation are resumed or abandoned (85). These are complex and continuous interactions. Hence, the need for including not only the performance but also the experience of occupation.

RETURN TO WORK AFTER STROKE

Work is an occupation of great concern for younger stroke survivors (108). Work provides a sense of social identity (109) and has been found as an important part of life long term after stroke and central in descriptions of participation (110). Return to work (RTW) has been reported as a primary goal in the rehabilitation process after stroke for most people of working age (98). Being able to return to work is described as an important milestone and sign of recovery for many stroke survivors (59, 111) related to a sense of regaining their former role, being the person they used to be, and to living up to internal and external expectations (111). Several studies have reported associations between returning to work and higher rates of subjective well-being and life satisfaction (112, 113), improved long-term quality of life, emotional outcomes (59) and improved self-esteem (109).

Few studies have examined RTW outcomes in relation to time since stroke onset, especially long-term (114) and the existing literature provides a varied picture. In the long-term perspective there is a need to address and differentiate between the different definitions of RTW found in the literature as it is one thing to return to work and another to be able to maintain employment. When RTW is used in this thesis it refers to the entire process of RTW. Young et al. describe this process (115) “as encompassing a series of events, transitions and phases and includes interactions with other individuals and the environment. The process begins at the onset of work disability and concludes when a satisfactory long-term outcome has been achieved” (p 559). The outcome of the process can be both returning to work and not returning (116). The process of returning to work is complex (115) and has numerous

challenges due to legal, administrative, social, political, and cultural aspects (116).

Currently most studies on RTW after stroke focus on the rates of RTW or factors leading up to a successful RTW. Medical and sociodemographic factors, such as stroke severity, level of education, age, gender and independence in activities of daily living (ADL) are reported to impact RTW outcome (97, 117-119). However, the impact of stroke is complex, with a number of personal and contextual aspects that can affect RTW and more studies exploring the influence of modifiable psychosocial and environmental factors as well as studies looking at the entire RTW process from the point of view of the stroke survivor are required (119, 120).

RATIONALE

Though life after stroke is gaining in interest there is currently insufficient knowledge on the long-term outcome and how to provide long term support and rehabilitation. In the literature it is recognized that stroke can have lifelong consequences and that these consequences become evident in the occupations that constitute everyday life. With an increase in prevalence and in the number of stroke survivors returning to independent living there is a need to understand the challenges that may face stroke survivors, not just in a short perspective, but also in the chronic phase of stroke where new or different challenges may present in many areas of life.

Outcome after stroke can be approached in different ways. Combining different methods to explore consequences of stroke can provide a more nuanced understanding that includes both objective outcomes and the subjective perspective of people living with these consequences. If the aim is to provide long-term support and rehabilitation there is a need to increase the knowledge base about what the long-term consequences are, how they are experienced and how to identify people that may require long-term interventions across a range of occupations and contexts.

Exploring occupational engagement after stroke and how it evolves over time can provide important aspects on recovery and the type of, and timing of support and rehabilitation needed. Occupational engagement can be both means and goal of the process of adaptation that follows in response to the challenges presented by the onset of stroke. This implies that occupational engagement can be used to motivate and facilitate the process of adaptation. However, the importance of occupational engagement over a long period of time has rarely been addressed in stroke research.

AIM

The overall aim of this thesis is to explore long-term performance and experiences of everyday life occupations for young and middle-aged stroke survivors and factors that may affect the ability to engage in occupation

SPECIFIC AIMS

- Study I To explore performance of instrumental activities of daily living seven years post-stroke onset
- and
- Identify predictors of long-term performance of instrumental activities of daily living based on commonly employed acute measures and demographic characteristics in young and middle-aged stroke survivors
- Study II To explore the impact of cognitive dysfunction, emotional problems, and fatigue on long-term performance of instrumental activities of daily living in young and middle-aged stroke survivors
- Study III To explore stroke survivors' experiences of occupational engagement and how engagement changed over time and across contexts
- Study IV To explore how stroke survivors' viewed return to work and how they experience that work has affected their everyday life long-term after stroke

PARTICIPANTS AND METHODS

STUDY DESIGN

This thesis combined quantitative and qualitative research methods to explore different aspects of occupational engagement after stroke. Study I and II were outlined beforehand, whilst study III and IV also included planning based on the findings of study I and II. The quantitative studies were designed to explore IADL as a long-term outcome. That is, what is the frequency of performance and can we predict long-term outcome (study I). Further, do so called hidden dysfunctions such as fatigue, anxiety, depression and cognitive dysfunction have a persistent impact on IADL for young and middle-aged stroke survivors (study II). These studies provided knowledge of the more objectively observable outcome of performance as one aspect of occupational engagement. The qualitative studies were designed to address the subjective experiences of occupation to reach a deeper understanding from the point of view of the stroke survivors who have experienced the impact of stroke in their everyday life. The interview guide was designed to address occupational engagement over a longer time perspective and to address both occupational opportunities and challenges after stroke (study III and IV). An overview of the studies is presented in Table 1.

Table 1: Overview of the studies

Study	Aim	Participants	Design	Data collection	Data analysis
I	To explore performance of IADL seven years post-stroke onset To identify predictors of long-term performance of IADL	237 stroke survivors at stroke onset and 7 years post stroke	Quantitative Cross-sectional and prospective with consecutive selection	Measurements: FAI BI mRS SSS (NIHSS)	Descriptive statistics Non-parametric statistics for comparisons between groups and correlations Multivariable logistic regression analysis
II	To explore the impact of cognitive dysfunction, emotional problems, and fatigue on long-term performance of instrumental activities of daily living in young and middle-aged stroke survivors	296 stroke survivors at 7 years post stroke	Quantitative Cross-sectional with consecutive selection	Measurements: FAI NIHSS BNIS HAD FIS	Descriptive statistics Non-parametric statistics for between groups and correlations Multivariable logistic regression analysis
III	To explore stroke survivors' experiences of occupational engagement and how engagement changed over time and across contexts	9 stroke survivors at 15-18 years post stroke.	Qualitative Inductive design	Individual semi-structured interviews	Thematic analysis
IV	To explore how stroke survivors' viewed return to work and how they experience that work has affected their everyday life long-term after stroke.	9 stroke survivors at 15-18 years post stroke.	Qualitative Inductive design	Individual semi-structured interviews	Thematic analysis

PARTICIPANTS AND SAMPLING PROCEDURE

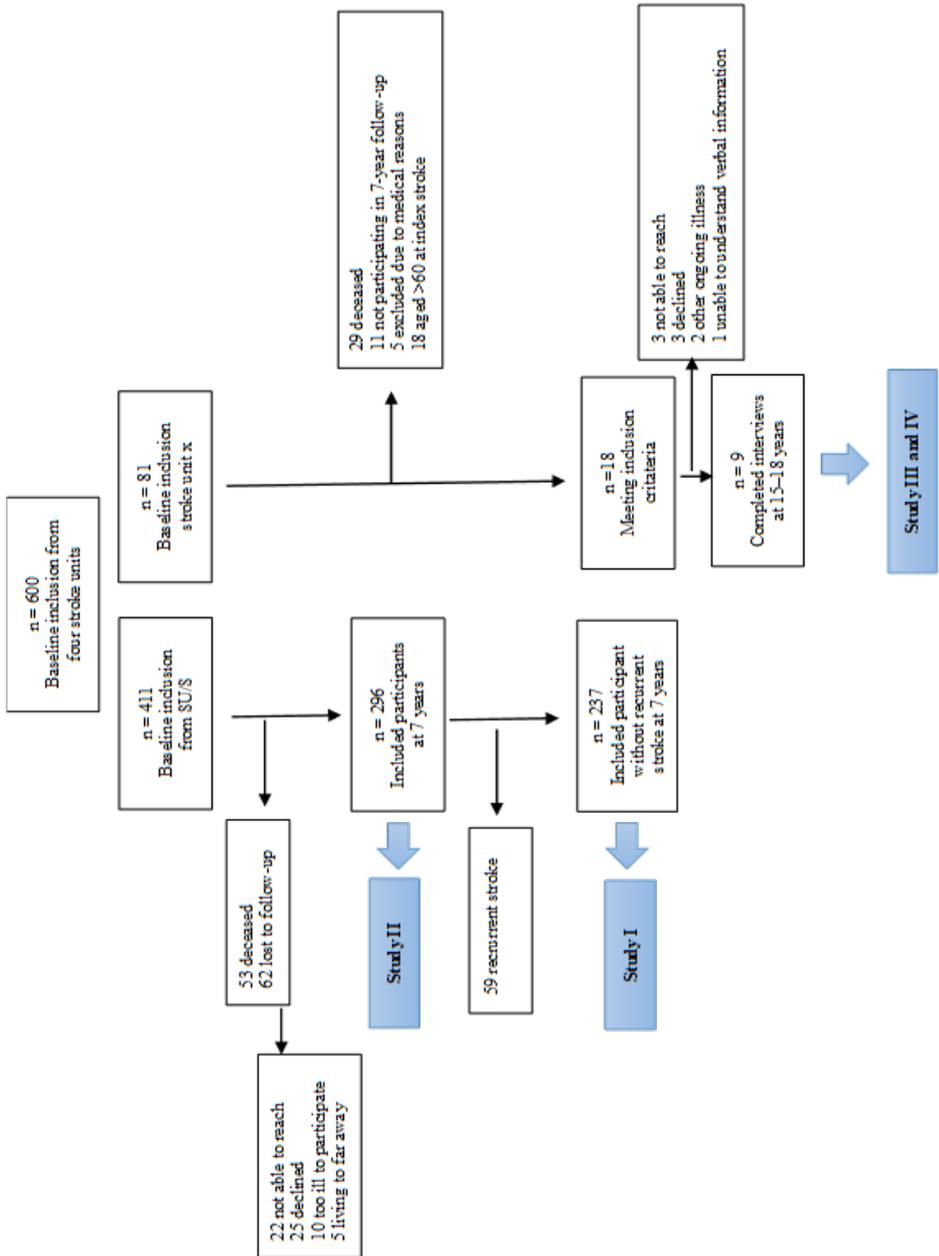
THE SAHLGRENKA ACADEMY STUDY ON ISCHAEMIC STROKE (SAHLSIS)

All studies in this thesis are part of the Sahlgrenska Academy Study on Ischaemic Stroke (SAHLSIS), described in full by Jood et al. (121). The study was originally designed for the purpose of investigating genetic and haemostatic factors in ischaemic stroke. Participants in this thesis were all recruited from the first SAHLSIS cohort of 600 Caucasian adult people diagnosed with a first-ever or recurrent acute ischaemic stroke before the age of 70 years. Participants were consecutively recruited to SAHLSIS when seeking medical care at either one of four different stroke units in western Sweden from 1998 to 2003 if the following criteria were fulfilled: (a) acute onset of clinical symptoms suggestive of stroke (b) no haemorrhage on Computed Tomography scan or Magnetic Resonance Imaging of the brain. Patients were excluded if (a) they were > 69 years (b) the following evaluation showed another aetiology than ischemic stroke, and (c) they had a diagnosis of cancer at advanced stage, infectious hepatitis or HIV.

The stroke survivors were examined in the acute phase and then prospectively followed with assessments at three months, two years and seven years after stroke onset. Recurrent stroke and deaths between baseline and follow-ups have been identified using the Swedish Cause of Death Register, the National Patient register and medical records as previously described by Redfors et al. (122).

Data for the seven-year follow-up were collected by a questionnaire sent to the subjects' homes with questions regarding background variables and self-rating instruments concerning health issues. Stroke survivors included at the stroke unit of Sahlgrenska University hospital in Gothenburg, Sweden (n=358) were invited to participate in a comprehensive assessment, including measures of current ADL performance. This part of the study is referred to as SAHLSIS Outcome. The follow-up study protocol for SAHLSIS Outcome included a postal questionnaire, a visit to a study nurse trained in the use of the instruments and a visit to a study physician. Participants who were unable to visit the clinic were offered a home visit. A flowchart of the inclusion of participants, along with reasons for non-participants is given in Figure 1.

Figure 1. Flowchart of inclusion of participants



STUDY I AND II

Study I and II included participants from the subsample recruited at the stroke unit of Sahlgrenska University hospital in Gothenburg, Sweden (n 411) as this group constituted the first cohort of SAHLSIS Outcome. Inclusion criteria were the same as those described for SAHLSIS. An additional exclusion criterion for study I was one or more recurrent strokes between baseline inclusion and follow-up.

STUDY III AND IV

Study III and IV included participants from a subsample recruited at one of four stroke units between 2000 and 2003. At baseline, inclusion the criteria were the same as for all participants in SAHLSIS. Inclusion criteria specific to study III and IV were as follows; previously participating in SAHLSIS with data from baseline and seven-year follow-up, 18-60 years of age at time of index stroke, verbal ability in Swedish. Persons with severe language or cognitive dysfunctions were excluded only if it affected their ability to understand oral and written information. Persons with a concurrent acute illness during the recruitment phase were discussed with a physician and excluded if this was considered to affect the interview topics.

In these studies a model presented by Malterud et al.(123) was used to guide sample size based on information power rather than saturation. A purposive sampling was utilised, striving for variation with regard to demographics and vocational status. A priori, we estimated 8-10 participants. An invitation letter explaining the purpose of the study along with a contact form and prepaid return envelope was sent to 11 eligible participants. A follow-up phone call was made after two weeks to answer possible questions and, if verbal consent was given, to book a time and place for the interview. Of these 11 persons, 6 were able to take part in interviews and further sampling continued until attempts had been made to contact all 18 eligible participants, resulting in a total of 9 participants. Demographic data and information about stroke severity were collected from the SAHLSIS database and by a brief questionnaire at the time of the interview. The consolidated criteria for reporting qualitative research (COREQ) (124) was used throughout sampling and analysis.

DATA COLLECTION

INSTRUMENTS

Study I and II use baseline and follow-up data from the SAHLSIS database. Baseline assessments were carried out on day 1-7 and for the mRS at 3 months. Follow-up assessment were carried out seven years after stroke onset. Demographic data were gathered acute and at follow-ups.

Frenchay Activities Index

The Frenchay Activities Index (FAI) was used as the primary outcome to assess instrumental ADL in study I and II. It comprises 15 items covering a range of complex activities that require some decision-making and organization on behalf of the patient and correspond to our chosen definition of IADL, including domestic, work and social activities. The Frenchay Activities Index was originally developed by Holbrook and Skilbeck (125) as a brief scale intended to reflect the broader everyday activities of normal living and record changes in these activities following stroke. It had been established as a valid, reliable and sensitive measure of social activity and IADL in patients with stroke (126-129) and is widely used in stroke research (91, 130). Ten of the items refer to activities carried out over the last three months and five items refers to more seasonal activities carried out over the last six months. The FAI consists of a single summary score, ranging from a 0 (inactive) to 45 (highly active), that can be divided into subscale scores. The item scoring is based upon the frequency with which an activity is performed with 0 being low frequency and maximum score of 3 representing high frequency (91). Here, the questions were asked by the research nurse and participants rated their frequency of performance during the interview. Research by Lin et al. (130) suggests the FAI to be divided into two subscales as this would minimize the risk of items overlapping. These two domains, used for analysis in this study, are domestic chores and work/leisure.

