

# Participation after stroke in a short- and long-term perspective

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\*Oxford Dictionary of Proverbs by Jennifer Speake. Oxford University Press, 2015.

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*"Experience are the  
glasses of the mind"*

Arab proverb\*



# Abstract

The main scope of this thesis was to study, evaluate and describe perceived participation among persons with stroke. In doing so, different timepoints were chosen to make a more complete picture of participation after stroke. The two first studies were performed using quantitative methods. In study I the objectives were to describe self-assessed physical, emotional and cognitive impact of stroke and to investigate associations with stroke severity and participation at 1 month after onset. In study II the aim was to investigate how participation was related to background characteristics and rehabilitation outcomes at 1, 6 and 12 months after stroke. In study I and II a self-assessment questionnaire, the Stroke Impact Scale (SIS) 3.0, was used to capture experienced functioning and participation. The results of study I demonstrated that emotional health, communication skills, and the ability to remember were perceived as quite good one month after stroke. Nearly 60% rated their participation as limited, which was related to a lower scoring of physical functioning. The findings of study II showed that participation scores were widely distributed within the study group during the first year after stroke. Associations between perceived physical capacity and participation were found at 1, 6, and 12 months. High levels of emotional health and cognitive skills were only found in combination with, at the very least, a moderate participation score. Findings of study I and II indicate that physical functioning was important for perceived participation during all timepoints that were investigated in the first year after stroke. A continuous focus on physical functioning in rehabilitation should therefore also be beneficial for perceived participation.

Study III and IV had qualitative designs and aimed to exemplify, describe and to deepen our understanding of how participation, and life in general, may be experienced in a long-term perspective after stroke. In study III, eleven participants of working age were recruited 7-8 years after their stroke.

Participants (n 11) in study IV were enrolled from previous study projects at our department and from various stroke patient organizations in Gothenburg. Participants used photovoice and took pictures of everyday life for up to four weeks and then met to discuss all the images in a focus group setting.

Results of study III showed that participants most often emphasized work and social life when describing their participation. They had adapted to a somewhat altered way of living and the importance of consequences after stroke in everyday life had decreased. This result was partly confirmed by the results of study IV, which showed that participants had found new ways to approach difficult situations in everyday life. However, the more multi-dimensional result of study IV showed that several participants still felt depressed many years after onset and were not content with how life had turned out at all. Findings of both qualitative studies showed a need for more knowledge about how participation can be promoted many years after stroke, so that more persons after stroke may achieve a positive identity and a life which they consider meaningful.

Keywords: stroke, rehabilitation, physical functioning, participation, interview study, photovoice.

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# Sammanfattning på svenska

Det övergripande syftet med den här avhandlingen var att undersöka upplevd delaktighet hos personer efter en stroke – på kort såväl som lång sikt efter insjuknandet. För att uppnå en mer heltäckande bild av området valdes tre nedslag under det första året efter stroke, samt 7-8 år i studie III och i den fjärde studien studerades deltagarnas upplevelser minst två år efter stroke.

Syftet med studie I var att beskriva självskattad fysisk, emotionell och kognitiv påverkan av stroke och att undersöka dessa faktorer eventuella samband med självskattad delaktighet, så tidigt som en månad efter stroke. Syftet var även att visa eventuella samband till stroke svårighetsgrad. I studie II var syftet att undersöka samband mellan en persons upplevda delaktighet och bakgrundsfaktorer (såsom kön och ålder) och självskattad fysisk, emotionell och kognitiv funktion 1, 6 och 12 månader efter insjuknande.

I både studie I och II användes ett självskattande och strokespecifikt frågeformulär (SIS), för att undersöka studiepersonernas upplevda funktionsnivå och självskattade delaktighet efter stroke. Resultaten i studie I visade att emotionell hälsa, kommunikativ förmåga och förmågan att komma ihåg saker skattades relativt högt av deltagarna redan en månad efter stroke. Nästan 60 % av studiegruppen skattade sin delaktighet som begränsad, vilket också kunde relateras till en lägre självskattad fysisk funktionsnivå.