Barthel Index

Outcome in basic ADL was assessed with the Barthel Index for activities of daily living (BI) (131). It was first developed as a simple index of independence to score the ability of a patient with a neuromuscular or musculoskeletal disorder to care for them self and to assess improvement during inpatient rehabilitation (131). The BI has 10 items of ADL, such as dressing and feeding. Scoring is based on the time and amount of actual physical assistance required to complete an item. Different guidelines and scoring systems exist. This thesis used the scoring of 0-100 proposed in the original article, with 0 representing the highest level of dependency (131). The

BI is a reliable and valid measure of ADL and the most cited measure of functional outcome within rehabilitation research (132-134). However, it is a measure of basic ADL and thus should be interpreted as such and it has known ceiling effects (133, 134). To avoid problems with multicollinearity the BI was not included in analyses.

modified Rankin Scale

The modified Rankin Scale (mRS) measures the global functional independence of stroke survivors and takes into account previously performed activities (135). The single item rating scale as described by Dromerick et al. (136), ranges from 0 (no symptoms) to 6 (dead), but for this thesis on stroke survivors, 0-5 was used. The instrument has been tested for validity and reliability (135-137), and it has been reported as less sensitive to changes in disability compared to the BI (136)

Fatigue Impact Scale

The Fatigue Impact Scale (FIS) was used to assess fatigue in relation to daily activities. The FIS was originally developed to improve understanding on the effects of fatigue on common daily activities and quality of life in persons with multiple sclerosis (138) but has proven useful also in others diagnoses (138-140). The FIS consists of 40 items intended to reflect activities and common situations in everyday life where fatigue can have a profound impact. Ten of the items address a physical dimension, ten items a cognitive dimension, and 20 items a psychosocial dimension (138). Score ranges from 0-160 with higher scores indicating a higher degree of impact of fatigue. Flensner et al. (140) investigated the reliability and validity of the Swedish version of the FIS and found the instrument to be a homogenous and reliable tool to measure the impact of fatigue in daily life.

Hospital Anxiety and Depression Scale

Anxiety and depression were assessed using a Swedish version of the Hospital Anxiety and Depression Scale (HAD). The instrument, originally designed by Zigmond et al. (141) has been tested in Swedish (142, 143). The HAD consists of one subscale for anxiety and one for depression, which are summarized separately. Each scale ranges from 0-21, with higher scores indicating inferior mood. A cut-off of ≤ 7 was used for no depression/anxiety. The HAD has been found a valid instrument for screening for depression in both the acute and chronic phases of stroke (141, 144, 145).

Barrow Neurological Institute Screen for higher cerebral functions
Cognitive functions were screened using a Swedish translation of the Barrow Neurological Institute Screen for higher cerebral functions (BNIS) that has been previously validated (146, 147). Boosman et al. (148) investigated the

usefulness of BNIS for cognitive screening in patients with good functional outcome and found high internal consistency, no ceiling effects and adequate concurrent validity. Further, the BNIS has been used and shown good screening qualities for cognitive dysfunction in a previous study based on data from SAHLSIS (66). The BNIS test comprises a pre-screen to evaluate whether the patient is capable to take part in further testing and seven subscales. The total score (maximum 50 points) reflects the overall cognitive function. A cut-off level for possible dysfunction was set at <47 in accordance with a previous study on the same study population (66).

Scandinavian Stroke Scale and National Institute of Health Stroke Scale

Initial stroke severity based on stroke-related neurological deficit was assessed with the Scandinavian Stroke Scale (SSS) (149), ranging from 0-58, with higher score indicating less severe stroke. Stroke severity can be classified as mild (43-58), moderate (26-42) and severe (0-25) using the SSS (150). At follow-up, the National Institute of Health Stroke Scale (NIHSS) (151) was used. To allow for comparison to other studies and Swedish register data, that presently use the NIHSS, acute SSS scores were converted to NIHSS by a mathematic equation (152). The NIHSS provides a graded neurological examination rating speech and language, cognition, visual field deficits, motor and sensory impairments, and ataxia (153). Scores range from 0-42, with 0 indicating better outcome. For this thesis a cut-off level was set at 0 in study II to capture those with no or minimal remaining neurological deficits at the follow-up examination. In studies III and IV converted NIHSS score at baseline was used to categorize stroke severity at baseline as very mild (0-2), mild (3-4), moderate (5-15) and severe (16-42).

INTERVIEWS

In study III and IV data was collected by conducting individual face-to-face interviews with stroke survivors 15-18 years after inclusion in SAHLSIS. In an interview the researcher can gain access to personal descriptions of events and how they are perceived in the context where they took place (154). The qualitative approach in study III and IV provided a way of exploring the subjective experience that as one aspect of occupational engagement and allowed the exploration to stretch over a long period of time. Qualitative studies have demonstrated value to explore and provide a greater depth of understanding regarding the experience of engaging in occupation following stroke (155). An interview guide was constructed to cover four main areas: Returning to everyday life after stroke, Occupational engagement over time, Occupational engagement within a context, Development and application of

strategies in everyday life. The interview guide was constructed with the theoretical constructs' occupational engagement and occupational adaptation in mind and in the hope that findings would complement knowledge gained in the first two studies. Many stroke survivors are reported to start by talking about the onset of stroke (156). The interviews therefore started with an open question about returning home after stroke and then moved towards the present. In line with an inductive approach the questions were open-ended and prompts and follow-up questions were used to encourage participants to elaborate further. Given the long timeframe of the study and that participants were stroke survivors who might not be able to participate in long interviews, a choice was made of interviewing each participant twice. Hence, questions, more specific to person, were formulated for the second interview as the interviewer listened to the first interview and made notes to prepare for the second. The second interview began with the interviewer asking the participant if they had any thoughts or questions that they wanted to start with. If not, a brief summary was made of the previous interview and the interviews were focused on clarifying and elaborating on what had been previously discussed. The first set of interviews were regarded as a pilot. However, following discussions of the transcribed data, it was included in the studies as no changes were made to either the interview guide or the strategy of interviewing each participant twice.

The place for the interview was agreed upon during initial telephone contact. Seven participants chose to be interviewed in their homes. One participant chose to be interviewed at a clinic and one in the home of a significant other. Two of the participants choose to have a significant other present during the interviews. For one it was due to responsibility for a significant other who was unwell. This person did not participate in the interview but was present in the room. For the other participant it was due to communication difficulties caused by the stroke. The significant other did participate in the interview, but only when asked to make clarifications by the person being interviewed. Each interview lasted between 13-83 minutes, with a median total interview time for each participant of 106 minutes. The number of days between the first and second interview was 5-45 (median 7 days). All interviews were audiotaped and transcribed verbatim by the author of this thesis.

DATA ANALYSIS

STATISTICAL ANALYSIS

Study I and II focused on performance of IADL and factors that may predict (prospective data) or explain (cross-sectional data) outcome. The distribution of variables was presented as mean and SD and median and first (Q1) and third (Q3) quartiles for continuous variables and as number and percentages for categorical variables. Most instruments use ordinal scales and yielded skewed data distribution. Thus, nonparametric statistics were used. Decisions were guided by a book on medical statistics by Gellerstedt (157) and dialogue with statisticians.

Differences between groups

In study I univariable differences in baseline variables between participants who 1) were included, 2) suffered a recurrent stroke during the follow-up period, 3) were lost to follow-up and 4) died before follow-up were tested using Kruskal-Wallis one-way analysis of variance for continuous variables and chi-square test for categorical variables. Significant overall tests were followed by two-group comparisons between the included group and not included participants using Mann-Whitney U test for continuous variables and chi-square test for dichotomous variables. Significant differences in follow-up data were tested using Mann-Whitney U test for continuous variables and chi-square test for dichotomous variables. In study II, two-group comparisons between participants with a NIHSS score of 0 and participants with a NIHSS score above 0 were done using Mann-Whitney U test for continuous variables and Fisher's exact test for dichotomous variables.

Univariable and multivariable analysis

Both studies used Mann-Whitney U test for dichotomous variables and Spearman's rank-order correlation (r_s) for continuous variables to study univariable correlations between FAI and predictive or explanatory variables. In Study II a univariable logistic regression was performed, in addition to Spearman's rank-order correlation in order to more easily compare the univariable and multivariable results. Variables with a significant univariable correlation with FAI summary score and scores for domain of domestic chores and domain of work/leisure activities were included in multivariable stepwise forward logistic regression analyses in order to select variables that were independently predictive or explanatory of worse outcome on the FAI. Since the FAI is not normally distributed in this sample, the FAI and subscales were dichotomised in order to perform multiple regression analyses. Worse outcome was defined as a score below the study population median.

All significance tests were two-sided and conducted at the 5% significance level. Data were analysed using SPSS software (PASW Statistics version 22.0). Further details are found in each paper.

THEMATIC ANALYSIS

Study III and IV used thematic analysis. The method of thematic analysis involves the searching across a data set to find repeated patterns of meaning. It is a flexible method that can provide a rich and detailed, yet complex account of data (158). However, with flexibility also comes challenges, and thematic analysis has been criticised for being vaguely defined (158) and lacking consistency across reports (159). In response to the critique the need for guidelines has been addressed, and in this thesis the guidelines provided by Braun and Clarke (158) were used to guide analysis. As there is limited knowledge on the research area an inductive approach was used, reflected in the broad and open questions of the interview guide and throughout the analysis. An inductive approach means that the themes identified are strongly linked to the data themselves (160), although the latent level also involves interpretation and that data are theorized (158). In an inductive approach where data is collected by interviews the themes being developed through the analysis may bear little relation to the specific questions that were asked to the participants. Such approach can therefore generate unanticipated insights (158). In this thesis, this was the case for the occupation work. In the interview guide questions were not specifically directed towards work as most participants had passed the age of retirement. However, during the interviews participants often used situations related to their work life to describe everyday life after stroke. When all data had been transcribed and initial codes were being generated it became evident that work was a central occupation and a core aspect in the life of participants. Therefore, extracts addressing aspects within an in relation to work were coded specifically. Due to the magnitude of these codes a decision was made to go forth with these as a separate dataset. Thus, from this phase of the analysis and onwards the interview data was analysed as two separate sets.

The guidelines for analysis provided by Braun and Clarke (158) is described through six phases, stretching from how to familiarize with data to producing the report. However, it is not to be viewed as a straight forward linear process. Rather, the analysis involves a constant moving back and forth between the entire data set, the coded extracts of data and the themes that are developed through the analysis. Although data is coded at the level of smaller individual data extracts, the analysis can include larger parts of text. During the analysis the data program NVIVO 12 pro was used to move between different levels of

data and mind-maps to visualise and discuss if and how themes and subthemes were distinct from each other or should be collated into new themes.

In this thesis phase one of the analysis began already during data collection as the author of this thesis listened to the first interview of each set of interviews. This was done to prepare for the second interview and involved transcribing, re-listening and then reading the transcript. During listening and reading, short comments were noted in the margins to indicate areas to elaborate on but also potential codes for the area. These notes were used in the second interview but no changes to the interview guide were made based on these. Hence, the first interview with each participant was based on the same topics. When all interviews had been completed two authors (CW and GC) were active in all phases of the analysis. All coding was done separately and then together to compare codes and start searching for themes. Further two authors (CB and LC) read the transcripts, coding schemes and descriptions of themes. In the guidelines there are no set rules for what counts as a theme. Rather the guidelines call for flexibility and researcher judgment to determine what a theme is. Themes are not necessarily based on the most frequent codes but on whether they capture important aspects in relation to the overall research question (158). During the analysis regular meetings were held to progress the developing of themes. In the final phases a fifth author (KJ) was involved to provide input in finalizing the themes and analysis continued until consensus was reached on the definitions and names for all themes and subthemes.

THEORETICAL AND EPISTEMOLOGICAL POSITIONS

The very starting point of this thesis is guided by a particular interest in the occupational lives of long-term stroke survivors. Hence, this thesis is guided by my experience as an occupational therapist and theoretical understanding of constructs within occupational therapy and occupational science as described in the introduction section.

The different methods used in this thesis to some extent align with different epistemological perspectives. Study I and II use objective outcomes and statistical analysis to study and draw conclusions about occupational performance, thereby aligning with objectivism. Study III and IV aims at exploring experiences of occupational engagement within a specific context, thereby aligning with subjectivism. That is, whilst one method seeks an objective and true reality, where results can be verified and generalized, the other method acknowledges multiple realities that vary from person to person and are contextually bound. By combining different perspectives to study

occupational engagement after stroke this thesis does not strictly comply with either epistemological endpoints alone and it may be argued that the perspective on occupation as a subjective event can never be fully understood by objective methods.

The qualitative studies use thematic analysis which can be applied within different theoretical and epistemological approaches. Braun and Clarke (158) state that theoretical positions and values of the researcher must therefore be made explicit as it will guide choices throughout the process. In thematic analysis the researcher plays an active role in identifying, selecting and reporting themes (158). Thereby the final report cannot be entirely objective as the preunderstanding of the researcher will affect (154). Study III and IV recognize that the individual experience of occupation is subjective and affected by contextual factors, but also that the researcher is a subjective part in interviews and analysis. In a thematic analysis at the latent level the development of themes themselves involves interpretative work and the analysis that is produced is not just descriptions but already theorized (158). Epistemologically Study III and IV most closely align with interpretivism and more specifically constructivism as they aim at understanding the experiences of participants by interpreting the personal experiences that a person has of occupation. Occupation is viewed as contextually bound. Interpretivism and constructivism embrace subjectivity and are context sensitive (154, 161) and the interpretative approach aims at grasping the diversity of experiences (162).

ETHICAL CONSIDERATIONS

The Sahlgrenska Academy on Ischemic Stroke has been approved by the Regional Ethical Review Board in Gothenburg, Sweden on several occasions related to different phases of the project. Studies I and II were approved in March 2000 (Dnr: Ö469-99) and April 2004 (Dnr: 413-04). Written informed consent was obtained from all participants. For participants who were unable to communicate, consent was obtained from their next-of-kin

Studies III and IV partly use data from SAHLSIS that have been approved in above applications. A new application regarding the interviews was approved by the Regional Ethical Review Board in Gothenburg, Sweden in March 2018 (dnr: 1100-17). Written and verbal consent was given by all participants prior to the interviews and steps were taken to allow for questions and concerns to be addressed. Prior to contact, medical record were controlled to ensure that those previously participating in SAHLSIS were still alive. A letter containing information about the studies was sent out two weeks prior to telephone contact to enable participant time to read the information and prepare questions they may want to ask. Verbal information was given on several occasions prior to the interviews, stressing that participation is voluntary and that participants at any time can chose to end their participation or refrain from questions they do not wish to answer.

Although no immediate risk for participants has been identified for these studies, some of the questions asked both during assessments and interviews may be emotionally difficult for participants to answer as they highlight difficulties in carrying out everyday life. All participants were offered support from persons responsible for the studies if the interview was experienced as emotionally difficult or they had question relating to their participation in the study. Support in establishing contact with other health care professionals was also offered.

One aspect arising from the interviews is the aspect of confidentiality. The participants were recruited from a relatively small sample in a specific geographic area. To ensure confidentiality details that pose a potential risk for identification will not appear in the text. All data was coded using the original coding for SAHLSIS.

RESULTS

In the following chapter the combined findings from the four studies included in this thesis are presented. Together these studies showed that occupational performance is often limited by stroke in terms of reduced frequency of performance (study I and II), less varied in terms of physical and social contexts, and changed in terms of losses, new opportunities and priorities (study III and IV). This in turn related to the experience of occupational engagement (study III and IV). The effects of stroke were more profound within the more complex work and leisure activities (all studies) and work in particular was described as a central occupation affecting everyday life (study IV). In regression analyses independent predictors of FAI outcome were identified (study I and II). The subjective experiences of participants described during interviews (study III and IV) deepened the understanding of occupational engagement and how this relate to the process of adaptation over time.

PARTICIPANTS

At the time of the seven-year follow-up 296 stroke survivors completed the FAI which was part of the more extensive follow-up of SAHLSIS outcome. Data from these participants formed the basis for study I and II. However, as study I aimed to identify predictors for worse outcome on the FAI based on baseline data, stroke survivors with one or more recurrent strokes since baseline were excluded in analyses for study I. Participants in study III and IV are 9 stroke survivors that took part in a less extensive seven-year follow-up and were interviewed 15-18 years after inclusion in SAHLSIS. Table xx. show characteristics, baseline and outcome data for studies I-IV. Significant differences in baseline data was found for the SAHLSIS outcome sample when comparing participants included or not included in the follow-up. Significant differences in baseline data were also found between those with recurrent and non-recurrent stroke. These are shown in paper I. In study II significant differences were found between participants with a NIHSS score of 0 and those scoring ≥ 1 on NIHSS. Participants with a NIHSS score of 0 had significantly better scores ($p < 0.001$) on all outcome measures except for the anxiety part of the HAD ($p = 0.528$), were younger ($p < 0.05$) and more often living with another adult ($p < 0.01$).

Table 2. Characteristics, baseline and outcome data of participants in study I-IV

	Study I n 237	Study II n 296	Study III & IV n 9
Age at stroke onset Mean (SD)	54 (10.7)	55 (10.9)	54 (3.7)
Age at time of study Mean (SD)	61 (9.4)	62 (10.9)	71 (4.5)
Gender (male)	63%	62%	44%
<i>Baseline</i>			
Living with another adult	75%	74%	89%
NIHSS at onset	2.5	2.5	1.6
mRS	2	2	0
Employment			
Full time	54%	51%	67%
Part time	6%	6%	22%
Sick leave/disability pension	18,5%	19%	11%
Retired	12,5%	17%	-
Other/ unemployed/ parental leave	9%	7%	-
<i>7 year follow-up</i>			
Living with another adult	66%	65%	78%
Employment			
Full time	16%	15%	11%
Part time	14%	14%	33%
Retired (age or agreement)	42%	45%	22%
Sick leave	2,5%	2%	-
□ Unknown	25,5%	24%	34%
FAI	28	27	*
BI	100	100	100
mRS	2	2	2
NIHSS	0	0	*
BNIS	40	37	*
FIS	27	30	*
HAD-D	3	3	5
HAD-A	3	3	8

*Not assessed at follow-up for this sample

Score on instruments given in median. NIHSS, National Institute of Health Stroke Scale; mRS, modified Rankin Scale; FAI, Frenchay Activities Index; BI, Barthel Index; BNIS, Barrow Neurological Institute Screen for higher cerebral functions; FIS, Fatigue Impact Scale; HAD, Hospital Anxiety (A) and Depression (D) scale.

OCCUPATIONAL PERFORMANCE

Presented in Table 3 is the frequency of occupational performance as rated by participants using the FAI. Here, results are based on the sample for study II. As this include also those with recurrent stroke the frequency for each domain and on many of the items is lower than presented in paper I and represent long-term outcome of consecutively recruited participants. For the summary score the median was 27 in this sample. The variation between participants covered almost the entire scale of the FAI, ranging from 0-44. Seven years after their index stroke, 29% of participants were classified as highly active, 49% as moderately active and 22% as inactive. Frequency of performance of IADL was lowest for work/leisure activities, where the proportion of highly active participants decreased compared to domestic chores. The highest proportion of inactive participants was found for gainful work.

Table 3. Score on Frenchay Activities Index. *n* =296

Summary score	Mean (SD) Median (Q1-Q3) Min-max	24.1 (10.3) 27 (18.25-32) 0-44		
Domain of domestic chores	Mean (SD) Median (Q1-Q3) Min-max	11.4 (5.7) 12.5 (8-16.75) 0-18		
	Never	Under once weekly	1-2 times a week	Most days
Preparing meals	93 (31.4%)	7 (2.4%)	70 (23.6%)	126 (42.6%)
Washing dishes	53 (17.9%)	6 (2%)	63 (21.3%)	174 (58.8%)
	Never	1-2 times in 3 months	3-12 times in 3 months	At least weekly
Washing clothes	125 (42.2%)	9 (3%)	43 (14.5%)	119 (40.2%)
Light housework	111 (37.5%)	7 (2.4%)	51 (17.2%)	127 (42.9%)
Heavy housework	98 (33.1%)	9 (3%)	34 (11.5%)	155 (52.4%)
Local shopping	56 (18.9%)	3 (1%)	11 (3.7%)	226 (76.4%)
Domain of Work/Leisure	Mean (SD) Median (Q1-Q3) Min-max	12.7 (6.0) 13 (8-17) 0-26		
	Never	1-2 times in 3 months	3-12 times in 3 months	At least weekly
Social outings	78 (26.4%)	52 (17.6%)	79 (26.7%)	87 (29.4%)
Walks	63 (21.3%)	5 (1.7%)	9 (3%)	219 (74 %)
Hobby/Sport	128 (43.2%)	7 (2.4%)	13 (4.4%)	148 (50%)
Driving a car/ Travel on bus	55 (18.6%)	19 (6.4%)	31 (10.5%)	191 (64.5%)
	Never	1-2 times in 6 months	3-12 times in 6 months	At least weekly
Outings/ Car rides	62 (20.9%)	89 (30.1%)	107 (36.1%)	38 (12.8%)
	None	Light	Moderate	All necessary
Gardening	177 (59.8%)	35 (11.8%)	34 (11.5%)	50 (16.9%)
Household and/or Car maintenance	186 (62.8%)	35 (11.8%)	49 (16.6%)	26 (8.8%)
	None	1 in 6 months	Less than 1 a fortnight	Over 1 a fortnight
Reading books	120 (40.5%)	52 (17.6%)	56 (18.9%)	68 (23%)
	None	Up to 10 h/week	10-30 h/week	Over 30 h/week
Gainful work	205 (69.3%)	6 (2%)	34 (11.5%)	51 (17.2%)

Each item rated on a 0-3 scale representing lowest to highest actual participation in each activity
Proportions shown as n (%)

THE EXPERIENCE OF OCCUPATION

In interviews participants shared their subjective experiences of occupational engagement after stroke over a time period stretching from the early phase after stroke to 15-18 years after. The main theme “It takes time- integrating consequences of stroke into everyday life by engaging in occupation, using internal resources and adapting to context” described in paper III, show how occupational outcome was the result of a continuous process in which occupational engagement was a way of gradually integrating consequences of stroke into everyday life. Participants described how this was a time dependent process that involved having time for re-evaluation and acceptance in order to move on with life, but also the long time that it could take to discover and find different ways of adapting to changed abilities. The five themes and subthemes illustrated in Table 4. show how the process of integrating consequences of stroke was affected by a combination of contextual, personal and occupational aspects.

Table 4. Overview of themes paper III

It takes time – integrating consequences of stroke into everyday life by engaging in occupation, using internal resources and adapting to context				
An (un)controllable context	Relying on internal resources	Getting to know abilities and finding solutions through occupational engagement	Occupational losses and new opportunities	Moving on with life
	Believing in and mobilising own resources Taking responsibility and valuing own efforts	Understanding and adapting to changed abilities Having opportunities to discover a changed self	Replacing occupations Balancing value and consequence Value as a prerequisite for continued engagement Feeling like a changed person	Re-evaluation and acceptance

The reduced frequency of occupational performance found in study I and II was described also during interviews. Many had experienced changes in occupational performance and often occupational losses early after stroke, but this was not necessarily experienced as something negative. Some replaced lost occupations with new or spent more time in valued occupations. Describing occupations participants also described the context in which they took place and how the impact of stroke varied not only with time but also with contextual circumstances. Findings from study III show how the physical (study I), cognitive, and emotional consequences and fatigue (study II) became more or less salient depending on the context and how the experience of this influenced future occupational engagement. Increased occupational performance was not necessarily a goal for participants. Rather they describe a balancing act between value and consequences across many occupations and contexts, where increased frequency in one occupation often meant a decrease in another.

The findings of high levels of inactive participants within gainful work in study I and II, were found also for participants in study III and IV. In interviews participants described working less and differently than before their stroke. During interviews participants often used situations related to work to describe everyday life after stroke. This indicated that work carried a central role in the life of long-term stroke survivors, both before and after stroke. In study IV three main themes, each with subthemes containing different dimensions of the main theme, describe participants experiences of work. The dimension of support was present in all main themes. Both participants who returned to work and those who did not, described how work affected everyday life. Work carried the potential to evoke both negative and positive feelings, such as loss or belonging, along with felt effects on physical and mental health. Participants described aspects that effected their view on and opportunities for return to work. These are presented as facilitators and barriers in the RTW process and in the work context. An overview of themes is presented in Table 5 and described in more detail in paper IV.

Table 5. Overview of themes paper IV

<p>Work affecting everyday life Affirmation and sense of belonging through work Paying the price of working Filling a void – life without working</p>	Experiencing sufficient support
<p>Facilitators and barriers in the process of RTW Reflections on working life before stroke affecting RTW A state of uncertainty Collaboration and communication essential to the RTW process</p>	
<p>Facilitators and barriers in the work context Returning to the familiar and having opportunities for adjustments Communicating about stroke</p>	

FACTORS AFFECTING OCCUPATIONAL ENGAGEMENT

In study I the independent variables were selected to explore if commonly used acute assessments and demographic data can be useful to identify those at risk of worse long-term outcome. Using baseline data, we found significant univariable associations between FAI and following variables: age, gender, cohabitation status, Scandinavian Stroke Scale and modified Rankin Scale. Table 6 show the results of multivariable logistic regression analyses. Apart from age, all included variables remained independently predictive in one or more of the three models using FAI summary or subscores as the dependent variable. For cohabitation status the direction of impact varied between subscores, such that those living with a partner had increased odds of worse outcome within domestic chores but decreased odds of worse outcome in work/leisure activities. Women had decreased odds of worse outcome in total and within domestic chores. No significant difference between men and women was found for work/leisure activities, although there was a non-significant tendency towards men being more active within this domain.

Table 6. Multivariable predictors of worse outcome on the Frenchay Activities Index, n 237

Dependent variable	Independent variables	OR (95% CI)	p-value	AUC
FAI summary score	Female	0.46 (0.25-0.86)	0.014	0.72
	SSS	0.97 (0.94-1.00)	0.045	
	mRS	1.67 (1.14-2.43)	0.008	
FAI work/leisure	SSS	0.94 (0.92-0.97)	<0.001	0.71
	Living with partner	0.48 (0.25-0.91)	0.025	
FAI domestic	Female	0.10 (0.05-0.20)	<0.001	0.80
	mRS	1.76 (1.28-2.42)	0.001	
	Living with partner	3.33 (1.547-2.2)	0.002	

FAI. Frenchay Activities Index; SSS. Scandinavian Stroke Scale; mRS modified Rankin Scale
 For SSS higher score indicate better outcome. For mRS higher score indicate worse outcome
 Worse outcome on FAI is defined as score < study population median
 For information regarding missing values, see paper I.

When these variables were addressed by participants during interviews they spoke of severity of stroke, age and having a significant other as important aspects for occupational engagement. A more severe stroke in terms of physical impairments, made it easier to accept not returning to work. Initial stroke severity was described to affect occupational performance but the significance and impact decreased with time. Ageing was by many described as positive by easing the way for new priorities. Though often resulting in decreased occupational performance participants described this as doing more of what is experienced as important and less of the things that they did not want to do. In relation to work participants described how they had been reliant on and received support from family members but also other people. This confirms that cohabitation status can have beneficial effect on work, but also how a significant other can be someone other than a live-in partner.

In our sample, where over 50% of participants in study II had no or minimal residual neurological deficit at follow-up, 89% still had possible cognitive deficits and 21% had possible anxiety and/or depression seven years after stroke. When these variables and fatigue were included in multivariable regression analyses results showed that cognitive dysfunction, depressive symptoms and fatigue did impact long-term performance of IADL in young and middle-aged stroke survivors. The explanatory value of these variables for IADL was higher for the more complex work and leisure activities. The results for each of the FAI variables is shown in Table 7. In a subsample with only participants that had no or minimal neurological deficits at follow-up (NIHSS=0), 83% had possible cognitive dysfunction, 17% possible anxiety and 14% possible depression. In this subsample, cognitive dysfunction and

depressive symptoms were independently explanatory of outcome on the FAI summary score.

Table 7. Variables independently explanatory of worse outcome on the Frenchay Activities Index, n 296

Dependent variable	Independent variables	OR (95% CI)	p-value	AUC
FAI summary score	BNIS	0.89 (0.84-0.95)	<0.001	0.78
	FIS [^]	1.07 (1.03-1.11)	0.002	
	NIHSS	1.29 (1.08-1.54)	0.005	
FAI work/leisure	BNIS	0.89 (0.83-0.94)	<0.001	0.83
	HAD-D	1.10 (1.02-1.19)	0.016	
	Gender male	0.46 (0.24-0.86)	0.015	
FAI domestic	Living alone	2.28 (1.22-4.26)	0.010	0.80
	NIHSS	1.64 (1.38-1.96)	<0.001	
	FIS	1.03 (1.0-1.06)	0.014	
	Age	1.03 (1.0-1.06)	0.035	
	Gender male	6.76 (3.35-13.67)	<0.001	
	Living alone	0.33 (0.17-0.66)	0.002	
	NIHSS	1.22 (1.09-1.38)	0.001	

FAI, Frenchay Activities Index; BNIS, Barrow Neurological Institute Screen for higher cerebral functions; FIS, Fatigue Impact Scale, [^]rescaled by dividing by 5; NIHSS, National Institute of Health Stroke Scale; HAD, Hospital Anxiety (A) Depression (D) Scale. For BNIS higher score indicate better outcome. For HAD, FIS, NIHSS higher score indicate worse outcome.

Worse outcome on FAI is defined as score < study population median

For information regarding missing values, see paper II

During interviews participants described how the less visible consequences of stroke explored in study II along with communicative difficulties had a continued impact on occupational engagement. The fluctuating nature of these symptoms often led to avoidance of places or situations that could increase these symptoms, thus resulting in reduced or less varied occupational performance. In particular work and social activities were described as more demanding, thus also more likely to increase symptoms. With time participants adapted to these consequences. One way was avoidance, but participants also used a range of adaptive strategies that enabled them to maintain valued occupations. In study II emotional problems were explored as symptoms of depression and anxiety. During interviews participants also spoke of being more emotional in the moment, both in terms of laughter and tears, and how this limited occupational performance. Fatigue and cognitive dysfunction contributed to not returning to work or to working less. For some, that described having a mild stroke, it was not until when they returned to work that they began to notice less visible consequences of stroke. Fatigue was by some described as a price of working, sometimes felt at the workplace but also in private life.