Studie II visade att deltagarnas upplevda delaktighetsnivå varierade stort under det första året efter stroke. Den multipla regressionsmodellen visade på signifikanta samband mellan självskattad fysisk funktionsnivå och delaktighet vid 1, 6 och 12 månader efter stroke. Scatterplots visade att god delaktighetsnivå även förutsatte en god emotionell samt kognitiv funktionsnivå. Det var dock flera som skattade sin emotionella och kognitiva förmåga som hög, men sin delaktighet som låg eller ganska låg. Det här

resultatet tolkades som att även andra delar i livet är viktiga för att en person ska lyckas uppnå en god delaktighet. Till exempel så visade både studie I och II att den fysiska funktionsnivån kunde associeras till nivån av upplevd delaktighet vid samtliga mättillfällen det första året efter stroke. Ett fortsatt fokus på fysisk funktion i stroke rehabilitering kan därför gynna personers upplevelse av delaktighet under det första året efter en stroke.

Studie III och IV är kvalitativt designade och syftar till att exemplifiera, beskriva samt fördjupa förståelsen av hur delaktighet och livet generellt kan upplevas i ett långtidsperspektiv efter stroke. Till studie III rekryterades elva deltagare från studiepopulationen ”the Stroke Arm Longitudinal Study of Gothenburg” (SALGOT) extended (n=281) [1] i arbetsför ålder ( $\leq 65$  år) och 7-8 år efter en förstagångsstroke. Deltagare till studie IV rekryterades från tidigare projekt kopplade till vår forskargrupp (rehabiliteringsmedicin), samt från olika strokeorganisationer i Göteborg. Med hjälp av metoden Photovoice fotograferade deltagarna i sin vardag under upp till fyra veckors tid, och träffades sedan i ett gruppformat för att presentera och diskutera sina bilder. Resultatet av studie III visade att deltagarna valde att berätta om sitt arbetsliv och sitt sociala liv när de beskrev sin delaktighet. De hade gjort vissa anpassningar i sina liv för att kunna hantera samt övervinna konsekvenser av sin stroke, samt gått vidare känslomässigt i den mån att mentala processer och allmänt mående inte i särskilt hög grad var kopplade till stroke-konsekvenser. Det här resultatet bekräftades delvis av studie IV, som också visade att deltagarna hade hittat nya sätt att hantera komplicerade situationer i vardagen. Ändå visade studie IV på en större spridning när det gällde hur deltagarna upplevde sina liv efter stroke. Flera beskrev att de ofta kände sig deprimerade och att de inte var nöjda med hur livet hade blivit efter stroke. Resultaten i studie IV visade ett behov av mer kunskap kring hur delaktighet för personer efter stroke kan främjas många år efter insjuknandet.



# List of papers

This thesis is based on the following studies, referred to in the text by their Roman numerals.

- I. Törnbohm K, Persson HC, Lundälv J, Sunnerhagen KS. Self-Assessed Physical, Cognitive, and Emotional Impact of Stroke at 1 Month: The Importance of Stroke Severity and Participation. *Journal of stroke and cerebrovascular diseases*. 2017 Jan; 26(1):57-63. Epub 2016 Sep 9.
- II. Törnbohm K, Persson HC, Lundälv J, Sunnerhagen KS. The impact of physical function on participation in the first year post-stroke. *Acta Neurologica Scandinavica*. 2017 Jun;135(6):649-655. Epub 2016 Aug 11.
- III. Törnbohm K, Lundälv J, Sunnerhagen KS. Long-term participation 7-8 years after stroke: Experiences of people in working-age. *Plos One* 2019 Mar 13;14(3).
- IV. Törnbohm K, Lundälv J, Palstam A, Sunnerhagen KS. "My life after stroke through a camera lens"- A Photovoice study on participation in Sweden. *Plos One* 2019 Sep 11;14(9).