DISCUSSION

The overall aim of this thesis was to explore long-term performance and experiences of everyday life occupations for young and middle-aged stroke survivors and factors that may affect the ability to engage in occupation. The studies included in this thesis used different methodological approaches. In this thesis the findings are combined in the wider construct of occupational engagement to capture both objective and subjective perspectives on occupation. In the following section I will address key findings and how bringing different perspectives together has resulted in a more nuanced understanding of occupational engagement.

OCCUPATIONAL PERFORMANCE

After seven years, close to, or more than one third of participants were inactive in many of the items concerning domestic chores. Some of the items within this domain of FAI, such as meal preparation, housework or washing clothes, concern activities that someone must do. With close to 90% of participants living independently without community aid this show a potential discrepancy between received help and required help. When asked if they needed support in everyday life 32% of participants answered yes, and the findings indicate that significant others carry responsibilities for many of the domestic chores. Our findings are in line with a long-term Riksstroke report (77) where 24% of men and 41% of women under the age of 75 years reported being partly or fully dependent on the support of significant others. As discussed in paper I, this can have negative consequences for significant others and a previous study from the SAHLSIS group reported reduced health related quality of life in spouses of stroke survivors compared to a control group (163). Given the predominance of mild strokes in our population, physical inability to perform these activities are likely only part of the explanation for a low frequency of performance. Hence, other aspects such as performance prior to stroke and priorities should be addressed. Although significant others may naturally take a greater responsibility in the early phase after stroke, findings indicate that there may be a need to support both the stroke survivor and significant other in reaching a balance between support and responsibility over time.

In line with previous studies reporting less favourable outcome in work/leisure and outdoor activities on the FAI (94) and persisting changes and restrictions in leisure activities (8, 68, 91), findings of paper I showed a difference in activity level, with higher levels of inactive participants within work/leisure activities on the FAI. This difference in activity level is found in all four

studies, with greater difficulties in more complex occupations. In a study on consequences one year after mild stroke it was reported that participants frequently felt that it was impossible to take part in activities such as movies, concerts, sport event or shopping (106). These are the type of activities included in the FAI items social outing and hobby/sport, and activities that more than a quarter of participants in this thesis reported never taking part in. In study III and IV many participants specifically addressed changes and limitations in relation to social activities and work. Considering the known effects of social (90, 91), leisure (92, 93) and work (93) activities for well-being and satisfaction with life the reduced frequency found within this domain warrant attention in all phases after stroke.

The lowest frequency was reported for work, where over 50% of those of working age reported not working seven years after their stroke. The rate of RTW after stroke vary between studies, from under 10% to around 85% (114, 118, 164), partly due to differences in how RTW is defined and assessed, study populations and likely also as a consequence of differences in health and welfare systems between countries. Comparing our figures to more recent Swedish studies our figures are low. Two recent Swedish studies (117, 118) report an increase in RTW over time, with just over 85% returning within 5 years (118). Riksstroke data for 2018 show that 63% RTW within one year (75). One plausible reason for the lower figures found in our studies is the definition of RTW. Whilst Westerlind (118) and Palstam (117) reported initial RTW, our studies reported those at work seven years after stroke. Thus, in our sample there were participants that initially did RTW but did not maintain employment. If the goal of the RTW process is to achieve a satisfactory long-term outcome as described by Young et al. (115), including those who find it difficult to maintain work is highly important. Inability to sustain employment has also been reported in other studies (8, 98) and whilst the figures for initial RTW can increase with time (114), figures for maintaining employment are reported to decrease (59, 98). Other plausible factors for the lower rates in our sample are that more recent effective acute treatments of stroke, such as thrombolysis and thrombectomy, may have resulted in better outcomes in more recently recruited populations. Further, changes in legislation, social insurance system and labour market affecting the RTW process are likely to affect both frequency and experiences of work.

Although there is no normative reference for FAI score in younger populations the conclusions drawn about a reduced frequency of occupational performance in our sample is strengthened by comparing our findings to existing literature. During work on this thesis two other long-term studies using the FAI in stroke populations (94, 165) were conducted in other regions in Sweden. Though

participants in our study were younger than in the studies by Singham et al. (94) and Norlander et al. (166) the total scores on FAI were slightly lower in our studies. The proportion of inactive participants was similar to that reported by Norlander et al. (166) (22% vs 23%), but the proportion of highly active participant was much lower in our study, with 29% rated as highly active compared to 49%. With younger age reported as predictive of a favourable outcome on the FAI (94, 165) this was an unexpected difference, but strengthen the conclusion of reduced performance. Similar finding have been reported for younger stroke survivors by Boosman et al. (90). Despite the low mean age of 59 years, only 16% of participants in their study were highly active at three years post stroke. By comparing pre and post-stroke scores on the FAI, Singham et al. (94) contribute a highly relevant aspect on the use of cut-offs to classify outcome on the FAI. In their study it was reported that although 83.5% were active according to the commonly used cut-off on FAI, only 35% of their sample had returned to their pre-stroke level. Their finding is in line with a Riksstroke report where 35% reported that they had returned to their previous life and activities five years after stroke (77). Hence, the use of cut-offs seems inadequate in exploring changes in IADL, and of questionable relevance in younger populations that are often more active prior to stroke.

THE EXPERIENCE OF OCCUPATION OCCUPATIONAL CHANGES

All four studies included in this thesis show how the onset of stroke disrupt and affect everyday life. Findings show how long-term outcome is more complex than increased or decreased performance. Whilst the finding of study I and II showed that occupational performance is often limited by stroke in terms of reduced frequency of performance, the experiences described by participants in study III and IV were not just those of limitations but also of new opportunities. The inclusion of subjective experiences of occupational engagement provided a more nuanced picture of stroke outcome and what it means to the person living with potential consequences. Many had experienced changes in occupational performance and often occupational losses early after stroke which aligns with previous research (7, 165). How these early losses were described from a longer perspective was related to how participants had re-evaluated and replaced occupations, which in turn has been reported to relate to a strive for meaning (167). One occupation where the significance of replacing an occupational loss became clear was work. In study IV participants who had not returned to work were also included. Some experienced significant losses when unable to work whilst others focused on the opportunities of not working. Work provided a social context and

contributed to a sense of belonging. Thus, when replacing work, it had been important to not just fill the day with new occupations but to find the sense of meaning previously gained from work.

IT TAKES TIME

Occupational adaptation has been described as a non-linear, dynamic and ongoing process (12, 42, 43) affected by time (15). In this process occupational engagement has been described as a key factor (7, 12). Still, the importance of occupational engagement over a long period of time has rarely before been addressed in stroke research. Though all four studies concluded that many participants had residual consequences after their stroke, findings from study III show that participants experienced that they have moved on with life and reached a stage where they felt in control and able to do all or most thing that they wanted to do. Though no specific timeframes were given participants addressed the importance of time for reaching this stage. This involved time to discover what they could do, re-evaluate what is important to do and accept the things that they could not do. Previously Wallenbert and Jonsson (168) have reported on how participants facing the disruption of habits brought on by the onset of stroke may find themselves in a situation characterised by waiting. In this situation participants were described to face a dilemma of accepting a need for adaptation, which could be seen as relinquishing the struggle to get better, or wait for improvements. Sarre et al. (7) have argued that acceptance lies somewhere on a continuum of between despair, resignation and adjustment. Our findings show how the passing of time can move acceptance along this continuum. Whilst participants in the study by Wallenbert and Jonsson (168) were interviewed within the first 1,5 to 7 months after stroke, participants in our study spoke from their experiences across 15-18 years after stroke. From this perspective, acceptance had been important to move on with life, but it was often preceded by a long-period of trial and error in which occupational engagement was central for moving forward. Findings in this thesis indicate the importance of sometimes allowing time for discovery before going forward with adaptations. This does not mean that some stroke survivors will not need adaptations early after stroke, but that time for discovery and acceptance and how to support this should be considered. This can affect the timing of rehabilitative interventions.

OCCUPATIONAL ENGAGEMENT AS MEANS

In this thesis occupational engagement was described as a way of discovering and integrating consequences of stroke into everyday life (study III). Discovery can be viewed as the first step in a process of adaptation and participants stressed the importance of discovery through their own doing, which included being allowed to make mistakes. In study III participants described a very conscious use of everyday occupations in their home environment, and sometimes also work environment. For participants these occupations provided means of both recovery of function and adaptation aimed at re-engaging in previous occupations and participants described how they kept on engaging in occupations that were difficult for the sake of improvement. The use of occupations as a means of recovery and adaptation require not only opportunities to engage, but also understanding of how they relate to individual goals. The occupations described were occupations that are accessible to many after discharge from hospital. Thus, if used consciously they can provide diverse opportunities for recovery and adaptation. Our findings suggest that enabling occupational engagement and supporting stroke survivors to find their own way of dealing with occupational challenges can help the process of adaptation after stroke. Based on our findings an important aspect for enabling occupational engagement is information on how to use everyday occupation as means. Such information should also be given to significant others to promote opportunities for discovery through occupational performance.

MAKING PRIORITIES AND THE IMPORTANCE OF VALUE

In this thesis the construct of occupational adaptation was used as a theoretical base for exploring the changes that may take place as stroke survivors engage in occupation. Adaptation can include an array of responses to the changes brought on by stroke. In study III participants described how they used various strategies to gain control and reduce the impact of stroke related symptoms. In line with findings by Brunborg et al.(167) some adaptations were related to positive lifestyle changes and included efforts to reduce stress, increase physical activity and making dietary changes. In study IV specific adaptations in the work context such as reducing number of work hours and adapting tasks were described. However, these adaptations were not always experienced as positive and our findings confirm that occupational adaptation can have negative outcomes that results in feelings of loss and decrease belonging (41, 42). Our findings support previous findings by Norlander et al. (165) of how

giving up activities can be a result of adaptation. In study III we found that although occupational engagement provided means of adaptation, the goal was not necessarily increased occupational performance and one way of adapting was to make priorities.

Based on the findings of study III and IV the reduced frequency of occupational performance reported in study I and II is likely not just related to inability to perform specific occupations but to priorities brought on by symptoms of stroke. After a stroke occupations can take longer time to perform (168) and increase symptoms (study III and IV). Thus, stroke survivors may find themselves having to make priorities as they can no longer do all things that they used to. Participants described making these priorities as a balancing act between value and consequences, where consequences referred to both increased symptoms, financial aspects and effect for others. The priorities were made across a range of occupations and contexts where increased frequency in one occupation often meant a decrease in another. Similar ways of balancing value and meaning against potential consequences and losses and how this result in giving up activities have been reported in other studies (14, 83) and found to influence motivation to engage in social and leisure activities (165). A starting point in study IV was the assumption that maintaining work can affect private life as previous studies have reported that in order to maintain work participant may need to make priorities of their social and leisure activities in relation to work (82, 169). Our findings support this assumption. For those returning to work this was an occupation that was often prioritized over other occupations which had consequences for their private life. For some the experienced increase of fatigue when working led them to pursue fewer social activities after work. Findings of study IV indicated that finding and maintaining a balance can be difficult and participants reported experiencing both immediate and long-term consequences that affected social occupations, relationships and health that eventually led them to give up work. This stress the need for long-term support in order to maintain work.

The perceived value of activities contribute to the reasons why people with stroke prioritise certain activities over others (14). Thus, to understand the priorities made it is important to understand how participants derive value or meaning from occupational engagement. In this thesis occupational engagement is understood as encompassing performance and experience across a wide range of occupations, that are not necessarily ascribed a positive

value by those performing them. Thus, acknowledging that occupational engagement can evoke both positive and negative experiences of meaning. In study III a positive value was described as a prerequisite for continued engagement, and findings showed that if the value of a specific occupation was higher than the consequence participants would prioritize valued occupations over less valued occupations even if they had fewer negative consequences. Study III and IV also provided findings related to loss of meaning and how this can cause a gradual decrease in occupational engagement. Further, participants described how meaning can be derived from not engaging in occupations. Thus, to understand the priorities made different aspects of meaning should be considered.

FACTORS AFFECTING OCCUPATIONAL ENGAGEMENT

PHYSICAL AND COGNITIVE

Many studies report that physical impairments negatively affect activities of daily living (7). This was found also in our studies where stroke severity in the acute phase (study I) and residual neurological deficits (study II) remained independently predictive of outcome on the FAI. However, the weak to moderate associations found in study I indicated that although scales such as mRS or NIHSS can have prognostic value that can be useful in discharge planning other factors will likely have impact long-term. This was further explored in study III and IV. Participants addressed how stroke severity, particularly in the early phases after stroke could limit occupational performance (study III) but also make it easier to accept that returning to work was not possible (study IV). The impact and significance of physical impairments decreased with time (study III). Likely as a combined result of recovery and finding ways of adapting to residual deficits. Reduced importance of physical function over time has been reported also in other studies. Eriksson et al. (170) did not find significant relations between acute score on the NIHSS and perceived participation at 6 months post stroke and findings by Norlander et al. (171) indicate that other factors than body functions are more important for frequency of occupational performance at 10 year post stroke. Mobility, especially outdoors, is one area related to physical functioning reported to affect occupational performance by limiting access to activities in various environments (94, 168, 171). Driving restrictions were described as a cause of less frequent occupational performance shortly after stroke (study III) and a barrier for RTW (study IV). However, mobility did not seem to explain long-term outcome in leisure or work activities in our sample.

For our sample the majority of strokes (67%) would at onset be classified as very mild or mild on the basis of the score on the NIHSS. Although the impact of physical consequences of stroke appear to decrease with time, findings of study II-IV show that the impact of cognitive dysfunction, depressive symptoms, fatigue and communicative difficulties on IADL were persistent and may not be experienced as mild by the person living with these consequences.

Our findings of cognitive dysfunction, fatigue and depressive symptoms as independently explanatory of outcome on the FAI differ from several previous studies using the FAI. Whilst cognitive dysfunction showed strong correlation with FAI seven years post stroke and remained independently predictive of outcome also when controlling for neurological deficits and demographics in study II, neither Norlander et al. (171) nor Singham et al. (94) found association between cognitive dysfunction and long-term outcome on the FAI. One plausible explanation for this is the use of different instruments to assess cognition. Whilst other studies used the MMSE (171) and self-reported SIS memory and thinking as a proxy (94), we used the BNIS which is a more sensitive measure of cognitive dysfunction (66). Further, the timepoint of seven years post stroke for assessing cognition differ from these studies which used assessments at 3 and 16 months. Fatigue has been reported as highly prevalent and affecting everyday life (172-174). However, the subjective experience appears to differ from what is found when using more objective assessments to study associations (175, 176). Furthermore, a difficulty in measuring fatigue is that the concept lack a clear definition and operationalization (139). In line with previous studies (175, 176), combined findings of study II and III show how fatigue can be experienced as one of the worst consequences of stroke in everyday life, yet not show strong correlations with IADL. This confirm a need for clear definitions and consensus on how to assess fatigue.

Whilst cognitive dysfunction was the strongest predictor in study II, participants in study III and IV to a higher degree related felt problems with occupational performance to fatigue, describing how lack of concentration or memory problem only presented when they felt tired and how it was alleviated by rest. This shows the fluctuating nature of these symptoms, meaning that although participants described having residual consequences, for some these only became apparent under certain conditions such as crowded places or stressful situations at work. Over time participants had also learned to understand, and to a certain level prevent these symptoms through different types of adaptation. Thus, it is possible that a person may experience reduced fatigue because they stopped doing the occupations that increase fatigue. In a

long-term perspective it is therefore relevant to address if or how a person has adapted to these consequences, rather than just the presence of symptoms.

In study III and IV, work and social activities were particularly described as more demanding, thus also more likely to increase symptoms. These were areas where the impact of stroke was found greater in all four studies. One suggested explanation for this is that these activities require higher cognitive and social skills (92). Our findings are in line with other studies that have reported on how more intellectually demanding occupations often are affected (83) and how stroke survivors struggle to use and maintain strategies in occupations that demand cognitive capacity (44). One specific occupation that often required a higher capacity was work. For some participants with mild stroke we reported on how it was sometimes not before actually returning to work that they became aware of their less visible problems. In a review on RTW after stroke Treger et al. (177) report that although stroke severity is the most consistent predictive factor for RTW, there are studies that have reported cognitive and behavioural impairments as more important than physical deficit for vocational prognosis. A strong predictive value of cognitive dysfunction on the ability to return to work has previously been found in young stroke patients with first-ever ischaemic stroke (178). Post-stroke fatigue has been reported to reduce the chances of RTW and managing jobs as prior to stroke (179). In line with these findings, participants in study IV described how fatigue and cognitive dysfunction contributed to not returning to work or to working less and how adapting to these consequences in a work context was an ongoing challenge. Despite adaptation some continued to experience work as a source of fatigue, sometimes throughout their work life and expressed fatigue as paying the price of working.

Kristensen et. al. (64) have previously pointed to a risk that shorter inpatient hospital stays and a limited focus on evaluating patients occupational performance problems can lead to patients with mild stroke not being referred for further rehabilitation after discharge from hospital. With more subtle problems, not captured by the use of standard discharge instruments such as the Barthel Index (BI), Stroke Impact Scale (SIS) and National Institutes of Health Stroke Scale (NIHSS) (180, 181), the population with mild to moderate stroke poses a new challenge for rehabilitation specialists (182). With treatments such as thrombolysis and thrombectomy and immediate access to acute stroke units, the group with mild stroke is likely to increase. Currently, there is limited evidence for the effectiveness of interventions targeting cognitive deficits, post stroke fatigue, and depression (67, 183, 184). Study III and IV provided important knowledge of the impact of these consequences and how they can be handled in everyday life. A deeper understanding for the

impact of these consequences in everyday life may provide guidance in designing interventions that promote occupational engagement and adaptation after stroke rather than recovery of specific functions.

PERSONAL

Although participants in study III acknowledged age-related changes they did not necessarily experience these as limitations. Rather many described ageing as positive by reducing expectations from self and others. Though often resulting in decreased occupational performance, participants described this as doing more of what they experience as important and less of the things that they did not want to do. Thus, the univariable association reported between age and worse outcome on the FAI in study I can be a result of priorities rather than inability. Jellema et al. (85) reported on how older stroke survivors more easily refrain from activities as the public no longer expects them to perform them in the same way. From this perspective ageing can be viewed as having the potential to enable a higher degree of personal choice.

In study III experiences of choice in relation to occupational engagement were described under the theme “Relying on internal resources”. Relying on their internal resources meant that participants trusted their own ability to make choices, which in turn eased the way for new priorities and adaptations. The findings show the importance of making personal choices and how participants conferred great value to their own efforts in moving forward with life after stroke. Participants ascribed their motivation and successes to personality traits and attitudes. Personal characteristics have previously been described to affect adaptation (7, 41), strategies (165) and the ability to pursue personal choices (14). Woodman et.al (14) have reported on how building confidence and pursuing personal choices is important for overcoming barriers after stroke. The high value placed on choice and own accomplishments strengthen the need for person-centred approaches. It should however be acknowledged that the value ascribed to own efforts and successes is made from a long-term perspective and by people with predominantly mild physical symptoms, thus in less need of physical assistance. Hence, it is possible that the value ascribed to personal factors may be different in people with more severe stroke, of older age or closer in time to stroke onset.

PHYSICAL, SOCIAL AND CULTURAL ENVIRONMENT

In study III the theme “an (un)controllable context”, contains descriptions of how occupational engagement after stroke became less varied in terms of physical and social contexts as participants avoided places or situations that they could not control. The risk of having to deal with the unforeseen became a barrier for engaging in occupations. Particularly those that involved other people. This avoidance of certain contexts in a strive for control of situations is similar to findings of Jellema et al. (85) on how stroke survivors tend to restrict engaging in changing situations and activities. For some participants in study III the avoidance of social contexts was an accepted and sometimes valued choice. For others it carried the risk of negatively affecting the meaning derived also from other occupations than social. Thus, it is important to address the motives behind avoidance strategies along with potential consequences.

Occupational engagement can be viewed as embedded within a broader environmental context (5) and findings in this thesis show how physical, social and cultural aspects within the environmental context affect both performance and experience of occupation. Just as the environment can present barriers that can cause stroke survivors to give up activities, it can also promote and enable re-engagement (85, 165, 185). One specific aspect of the environment that was identified as important in this thesis was the level of support required and gained from others. In study I and II having access to support in terms of living with another adult, was associated with increased frequency of performance in work and leisure activities and a decreased performance in domestic chores. Previous studies have reported on how support can facilitate community reintegration (185), RTW (81, 185) and act as buffer against social isolation (165). Social support is important for re-engaging in occupations, but can also present a barrier if others take over occupations and don't allow for autonomy (85). Hence, the varied impact of cohabitation status may partly be explained by a balanced level of support in work and leisure activities but a less balanced level of support in domestic chores. However, it may also be a consequence of partners supporting the stroke survivors in domestic chore to allow them the energy to pursue other occupations. In study III participants spoke of how the opportunities to engage in occupations were dependent on the support of others in terms of being entrusted and allowed a certain level of autonomy.

In study IV participants addressed the benefits of having a specific person to support them both in the RTW process and when they had returned to work. This could be a family member but also the employer or healthcare professionals. Some of the participants in study IV had received support from

healthcare professionals during the initial period of returning to work and expressed positive experiences of feeling supported during conversations aimed at planning for RTW and of receiving support once back in a work context. However, over time the work context could present new challenges and some of the participants would likely have benefited from support also in longer perspective in order to maintain work. Support has previously been described as crucial for a sustainable work situation (169). Positive benefits of support from healthcare professionals in enabling RTW has recently been reported in studies on a rehabilitation program termed ReWork-Stroke, which has been developed and evaluated in Sweden (116). This program is situated within the healthcare system, with the coordinators that are part of this program working at specialist brain injury rehabilitation units. In line with the facilitators identified in study IV, knowledge of stroke, strategies and a straightforward communication was reported to facilitate the possibility to adapt to the situation for the persons that had had stroke (116).

METHODOLOGICAL CONSIDERATIONS

In this thesis a combination of methods was used. As knowledge on long-term outcome is limited all studies were by nature explorative and chosen to address different aspects of occupational engagement after stroke. From my perspective as a PhD student the use of different methods also had the benefit of allowing me to gain understanding of different perspectives in research and the gains of combining them.

SAMPLING

All four studies included in this thesis build on data from participants included in SAHLSIS. A main strength is the large sample of consecutively recruited stroke survivors, including also those with cognitive and communicative difficulties. Study I and II use data from SAHLSIS outcome. Despite the long-term follow-up, SAHLSIS outcome had a response rate of 83%. Information concerning deaths or loss to follow-up was available from baseline until the seven-year follow-up, thus allowing for comparison between included and non-included participants. Study III and IV involved further sampling. For practical reasons recruitment was limited to one of the four stroke units that took part in SAHLSIS at baseline inclusion. This narrowed the sample and although a purposive sampling was attempted the final sample was the result of convenience sampling where all available participants that agreed to take part in interviews were included. However, the *a priori* estimated number of participants was reached. When all nine available participants had been interviewed the model by Malterud et al. (123) for considering information power was reviewed again. The two dimensions affecting information power that we could not control for beforehand were specificity and dialogue. Despite the convenient sampling there was judged to be sufficient specificity within the sample and the dialogue was generally strong. Thus, the researchers together decided the information power was sufficient and that no further recruitment was necessary. The inclusion of people with communication difficulties also in interviews is considered a strength as this is common in stroke survivors but still often an exclusion criteria.

SAHLSIS was originally designed for the purpose of investigating genetic and haemostatic factors in ischaemic stroke. The sampling was limited to ischaemic stroke in Caucasian adults within a specific geographic region. Further inclusion criteria for SAHLSIS was under 70 years of age at time of stroke. Though limiting generalisability to older populations, the younger age of participants allowed for long-term follow-up and the exploration of the

consequences of stroke for those previously living active lives. Based on the longer life expectancy and increased prevalence of younger stroke survivors, this group is important to highlight when studying long-term consequences. It is also a group where long-term outcome studies are lacking as most research is done on all ages, resulting in higher mean ages, or limited to those under the age of 50 years (186).

This thesis grasp over a long period of time. As findings represent those still available at different timepoints, i.e. 7 years for study I and II and 15-18 years for study III and IV, the samples are naturally increasingly selective towards participants with better outcomes as time pass. The long period of time also raises the issue of how the findings can be transferred to people having a stroke today. Participants in our study were recruited between 1998 and 2003. Since then, considerable changes in stroke care and rehabilitation have taken place. Other aspects to be considered are the cultural and societal changes that may affect the experience of life after stroke.

For study I and II, a limitation of the study design is that the FAI was not used at baseline, thus changes in performance of IADL were not recorded. As long-term outcome is partly affected by other aspects than short-term outcome, such as adaptation, the finding should not be generalised to a short term-perspective. Further, comparison between participants and non-participants in study I showed that non-participants had worse outcome on the mRS. As this was a predictor for worse outcome on the FAI, our findings are most likely an underestimation and thus may not be representative for people with more severe stroke at onset.

For the qualitative studies transferability is affected by the selective sample. Thus, findings should be interpreted in relation to demographic and contextual aspects and may not be transferable to stroke survivors of other ages, social situations and cultural backgrounds. One aspect for transferability that was addressed by the participants themselves are the societal changes occurring over the last 20 odd years. In particular, transferability to present work context is limited by the long timeframe as considerable changes in work climate and legislation guiding RTW has occurred since. However, the findings from this study also provide knowledge that can be transferred to inspire future interventions as they are not just bound to context but address key factors for returning to and maintaining work that are applicable in present work contexts.

DATA COLLECTION

The choice of instruments to be used for data collection was based on the aims of SAHLSIS and SAHLSIS outcome. To assess IADL the choice of FAI was based on a review of the literature where FAI was commonly used in the few long-term studies reporting on IADL that were published at the time. Thus, allowing for comparability to other studies. A more thorough assessment of IADL performance, using both self-rate and observer assessments could have provided more objective findings, accounting for the fact that stroke survivors may over- or underrate their performance. Given the relatively large sample and long timeframe this was however beyond the scope of this study. Further, IADL cover a range of occupations occurring in contexts that are specific to person. Consequently, these are difficult to assess without the use of self-rate instruments.

Although earlier research has shown that the FAI is a valid, reliable and sensitive measure of social activity and IADL in patients with stroke (126-128, 130) it also has known limitations. Here I will address two specific issues. Firstly, the FAI consist of predefined occupations. As the instrument was developed almost 30 years ago, the relevancy of some of the items deserves consideration due to marked changes in society over the last decades. The relevancy of the FAI items have been questioned in older populations (187), thus the modification and extension of the Swedish version (166). The relevancy of items for younger stroke populations has to my knowledge not been assessed. In a general population the validity for (very) young people was questioned and it was suggested that age-specific question should be incorporated (188). When interpreting the results, it should therefore be noted that occupations such as computer gaming, social media and other later leisure activities are not covered by the FAI. Thus, a person may perform a valued social activity when interacting through social media, but be rated as inactive on FAI items such as hobby or social outings. Secondly, the item scoring is based upon the frequency with which an activity is performed. As addressed by Jansen et al. (91), it does not measure perceived problems and fulfilment of social roles. In this thesis where data for the FAI were cross-sectional, study I and II do not address if the occupations were performed prior to stroke and the instrument does not address the value of the occupation. Thus, the use of FAI alone does not provide knowledge of whether the frequency of performance is due to aspects such as lack of interest, inability or priorities. One way of addressing the limitations of FAI was by combining the findings of study I and II, with the experience of occupation addressed in study III and IV.

Data collection for study III and IV was done through individual interviews using a semi-structured interview guide. The questions were open to encourage participants to speak freely. One issue raised concerning stroke research is that it has focused mainly on the problems of stroke, with little attention paid to positive strategies to cope with life after stroke or positive lifestyle changes that may follow (189). The open questions used here allowed for such aspects to be addressed. In-depth and semi-structured interviews explore the experiences of participants and the meanings they attribute to them (124). Beforehand the decision was made to interview each participant twice. This decision was based on the fact that the interviews covered a long period of time, thus it was felt important to follow-up on the experiences brought to surface during the first interview. The decision was also made in consideration of the fact that participants were stroke survivors who may not have the mental or physical energy to take part in long interviews. Repeat interviews can influence the rapport developed between the researcher and participants, thereby affecting the richness of data (124). In this thesis the use of repeat interviews is considered a major strength, resulting in a more relaxed interview situation and richer interviews. The knowledge that clarifications and elaboration could be made during the second interview was also felt to contribute to participants speaking more freely and for the interviewer to allow for the interviews to at times stray from the interview topics, thereby having the potential for new and unanticipated findings to emerge. The fact that interviews were transcribed and notes made before the second interview further contributed to enrich data. During data collection co-authors, more experienced in qualitative research read transcripts and gave feedback. This was particularly useful for guidance between the first and second interview on areas to elaborate on or clarify. A limitation of conducting interviews long after stroke onset is the risk of recall bias. Another aspect that may have influenced the findings is the presence of significant others during some of the interviews. However, this also enabled clarifications and a deeper understanding from the perspective of those with communicative disorders.

DATA ANALYSIS

STATISTICAL ANALYSIS

In these studies, on long-term stroke survivors with predominantly mild stroke, data was often naturally skewed towards better outcomes. Several choices were made that affect the interpretation of findings in these studies. In particular, the use of cut-offs to enable analyses required careful consideration and all statistical planning and analyses were done in collaboration with two statisticians.

In both study I and II the FAI was used as the primary outcome variable in analyses. Regression analysis provide a method of analysing possible predictors of an outcome, which in turn is important to gain knowledge on how to identify stroke survivors at risk of dependency and diminished activity levels. In order to perform regression analysis using the FAI, data had to be dichotomized. The dichotomisation was done by using the sample median as a cut-off in order to explore variables that could predict (study I) or explain (study II) worse outcome on the FAI. Thus, interpretation of the results is limited to the direction of impact.

In analyses a choice was made to use both a summary score and sub scores for the FAI to highlight that there are different areas of IADL. Though most research indicate that the FAI is multidimensional, there is no consensus on the number of constructs (130). In this thesis we followed recommendations based on research by Lin et al. (130), suggesting that the FAI be divided into two subscales as this was found to minimize the risk of items overlapping. Since the start of this thesis, a modified version of the FAI has been linked to the ICF core set for stroke (166). As the ICF is commonly used in clinical settings this could have provided a more useful way of addressing different areas of IADL.

THEMATIC ANALYSIS

Before the interviews it was decided to analyse data using thematic analysis. Thematic analysis involves the searching across data to find repeated patterns of meaning. It is stated as a foundational method for qualitative research (158, 190) and as it does not require the detailed theoretical and technological knowledge of many other qualitative approaches it is a suitable method when new to qualitative studies (158). It also suitable when working in research teams and analysing large qualitative data sets (190). The flexibility of the method can be a strength by allowing a number of choices both relating to theoretical and epistemological underpinnings and in how to approach and analyse data. However the flexibility combined with lack of substantial literature compared to other methods can cause uncertainty on how to conduct a rigorous analysis (190). Thus it is important that the analysis is conducted in a consistent and exhaustive way (158). One question presenting early in the analytic process was how to go forth with the magnitude of initial codes relating to work. In thematic analysis it is up to the researcher to decide which parts of the data corpus (all data gathered for a specific project) will constitute a data set (data for a particular analysis) (158). After rereading the transcripts once more, followed by discussions in the research group the decision was made to analyse all initial codes relating to work as a separate data set. Although we had from start been open about the idea that the interviews could

generate data for more than one analysis, no specific questions relating to work were part of the interview guide and during the interviews participants were not specifically encouraged to elaborate on experiences of work, thus likely resulting in less rich data than if it had been a topic from the start.

To establish trustworthiness for the qualitative studies a number of steps were taken. These will be addressed here using the criteria presented by Lincoln and Guba (191) and recently addressed in an article by Nowell et al. (190) on how to meet criteria for trustworthiness in thematic analysis. Regardless of the analytical procedure used, credibility is enhanced if the data are analysed by more than one researcher (190). Here, two researchers were active in all phases of analysis, and initial coding was done individually and then together. Credibility was further enhanced by tape recording and transcribing all interviews making them available for two more of the co-authors. This allowed for regular discussions to challenge the progression of the analysis and to ensure that interpretations and findings remained grounded in the data, thereby also enhancing confirmability. The use of two interviews contributed to credibility of findings by allowing clarifications to be made. However, credibility would have been further enhanced if transcripts and findings had been checked by participants (124). Dependability and confirmability was strengthened by the use of and documentation in accordance with the COREQ guidelines. Along with this documentation, supporting notes were made of thoughts, discussions and choices made along the entire process from designing the studies to completing analysis. A limitation was that a more structured form of audit trail was not documented. Transferability is discussed separately under sampling.

In the COREQ guidelines it is stated that qualitative researchers closely engage with the research process and participants. Therefore personal bias cannot be completely avoided and should be addressed to improve credibility of findings (124). This is often referred to as reflexivity in research. The theoretical and epistemological positions that guided work on this thesis were discussed in the research group and reflections written down before and during data collection and analysis. I have worked as an occupational therapist within the field of stroke rehabilitation for more than 10 years. This has naturally affected the way I approached this research and my interaction with participants and data. To an extent this may have biased what was discussed during the interviews and how data was selected during analysis. However, being aware of the risks of my pre-understanding and discussing it with co-authors before and during data collection also allowed for me to use my experience as a resource during the interviews, contributing to a stronger dialogue. During the analysis my pre-understanding was continuously challenged by co-authors and the fact that

more than one profession and a wide range of experiences from the field of stroke care and rehabilitation were represented in the research team enhanced reflexivity. However, the research team only included researchers with pre-understanding of the research area. To further enhance reflexivity findings were also discussed with researchers and PhD students working within other fields than stroke.

CONCLUSION

Exploring occupational performance seven years post stroke findings of this thesis show that many stroke survivors have a reduced frequency of occupational performance. Though the majority of participants were independent in basic ADL and lived independently without community aid many remained inactive in the more complex instrumental activities of daily living. The lowest frequencies of occupational performance were found within work and leisure activities. This was later confirmed in interviews as participants described social and work activities as particularly affected after stroke.

Commonly used assessments such as the NIHSS and mRS can be useful to identify people at risk of limitations in IADL, but the significance and impact of problems identified by using these instruments may decrease with time. Early on it is important to also consider a person's age, gender and access to informal support in relation to the occupations they need or wish to engage in.

In both quantitative and qualitative studies less visible symptoms of stroke, such as cognitive dysfunction, emotional changes and fatigue, were found to affect occupational engagement. The impact of these symptoms was persistent and for many meant an ongoing need to choose between occupations and for continued adaptations. Given the advances in acute treatment and rehabilitation after stroke, more people will likely have mild stroke. Findings will hopefully contribute to the discussions of what defines a mild stroke. More importantly, findings show that regardless of how mild or severe a stroke is the impact for occupational engagement should be addressed to complement objective assessments.

The reduced frequencies of occupational performance were related to priorities where consequences of doing were balanced against the value of an occupation. The described experiences of occupational engagement provided important insights on how occupational engagement is key for adaptation and moving forward with life, which implies that occupational engagement can be used to motivate and facilitate the process of adaptation. Time was found important for moving on and show that many would likely benefit from rehabilitation that is more flexible in timing, stretch across longer periods of time and is more focused on supporting individual adaptive strategies.

Findings highlight the need to address RTW not just as an isolated outcome but as part of everyday life after stroke. Maintaining or replacing work with

new occupations was challenging and findings indicate a need for focusing on the ability to maintain work and on addressing the consequences of work in relation to other aspects of life. The fact that some participants were dependent on support and adjustments to maintain work, and that this was an ongoing challenge throughout their work life, indicate a need for a more flexible approach to supporting RTW that continues past the initial return. Findings provide knowledge about facilitators and barriers in the process surrounding return to work and at the workplace that can be used to support stroke survivors in these contexts

Adapting to the challenges brought on by stroke is a long process in which the performance and experience of occupations are co-dependent and key for moving forward. The inclusion of both objective and subjective perspective on occupation has enabled a more nuanced picture of the long-term consequences of stroke. The changes in occupational performance and experiences after stroke found in these studies indicate a need for long-term support and rehabilitation where attention should be paid to supporting stroke survivors to engage in occupations that enable them to find ways of adapting to consequence that are in accordance with individual goals and context. For younger stroke survivors' particular attention should be paid to work and encompass a broader perspective than initial return.

FUTURE PERSPECTIVES

- Findings suggest that understanding and adapting to changed abilities takes time. The findings contribute to a growing number of studies that suggest a need for long-term rehabilitation and support to stroke survivors as they face new occupational challenges over time. Findings of this thesis support a need for interventions that focus on enabling opportunities for occupational engagement in personally valued occupations. Such interventions require flexibility of the timeframe for interventions and need to be individualised, taking personal and contextual aspects into account.
- Though support was identified as an important factor for occupational engagement further research on the timing and content of such support is needed to understand how the healthcare system can meet a need for long-term support and rehabilitation. The implementation of structured and continuous follow-ups is one way to identify persons that require access to formal support, but in order to address the content of interventions and how these can be made available in a long-term perspective more research is required. Such research needs to consider the experiences of the people living with long-term consequences of stroke.
- Further studies are required to confirm or challenge the findings of this thesis. Further it is of interest to address the applicability of our finding in today's context.
- Though the use of the Frenchay Activities Index provided an accessible way of assessing occupational performance and compare finding to other studies the findings indicate a need for new or updated instruments that are adapted to use in current society and for younger stroke survivors. Further, the way of categorising occupations by type rather than significance for the person can be seen as a limitation of many current instruments. The development and evaluation of new instruments to operationalise occupational engagement provide a huge challenge for future research.
- The ReWork-Stroke program is promising in relation to the identified need of individual support and the barriers and facilitators for RTW identified in study IV. Further research on the ability to maintain work and how to provide long-term support is however needed as finding indicate a need to expand vocational rehabilitation to promote RTW in a longer perspective.
- Longitudinal studies that follow stroke survivors over time using repeat interviews and assessment are needed to understand more about how outcomes can change over time. This could also capture experiences of rehabilitation that were not addressed in this thesis.

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REFERENCES

1. Law M. Participation in the occupations of everyday life. *Am J Occup Ther.* 2002;56(6):640-9.
2. Ikiugu M, Pollard N, Cross A, Willer M, Everson J, Stockland J. Meaning Making through Occupations and Occupational Roles: A Heuristic Study of Worker-Writer Histories. *Br J Occup Ther.* 2012;75(6):289-95.
3. Christiansen CH, Townsend EA. Introduction to occupation: the art and science of living; new multidisciplinary perspectives for understanding human occupation as a central feature of individual experience and social organization. 2nd ed. Upper Saddle River, NJ: Upper Saddle River, NJ: Pearson; 2010.
4. Wilcock A. A theory of the human need for occupation. *J Occup Sci.* 1993;1(1):17-24.
5. Black MH, Milbourn B, Desjardins K, Sylvester V, Parrant K, Buchanan A. Understanding the meaning and use of occupational engagement: Findings from a scoping review. *Br J Occup Ther.* 2019;82(5):272-87.
6. Johnson CO, Nguyen M, Roth GA, Nichols E, Alam T, Abate D, et al. Global, regional, and national burden of stroke, 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet Neurol.* 2019;18(5):439-58.
7. Sarre S, Redlich C, Tinker A, Sadler E, Bhalla A, McKeivitt C. A systematic review of qualitative studies on adjusting after stroke: lessons for the study of resilience. *Disabil Rehabil.* 2014;36(9):716-26.
8. Walsh ME, Galvin R, Loughnane C, Macey C, Horgan NF. Community re-integration and long-term need in the first five years after stroke: Results from a national survey. *Disabil Rehabil.* 2015;37(20):1834-8.
9. Wolfe CD, Crichton SL, Heuschmann PU, McKeivitt CJ, Toschke AM, Grieve AP, et al. Estimates of outcomes up to ten years after stroke: analysis from the prospective South London Stroke Register. *PLoS Med.* 2011;8(5):e1001033.
10. Feigin VL, Barker-Collo S, Parag V, Senior H, Lawes CMM, Ratnasabapathy Y, et al. Auckland Stroke Outcomes Study: Part 1: Gender, stroke types, ethnicity, and functional outcomes 5 years poststroke. *Neurology.* 2010;75(18):1597-607.
11. Salter K, Hellings C, Foley N, Teasel R. The Experience Of Living With Stroke: A Qualitative Meta-Synthesis. *J Rehabil Med.* 2008;40(8):595-602.
12. Walder K, Molineux M, Bissett M, Whiteford G. Occupational adaptation - analyzing the maturity and understanding of the concept

- through concept analysis. *Scand J Occup Ther.* Online 2019. DOI:10.1080/11038128.2019.1695931.
13. Egan M, Davis CG, Dubouloz CJ, Kessler D, Kubina LA. Participation and well-being poststroke: Evidence of reciprocal effects. *Arch Phys Med Rehabil.* 2014;95(2):262-8.
 14. Woodman P, Riazi A, Pereira C, Jones F. Social participation post stroke: a meta-ethnographic review of the experiences and views of community-dwelling stroke survivors. *Disabil Rehabil.* 2014;36(24):2031-43.
 15. Kielhofner G. A model of human occupation: theory and application. 3. ed. Baltimore, MD: Baltimore, MD: Lippincott Williams & Wilkins; 2002.
 16. Grajo L, Boisselle A. Occupational Adaptation as a Construct: A Scoping Review of Literature. *Open J Occup Ther.* 2018;6(1).
 17. Maaijwee NAMM, Rutten-Jacobs LCA, Schaapsmeeders P, Van Dijk EJ, De Leeuw FE. Ischaemic stroke in young adults: Risk factors and long-term consequences. *Nat Rev Neurol.* 2014;10(6):315-25.
 18. Krishnamurthi RV, Moran AE, Feigin VL, Barker-Collo S, Norrving B, Mensah GA, et al. Stroke Prevalence, Mortality and Disability-Adjusted Life Years in Adults Aged 20-64 Years in 1990-2013: Data from the Global Burden of Disease 2013 Study. *Neuroepidemiology.* 2015;45(3):190-202.
 19. Feigin VL, Forouzanfar MH, Krishnamurthi R, Mensah GA, Connor M, Bennett DA, et al. Global and regional burden of stroke during 1990-2010: Findings from the Global Burden of Disease Study 2010. *Lancet.* 2014;383(9913):245-55.
 20. Njelesani J, Tang A, Jonsson H, Polatajko H. Articulating an Occupational Perspective. *J Occup Sci.* 2014;21(2):226-35.
 21. Glover JS. The literature of occupational science: A systematic, quantitative examination of peer-reviewed publications from 1996-2006. *J Occup Sci.* 2009;16(2):92-103.
 22. Wilcock A. Making Sense of What People Do: Historical Perspectives. *J Occup Sci.* 2003;10(1):4-6.
 23. Hasselkus B. Reaching consensus. *Am J Occup Ther.* 2000;54(2):127-8.
 24. Pierce D. Untangling occupation and activity. *Am J Occup Therapy.* 2001;55(2):138.
 25. Hammell KW. Self-Care, Productivity, and Leisure, or Dimensions of Occupational Experience? Rethinking Occupational “Categories”. *Can J Occup Ther.* 2009;76(2):107-14.
 26. Townsend EA, Polatajko HJ, Canadian Association of Occupational Therapists. Enabling occupation II: advancing an occupational therapy

- vision for health, well-being & justice through occupation: Ottawa: CAOT Publications ACE; 2007.
27. Kielhofner G, Taylor RR. Kielhofner's model of human occupation: theory and application. Fifth edition. ed: Philadelphia: Wolters Kluwer; 2017.
 28. Christiansen CH, Townsend EA. Introduction to occupation New Jersey: Pearson Education; 2004.
 29. Jonsson H. A new direction in the conceptualization and categorization of occupation. *J Occup Sci.* 2008;15(1):3-8.
 30. Bejerholm U, Eklund M. Occupational Engagement in Persons With Schizophrenia: Relationships to Self-Related Variables, Psychopathology, and Quality of Life. *Am J Occup Ther.* 2007;61(1):21-32.
 31. Morris K, Cox DL. Developing a descriptive framework for "occupational engagement". *J Occup Sci.* 2017;24(2):152-64.
 32. Kennedy J, Davis JA. Clarifying the Construct of Occupational Engagement for Occupational Therapy Practice. *OTJR.* 2017;37(2):98-108.
 33. Larsson-Lund M, Nyman A. Participation and occupation in occupational therapy models of practice: A discussion of possibilities and challenges. *Scand J Occup Ther.* 2017;24(6):393-7.
 34. Kielhofner G. Model of human occupation: theory and application. 4. ed. ed. Baltimore, MD: Baltimore, MD: Lippincott Williams & Wilkins; 2008.
 35. Hammell KW. Dimensions of Meaning in the Occupations of Daily Life. *Can J Occup Ther.* 2004;71(5):296-305.
 36. World Health Organization. International Classification of Functioning, Disability and Health: ICF. Geneva: World Health Organization; 2001.
 37. Hemmingsson H, Jonsson H. An occupational perspective on the concept of participation in the International Classification of Functioning, Disability and Health--some critical remarks. *Am J Occup Ther.* 2005;59(5):569-76.
 38. Mallinson T, Hammel J. Measurement of Participation: Intersecting Person, Task, and Environment. *Arch Phys Med Rehabil.* 2010;91(9):29-33.
 39. Cott CA, Wiles R, Devitt R. Continuity, transition and participation: Preparing clients for life in the community post-stroke. *Disabil Rehabil.* 2007;29(20-21):1566-74.
 40. Schkade JK, Schultz S. Occupational adaptation: toward a holistic approach for contemporary practice, Part 1. *Am J Occupational Therapy.* 1992;46(9):829-37.

41. Walder K, Molineux M. Occupational adaptation and identity reconstruction: A grounded theory synthesis of qualitative studies exploring adults' experiences of adjustment to chronic disease, major illness or injury. *J Occup Sci.* 2017;24(2):225-43.
42. Nayar S, Stanley M. Occupational Adaptation as a Social Process in Everyday Life. *J Occup Sci.* 2015;22(1):26-38.
43. Lexell EM, Iwarsson S, Lund ML. Occupational Adaptation in People with Multiple Sclerosis. *OTJR.* 2011;31(3):127-34.
44. Erikson A, Karlsson G, Borell L, Tham K. The Lived Experience of Memory Impairment in Daily occupation after Acquired Brain Injury. *OTJR.* 2007;27(3):84-94.
45. Aho K, Harmsen P, Hatano S, Marquardsen J, Smirnov VE, Strasser T. Cerebrovascular disease in the community: results of a WHO collaborative study. *Bulletin of the World Health Organization.* 1980;58(1):113.
46. Bamford J, Sandercock P, Dennis M, Warlow C, Burn J. Classification and natural history of clinically identifiable subtypes of cerebral infarction. *Lancet.* 1991;337(8756):1521-6.
47. Feigin V, Krishnamurthi R, Parmar P, Norrving B, Mensah G, Bennett D, et al. Update on the Global Burden of Ischemic and Hemorrhagic Stroke in 1990-2013: The GBD 2013 Study. *Neuroepidemiology.* 2015;45(3):161-76.
48. Sennfält S, Norrving B, Petersson J, Ullberg T. Long-Term Survival and Function After Stroke: A Longitudinal Observational Study From the Swedish Stroke Register. *Stroke.* 2019;50(1):53-61.
49. Socialstyrelsen. Nationella riktlinjer för vård vid stroke - Stöd för styrning och ledning. Stockholm: Socialstyrelsen; 2020.
50. Feigin VL, Nichols E, Alam T, Bannick MS, Beghi E, Blake N, et al. Global, regional, and national burden of neurological disorders, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *Lancet Neurol.* 2019;18(5):459-80.
51. Feigin LV, Norrving AB, Mensah AG. Global Burden of Stroke. *Circ Res.* 2017;120(3):439-48.
52. de Graaf JA, van Mierlo ML, Post MWM, Achterberg WP, Kappelle LJ, Visser-Meily JMA. Long-term restrictions in participation in stroke survivors under and over 70 years of age. *Disabil Rehabil.* 2018;40(6):637-45.
53. Norrving B, Barrick J, Davalos A, Dichgans M, Cordonnier C, Guekht A, et al. Action Plan for Stroke in Europe 2018–2030. *Eur Stroke J.* 2018;3(4):309-36.
54. Saka Ö, McGuire A, Wolfe C. Cost of stroke in the United Kingdom. *Age Ageing.* 2009;38(1):27-32.

55. Langhorne P, Bernhardt J, Kwakkel G. Stroke rehabilitation. *Lancet*. 2011;377(9778):1693-702.
56. Ghatnekar O, Persson U, Asplund K, Glader E-L. Costs for stroke in Sweden 2009 and developments since 1997. *Int J Technol Assess Health Care*. 2014;30(2):203-9.
57. Rosengren A, Giang KW, Lappas G, Jern C, Torén K, Björck L. Twenty-four-year trends in the incidence of ischemic stroke in Sweden from 1987 to 2010. *Stroke*. 2013;44(9):2388-93.
58. Singhal BA, Biller SJ, Elkind JM, Fullerton CH, Jauch JE, Kittner AS, et al. Recognition and management of stroke in young adults and adolescents. *Neurology*. 2013;81(12):1089-97.
59. Sen A, Bisquera A, Wang Y, McKeivitt CJ, Rudd AG, Wolfe CD, et al. Factors, trends, and long-term outcomes for stroke patients returning to work: The South London Stroke Register. *Int J Stroke*. 2019;14(7):696-705.
60. Persson J, Ferraz-Nunes J, Karlberg I. Economic burden of stroke in a large county in Sweden. *BMC Health Serv Res*. 2012;12(1).
61. Socialstyrelsen. Statistik om stroke 2018; 2020 [cited 2020 may 25]. Available from: <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/statistik/2019-12-6485.pdf>
62. Giang KW, Mandalenakis Z, Nielsen S, Björck L, Lappas G, Adiels M, et al. Long-term trends in the prevalence of patients hospitalized with ischemic stroke from 1995 to 2010 in Sweden. *PLoS ONE*. 2017;12(6):e0179658.
63. Bernhardt J, Hayward KS, Kwakkel G, Ward NS, Wolf SL, Borschmann K, et al. Agreed definitions and a shared vision for new standards in stroke recovery research: The Stroke Recovery and Rehabilitation Roundtable taskforce. *Int J Stroke*. 2017;12(5):444-50.
64. Kristensen H, Postat A, Poulsen T, Jones D, Minet LR. Subjective experiences of occupational performance of activities of daily living in patients with mild stroke. *Int J Ther Rehabil*. 2014;21(3):118-25.
65. Acciarresi M, Bogousslavsky J, Paciaroni M. Post-stroke fatigue: Epidemiology, clinical characteristics and treatment. *Eur Neurol*. 2014;72(5-6):255-61.
66. Redfors P, Hofgren C, Eriksson I, Holmegaard L, Samuelsson H, Jood K. The barrow neurological institute screen for higher cerebral functions in cognitive screening after stroke. *J Stroke Cerebrovasc Dis*. 2014;23(2):349-55.
67. McGeough E, Pollock A, Smith LN, Dennis M, Sharpe M, Lewis S, et al. Interventions for post-stroke fatigue. *Cochrane Database of Systematic Reviews*. 2009(3).

68. Teasdale TW, Engberg AW. Psychosocial consequences of stroke: A long-term population-base follow-up. *Brain Inj.* 2005;19(12):1049-58.
69. Murray J, Young J, Forster A, Ashworth R. Developing a primary care-based stroke model: The prevalence of longer-term problems experienced by patients and carers. *Br J Gen Pract.* 2003;53(495):803-7.
70. Douiri A, Rudd AG, Wolfe CDA. Prevalence of poststroke cognitive impairment: South London stroke register 1995-2010. *Stroke.* 2013;44(1):138-45.
71. Palstam A, Sjodin A, Sunnerhagen KS. Participation and autonomy five years after stroke: A longitudinal observational study. *PLoS ONE.* 2019;14(7):e0219513.
72. World Health Organization. *Rehabilitation in health systems.* Geneva: World Health Organization 2017.
73. Socialstyrelsen. Nationella riktlinjer [cited 2020 may 25]. Available from: <https://www.socialstyrelsen.se/regler-och-riktlinjer/nationella-riktlinjer/>.
74. Collaboration SUT. Organised inpatient (stroke unit) care for stroke. *Cochrane Database of Systematic Reviews.* 2013(9).
75. Riksstroke. Stroke och TIA. Riksstroke's årsrapport 2018. [cited 2020 may 25]. Available from: www.riksstroke.org/sve/forskning-statistik-och-verksamhetsutveckling/rapporter/arsrapporter/.
76. Socialstyrelsen. Nationella riktlinjer- Utvärdering 2018. Utvärdering av vård vid stroke. [cited 2020 may 25]. Available from: <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/nationella-riktlinjer/2018-12-59-socioekonomi.pdf>
77. Riksstroke. Fem och tre år efter stroke; 2018 [cited 2020 may 25]. Available from: <http://www.riksstroke.org/wp-content/uploads/2018/07/Fem-och-tre-%C3%A5r-efter-stroke.pdf>.
78. Feigin VL, Barker-Collo S, McNaughton H, Brown P, Kerse N. Long-term neuropsychological and functional outcomes in stroke survivors: Current evidence and perspectives for new research. *Int J Stroke.* 2008;3(1):33-40.
79. Dhamoon MS, Moon YP, Paik MC, Boden-Albala B, Rundek T, Sacco RL, et al. Long-term functional recovery after first ischemic stroke: The Northern manhattan study. *Stroke.* 2009;40(8):2805-11.
80. Sacco RL, Sandercock P, Endres M, Feigin V, Pandian J, Shinohara Y, et al. Review and prioritization of stroke research recommendations to address the mission of the World Stroke Organization: a call to action from the WSO Research Committee. *Int J Stroke.* 2015;10(SA100):4-9.

81. Daniel K, Wolfe CDA, Busch MA, McKeivitt C. What are the social consequences of stroke for working-aged adults?: a systematic review. *Stroke*. 2009;40(6):e431-e40.
82. Turner GM, McMullan C, Atkins L, Foy R, Mant J, Calvert M. TIA and minor stroke: a qualitative study of long-term impact and experiences of follow-up care. *BMC Fam Pract*. 2019;20(1):176.
83. Carlsson GE, Möller A, Blomstrand C. A qualitative study of the consequences of 'hidden dysfunctions' one year after a mild stroke in person < 75 years. *Disabil Rehabil*. 2004;26(23):1373-80.
84. Anderson S, Whitfield K. Social identity and stroke: 'They don't make me feel like, there's something wrong with me'. *Scand J Caring Sci*. 2013;27(4):820-30.
85. Jellema S, van Der Sande R, van Hees S, Zajec J, Steultjens EM, Nijhuis-van Der Sanden MW. Role of Environmental Factors on Resuming Valued Activities Poststroke: A Systematic Review of Qualitative and Quantitative Findings. *Arch Phys Med Rehabil*. 2016;97(6):991-1002.e1.
86. Mayo NE, Wood-Dauphinee S, Cote R, Durcan L, Carlton J. Activity, participation, and quality of life 6 months poststroke. *Arch Phys Med Rehabil*. 2002;83(8):1035-42.
87. Brewer L, Horgan F, Hickey A, Williams D. Stroke rehabilitation: Recent advances and future therapies. *QJM*. 2013;106(1):11-25.
88. Parker CJ, Gladman JRF, Drummond AER. The role of leisure in stroke rehabilitation. *Disabi Rehabil*. 1997;19(1):1-5.
89. Satink T, Cup EH, Ilott I, Prins J, De Swart BJ, Nijhuis-Van Der Sanden MW. Patients' views on the impact of stroke on their roles and self: A thematic synthesis of qualitative studies. *Arch Phys Med Rehabil*. 2013;94(6):1171-83.
90. Boosman H, Schepers VPM, Post MWM, Visser-Meily JMA. Social activity contributes independently to life satisfaction three years post stroke. *Clin Rehabil*. 2011;25(5):460-7.
91. Jansen HE, Schepers VP, Visser-Meily JM, Post MW. Social activity one and three years post-stroke. *J Rehabil Med*. 2012;44(1):47-50.
92. Sveen U, Thommessen B, Bautz-Holter E, Wyller TB, Laake K. Well-being and instrumental activities of daily living after stroke. *Clin Rehabil*. 2004;18(3):267-74.
93. Palmcrantz S, Widén Holmqvist L, Sommerfeld DK. Young individuals with stroke: A cross sectional study of long-term disability associated with self-rated global health. *BMC Neurol*. 2014;14(1).
94. Singam A, Ytterberg C, Tham K, Von Koch L. Participation in complex and social everyday activities six years after stroke: Predictors for return to pre-stroke level. *PLoS ONE*. 2015;10(12).

95. Svensson JS, Westerlind E, Persson HC, Sunnerhagen KS. Occupational gaps 5 years after stroke. *Brain Behav.* 2019;9(3).
96. Erikson A. Living with the Long-Term Consequences 11–13 Years After Stroke: A Phenomenological Study. *J Rehabil Med.* 2016;48(10):847-52.
97. Hackett ML, Glozier N, Jan S, Lindley R. Returning to paid employment after stroke: The psychosocial outcomes in stroke (POISE) cohort study. *PLoS ONE.* 2012;7(7).
98. Aarnio K, Rodríguez-Pardo J, Siegerink B, Hardt J, Broman J, Tulkki L, et al. Return to work after ischemic stroke in young adults: A registry-based follow-up study. *Neurology.* 2018;19(20):1909-e1917.
99. Babulal GM, Huskey TN, Roe CM, Goette SA, Connor LT. Cognitive impairments and mood disruptions negatively impact instrumental activities of daily living performance in the first three months after a first stroke. *Top Stroke Rehabil.* 2015;22(2):144-51.
100. Liman TG, Heuschmann PU, Endres M, Flöel A, Schwab S, Kolominsky-Rabas PL. Impact of low mini-mental status on health outcome up to 5 years after stroke: The Erlangen Stroke Project. *J Neurol.* 2012;259(6):1125-30.
101. Zinn S, Dudley TK, Bosworth HB, Hoenig HM, Duncan PW, Horner RD. The effect of poststroke cognitive impairment on rehabilitation process and functional outcome. *Arch Phys Med Rehabil.* 2004;85(7):1084-90.
102. Maaijwee NAMM, Tendolkar I, Rutten-Jacobs LCA, Arntz RM, Schaapsmeeders P, Dorresteijn LD, et al. Long-term depressive symptoms and anxiety after transient ischaemic attack or ischaemic stroke in young adults. *Eur J Neurol.* 2016;23(8):1262-8.
103. Muina-Lopez R, Guidon M. Impact of post-stroke fatigue on self-efficacy and functional ability. *Eur J Physiother.* 2013;15(2):86-92.
104. van de Port IGL, Kwakkel G, Schepers VPM, Heinemans CTI, Lindeman E. Is Fatigue an Independent Factor Associated with Activities of Daily Living, Instrumental Activities of Daily Living and Health-Related Quality of Life in Chronic Stroke? *Cerebrovasc Dis.* 2007;23(1):40-5.
105. White JH, Gray KR, Magin P, Attia J, Sturm J, Carter G, et al. Exploring the experience of post-stroke fatigue in community dwelling stroke survivors: A prospective qualitative study. *Disabil Rehabil.* 2012;34(16):1376-84.
106. Carlsson GE, Möller A, Blomstrand C. Consequences of mild stroke in persons <75 years - A 1-year follow-up. *Cerebrovasc Dis.* 2003;16(4):383-8.

107. Blömer AMV, Van Mierlo ML, Visser-Meily JM, Van Heugten CM, Post MW. Does the frequency of participation change after stroke and is this change associated with the subjective experience of participation? *Arch Phys Med Rehabil.* 2015;96(3):456-63.
108. Kuluski K, Dow C, Locoock L, Lyons RF, Lasserson D. Life interrupted and life regained? Coping with stroke at a young age. *Int J Qual Stud Health Well-being.* 2014;9(1).
109. Brannigan C, Galvin R, Walsh M, Loughnane C, Morrissey E-J, Macey C. Barriers and facilitators associated with return to work after stroke: a qualitative meta-synthesis. *Disabil Rehabil.* 2017;39(3):211-22.
110. Törnborn K, Lundälv J, Sunnerhagen KS, Dearborn-Tomazos J. Long-term participation 7-8 years after stroke: Experiences of people in working-age. *PLoS ONE.* 2019;14(3).
111. Medin J, Barajas J, Ekberg K. Stroke patients' experiences of return to work. *Disabil Rehabil.* 2006;28(17):1051-60.
112. Vestling M, Tufvesson B, Iwarsson S. Indicators for return to work after stroke and the importance of work for subjective well-being and life satisfaction. *J Rehabil Med.* 2003;35(3):127-31.
113. Roding J, Glader E, Malm J, Lindstrom B. Life satisfaction in younger individuals after stroke: different predisposing factors among men and women. *J Rehabil Med.* 2010;42(2):155-61.
114. Edwards JD, Kapoor A, Linkewich E, Swartz RH. Return to work after young stroke: A systematic review. *Int J Stroke.* 2018;13(3):243-56.
115. Young A, Roessler R, Wasiak R, McPherson K, Poppel M, Anema J. A Developmental Conceptualization of Return to Work. *J Occup Rehabil.* 2005;15(4):557-68.
116. Öst Nilsson A. ReWork-Stroke: content and experiences of a person-centred rehabilitation programme for return to work after stroke. [Dissertation]. Stockholm: Karolinska Institutet, Dept of Neuroscience; 2019.
117. Palstam A, Westerlind E, Persson HC, Sunnerhagen KS. Work-related predictors for return to work after stroke. *Acta Neurol Scand.* 2019;139(4): 382-8.
118. Westerlind E, Persson HC, Eriksson M, Norrving B, Sunnerhagen KS. Return to work after stroke: A Swedish nationwide registry-based study. *Acta Neurol Scand.* 2020;141(1).56-64.
119. Schwarz B, Claros-Salinas D, Streibelt M. Meta-Synthesis of Qualitative Research on Facilitators and Barriers of Return to Work After Stroke. *J Occup Rehabil.* 2018;28(1):28-44.
120. Hartke RJ, Trierweiler R, Bode R. Critical Factors Related to Return to Work After Stroke: A Qualitative Study. *Top Stroke Rehabil.* 2011;18(4):341-51.

121. Jood K, Ladenvall C, Rosengren A, Blomstrand C, Jern C. Family history in ischemic stroke before 70 years of age: The Sahlgrenska academy study on ischemic stroke. *Stroke*. 2005;36(7):1383-7.
122. Redfors P, Jood K, Holmegaard L, Rosengren A, Blomstrand C, Jern C. Stroke subtype predicts outcome in young and middle-aged stroke sufferers. *Acta Neurol Scand*. 2012;126(5):329-35.
123. Malterud K, Siersma VD, Guassora AD. Sample Size in Qualitative Interview Studies: Guided by Information Power. *Qual Health Res*. 2015;26(13):1753-60.
124. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349-57.
125. Holbrook M, Skilbeck CE. An activities index for use with stroke patients. *Age Ageing*. 1983;12:166-70.
126. Carter J, Mant J, Wade D, Winner S. Comparison of postal version of the Frenchay Activities Index with interview-administered version for use in people with stroke. *Clin Rehabil*. 1997;11:131-8.
127. Schuling J, de Haan R, Limburg M, Groenier KH. The Frenchay Activities Index. Assessment of functional status in stroke patients. *Stroke*. 1993;24:1173-7.
128. Wade DT, Legh-Smith J, Hewer RL. Social activities after stroke: Measurement and natural history using the Frenchay Activities Index. *Int Rehabil Med*. 1985;7(4):176-81.
129. Piercy M, Carter J, Mant J, Wade DT. Inter-rater reliability of the Frenchay Activities Index in patients with stroke and their carers. *Clin Rehabil*. 2000;14(4):433-40.
130. Lin KC, Chen HF, Wu CY, Yu TY, Ouyang P. Multidimensional Rasch validation of the Frenchay Activities Index in stroke patients receiving rehabilitation. *J Rehabil Med*. 2012;44(1):58-64.
131. Mahoney FI, Barthel DW. Functional evaluation: the Barthel Index. *Md State Med J*. 1965;14:61-5.
132. Collin C, Wade DT, Davies S, Horne V. The Barthel ADL Index: A reliability study. *Int Disabil Stud*. 1988;10(2):61-3.
133. Green J, Forster A, Young J. A test-retest reliability study of the Barthel Index, the Rivermead Mobility Index, the Nottingham extended Activities of Daily Living Scale and the Frenchay Activities Index in stroke patients. *Disabil Rehab*. 2001;23(15):670-6.
134. Wade DT, Collin C. The Barthel ADL Index: A standard measure of physical disability? *Int Disabil Stud*. 1988;10(2):64-7.
135. van Swieten JC, Koudstaal PJ, Visser MC, Schouten HJA, Van Gijn J. Interobserver agreement for the assessment of handicap in stroke patients. *Stroke*. 1988;19(5):604-7.

136. Dromerick AW, Edwards DF, Diringner MN. Sensitivity to changes in disability after stroke: A comparison of four scales useful in clinical trials. *J Rehabil Res Dev.* 2003;40(1):1-8.
137. Wolfe D, Taub NA, Woodrow EJ, Burney PG. Assessment of scales of disability and handicap for stroke patients. *Stroke.* 1991;22(10):1242-4.
138. Fisk JD, Ritvo PG, Ross L, Haase DA, Marrie TJ, Schlech WF. Measuring the functional impact of fatigue: Initial validation of the fatigue impact scale. *Clin Infect Dis.* 1994;18(1):79-83.
139. Dittner AJ, Wessely SC, Brown RG. The assessment of fatigue: A practical guide for clinicians and researchers. *J Psychosom Res.* 2004;56(2):157-70.
140. Flensner G, Anna-Christina E, Söderhamn O. Reliability and validity of the Swedish version of the Fatigue Impact Scale (FIS). *Scand J Occup Ther.* 2005;12(4):170-80.
141. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand.* 1983;67(6):361-70.
142. Sullivan M, Karlsson J, Sjostrom L, Backman L, Bengtsson C, Bouchard C, et al. Swedish obese subjects (SOS) - An intervention study of obesity. Baseline evaluation of health and psychosocial functioning in the first 1743 subjects examined. *Int J Obes.* 1993;17(9):503-12.
143. Saboonchi F, Wennman-Larsen A, Alexanderson K, Petersson L-M. Examination of the construct validity of the Swedish version of Hospital Anxiety and Depression Scale in breast cancer patients. *Qual Life Res.* 2013;22(10):2849-56.
144. Kang HJ, Stewart R, Kim JM, Jang JE, Kim SY, Bae KY, et al. Comparative validity of depression assessment scales for screening poststroke depression. *J Affect Disord.* 2013;147(1-3):186-91.
145. Aben I, Verhey F, Lousberg R, Lodder J, Honig A. Validity of the Beck Depression Inventory, Hospital Anxiety and Depression Scale, SCL-90, and Hamilton Depression Rating Scale as screening instruments for depression in stroke patients. *Psychosomatics.* 2002;43(5):386-93.
146. Denvall V, Elmståhl S, Prigatano GP. Replication and construct validation of the Barrow Neurological Institute Screen for Higher Cerebral Function with a Swedish population. *J Rehabil Med.* 2002;34(4):153-7.
147. Hofgren C, Esbjörnsson E, Aniansson H, Sunnerhagen KS. Application and validation of the Barrow Neurological Institute Screen for Higher Cerebral Functions in a control population and in patient groups commonly seen in neuro-rehabilitation. *J Rehabil Med.* 2007;39(7):547-53.
148. Boosman H, Visser-Meily JMA, Post MWM, Duits A, Van Heugten CM. Validity of the barrow neurological institute (BNI) screen for

- higher cerebral functions in stroke patients with good functional outcome. *Clin Neuropsychol.* 2013;27(4):667-80.
149. Aberg E, Adielsson G, Almqvist A, Andersson LO, Asplund K, Aursnes I, et al. Multicenter trial of hemodilution in ischemic stroke — background and study protocol. *Stroke.* 1985;16(5):885-90.
150. Govan L, Langhorne P, Weir CJ. Categorizing stroke prognosis using different stroke scales. *Stroke.* 2009;40(10):3396-9.
151. Brott T, Adams Jr HP, Olinger CP, Marler JR, Barsan WG, Biller J, et al. Measurements of acute cerebral infarction: A clinical examination scale. *Stroke.* 1989;20(7):864-70.
152. Gray LJ, Ali M, Lyden PD, Bath PMW. Interconversion of the National Institutes of Health Stroke Scale and Scandinavian Stroke Scale in Acute Stroke. *J Stroke Cerebrovasc Dis.* 2009;18(6):466-8.
153. Goldstein LB, Samsa GP. Reliability of the National Institutes of Health Stroke Scale: Extension to non-neurologists in the context of a clinical trial. *Stroke.* 1997;28(2):307-10.
154. Carcary M. The research audit trial - enhancing trustworthiness in qualitative inquiry. *Electronic Journal of Business Research Methods.* 2009;7(1):11-24.
155. Williams S, Murray C. The experience of engaging in occupation following stroke: A qualitative meta-synthesis. *Br J Occup Ther.* 2013;76(8):370-8.
156. Vestling M, Ramel E, Iwarsson S. Thoughts and experiences from returning to work after stroke. *Work.* 2013;45(2):201-11.
157. Gellerstedt M. M^{12} : medicinsk statistik. Merck S, Dohme, editors. Sollentuna: Merck Sharp & Dohme; 2004.
158. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol.* 2006;3(2):77-101.
159. Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nurs Health Sci.* 2013;15(3):398-405.
160. Patton MQ. *Qualitative evaluation and research methods.* 2. ed. Newbury Park, CA: Sage;1990.
161. Patton MQ. Two Decades of Developments in Qualitative Inquiry: A Personal, Experiential Perspective. *Qualitative Social Work.* 2002;1(3):261-83.
162. Kvale S. *Interviews : an introduction to qualitative research interviewing.* Thousand Oaks: SAGE; 1996.
163. Persson J, Holmegaard L, Karlberg I, Redfors P, Jood K, Jern C, et al. Spouses of Stroke Survivors Report Reduced Health-Related Quality of Life even in Long-Term Follow-Up: Results from Sahlgrenska Academy Study on Ischemic Stroke. *Stroke.* 2015;46(9):2584-90.

164. Chaker L, Falla A, Lee S, Muka T, Imo D, Jaspers L, et al. The global impact of non-communicable diseases on macro-economic productivity: a systematic review. *Eur J Epidemiol.* 2015;30(5):357-95.
165. Norlander A. Activity and participation long term after stroke. [Dissertation]. Lund. Lund University: Faculty of Medicine; 2019.
166. Norlander A, Jönsson A-C, 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. *Disabil Rehabil.* 2016;38(20):2028-37.
167. Brunborg B, Ytrehus S. Sense of well-being 10 years after stroke. *J Clin Nurs.* 2014;23(7-8):1055-63.
168. Wallenbert I, Jonsson H. Waiting to get better: A dilemma regarding habits in daily occupations after stroke. *Am J Occup Ther.* 2005;59(2):218-24.
169. Palstam A, Törnbom M, Sunnerhagen KS. Experiences of returning to work and maintaining work 7 to 8 years after a stroke: a qualitative interview study in Sweden. *BMJ Open.* 2018;8(7).
170. Eriksson G, Baum MC, Wolf TJ, Connor LT. Perceived participation after stroke: The influence of activity retention, reintegration, and perceived recovery. *Am J Occup Ther.* 2013;67(6):e131-e8.
171. Norlander A, Carlstedt E, Jönsson A-C, Lexell EM, Ståhl A, Lindgren A, et al. Long-Term Predictors of Social and Leisure Activity 10 Years after Stroke. *PloS ONE.* 2016;11(2):e0149395.
172. Glader E-L, Stegmayr B, Asplund K. Poststroke Fatigue: A 2-Year Follow-Up Study of Stroke Patients in Sweden. *Stroke.* 2002;33:1327-33.
173. Ingles JL, Eskes GA, Phillips SJ. Fatigue after stroke. *Arch Phys Med Rehabil.* 1999;80(2):173-8.
174. van der Werf SP, van den Broek HLP, Anten HWM, Bleijenberg G. Experience of severe fatigue long after stroke and its relation to depressive symptoms and disease characteristics. *Eur Neurol.* 2001;45:28-33.
175. Elf M, Eriksson G, Johansson S, Von Koch L, Ytterberg C. Self-reported fatigue and associated factors six years after stroke. *PLoS ONE.* 2016;11(8).
176. Crosby GA, Munshi S, Karat AS, Worthington E, Lincoln NB. Fatigue after stroke: Frequency and effect on daily life. *Disabil Rehabil.* 2012;34(8):633-7.
177. Treger I, Shames J, Giaquinto S, Ring H. Return to work in stroke patients. *Disabil Rehabil.* 2007;29(17):1397-403.

178. Kauranen T, Turunen K, Laari S, Mustanoja S, Baumann P, Poutiainen E. The severity of cognitive deficits predicts return to work after a first-ever ischaemic stroke. *J Neurol, Neurosurg Psychiatry*. 2013;84(3):316.
179. Andersen G, Christensen D, Kirkevold M, Johnsen SP. Post-stroke fatigue and return to work: A 2-year follow-up. *Acta Neurol Scand*. 2012;125(4):248-53.
180. Tistad M, Ytterberg C, Tham K, Von Koch L. Poor concurrence between disabilities as described by patients and established assessment tools three months after stroke: A mixed methods approach. *J Neurol Sci*. 2012;313(1-2):160-6.
181. Wolf TJ, Baum C, Connor LT. Changing face of stroke: Implications for occupational therapy practice. *Am J Occup Ther*. 2009;63(5):621-5.
182. Wolf TJ, Rognstad MC. Changes in cognition following mild stroke. *Neuropsychol Rehabil*. 2013;23(2):256-66.
183. Gillespie DC, Bowen A, Chung CS, Cockburn J, Knapp P, Pollock A. Rehabilitation for post-stroke cognitive impairment: An overview of recommendations arising from systematic reviews of current evidence. *Clin Rehabil*. 2015;29(2):120-8.
184. Eriksen S, Gay CL, Lerdal A. Acute phase factors associated with the course of depression during the first 18 months after first-ever stroke. *Disabil Rehabil*. 2016;38(1):30-5.
185. Walsh ME, Galvin R, Loughnane C, Macey C, Horgan NF. Factors associated with community reintegration in the first year after stroke: a qualitative meta-synthesis. *Disabil Rehabil*. 2015;37(18):1599-608.
186. Redfors P. Long-term post-stroke outcome - the Sahlgrenska Academy Study on Ischemic Stroke. [Dissertation]. Gothenburg. Gothenburg University. The Sahlgrenska Academy. 2014.
187. Appelros P. Characteristics of the Frenchay Activities Index one year after a stroke: A population-based study. *Disabil Rehabil*. 2007;29(10):785-90.
188. Turnbull JC, Kersten P, Habib M, McLellan L, Mullee MA, George S. Validation of the Frenchay Activities Index in a general population aged 16 years and older. *Arch Phys Med Rehabil*. 2000;81(8):1034-8.
189. Rutherford SJ, Theadom A, Jones A, Hocking C, Feigin V, Krishnamurthi R, et al. Capturing the stories behind the numbers: The auckland regional community stroke study (ARCOS IV), a qualitative study. *Int J Stroke*. 2014;9(1):64-70.
190. Nowell LS, Norris JM, White DE, Moules NJ. Thematic Analysis: Striving to Meet the Trustworthiness Criteria. *Int J Qual Methods*. 2017;16(1):160940691773384.
191. Lincoln YS, Guba GE. *Naturalistic inquiry*. Beverly Hills, California: Sage; 1985.