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# Abbreviations

ADL	Activities of Daily Living
AUC	Area Under the Curve
CI	Confidence Interval
CID	Clinically Important Difference
DALYs	Disability Adjusted Life Years
ECP	Empirical Analytical Paradigm
ESD	Early Supported Discharge
ICD -10	International Statistical Classification of Diseases and Related Health Problems - Tenth Edition
ICF	The International Classification of Functioning
NIHSS	National Institute of Health Stroke Scale
OGQ	Occupational Gaps Questionnaire
OR	Odds Ratio
PAR	Participatory Action Research
SALGOT	Stroke Arm Longitudinal Study
SF-36	Short Form-36 Health Survey
SIS	Stroke Impact Scale
STROBE	STrengthening the Reporting of OBServational studies in Epidemiology
WHO	World Health Organization



# Introduction

This thesis aims to increase the knowledge about participation after stroke at different timepoints. By using self-assessed data for study I and II, and by using qualitative approaches in study III and IV, a perspective that builds on experiences held by persons with stroke has been embraced. It is also a fact that Swedish health care recommendations [2] underlines the importance of listening to the person with stroke and respecting his/her autonomy and individuality. Therefore, the present thesis aims to provide support in this way of thinking concerning individuals and their experienced participation after stroke;

Quotes from study III and IV

*“When I’m socializing with other people, then I’m in my element. Then I feel involved in my life. And this has become absolutely better for me after the stroke! To be bold and prioritizing myself. Tomorrow it might be too late! That is what I’ve learned (Quote, study III).”*

*“I try to have faith in myself. So instead of just running and look something up, I pause, and say to myself; “take it easy, don’t stress out, try to remember”, and then I often remember it... I think that’s so important, to understand what you need (after stroke). And to struggle, and try to find things that works for you. (Quote study IV).”*

In order to facilitate the understanding of included papers, and the rationale for this thesis, a theoretical background and conceptual frameworks are provided as follows:

# Stroke

The WHO defines a stroke as "rapidly developed clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than of vascular origin" [3]. This definition includes cerebral ischemia, cerebral haemorrhage and subarachnoid haemorrhage [4].

Ischemic stroke is the most common form of stroke, accounting for around 85-90 % in the Western world. Ischemic stroke occurs when an artery is blocked (often by blood clots) and the supply of oxygen and nutrients to the brain cells are blocked off, causing damage to the brain [5]. Hemorrhagic stroke accounts for less than a third of all strokes in high income countries and nearly half of all strokes in middle and low income countries [6]. Intracerebral hemorrhage means that a blood vessel in the brain bursts, which causes blood to leak out and destroy surrounding brain cells, damaging the affected parts of the brain [7]. The least common form of stroke is subarachnoid hemorrhage, which is a bleeding between the brain and the tissues that cover the brain [5].

Symptoms from stroke vary and are dependent on different factors, for example; location, extent of lesion and the general brain condition [8]. Common impairments after a lesion in the right cerebral hemisphere are; left hemiparesis, problems in interpreting input of time and space, other people's emotions and changes in personality and mood [8]. Another consequence is a disorder of attention whereby the person with stroke fails to orientate, to report or to respond to stimuli located on the contralesional side – this is called neglect [9]. A stroke on the left side of the brain can cause hemiparesis in the right side of the body, difficulties with writing and communication impairments, for example aphasia. A stroke in the cerebellum or in the brain stem can cause symptoms of dizziness, balance or coordination problems, and may affect motor and sensory functions, or speech impairments [8].

Stroke is a global healthcare burden, which is increasing due to expanding populations, aging and higher prevalence of risk factors, especially in low- and middle-income countries [10]. Stroke is the second most common cause of death,



as well as the second cause of adult disability worldwide, and future forecasts indicate that without changed strategies for stroke management, the burden of stroke will not decrease in the coming decades [11, 12]. However, there is strong evidence that stroke is largely preventable, treatable, and manageable when approached in the right way and on different levels simultaneously [12].

In 2017, around 21 000 people in Sweden had a stroke [13], this number can be interpreted as a part of the declining trend of stroke events in Sweden, that has been present in recent years [14]. Since the beginning of the 21st century, both the incidence and mortality per 100 000 people in Sweden have decreased by around 40 percent [15].

Stroke is commonly a disease of the elderly, however approximately 20 % of the afflicted are under the age of 65 [15]. Among young people, 35-44 years, the percentage who suffer a stroke has increased during the last decades [16]. Because most people will survive the initial illness, the greatest health consequences for individuals with stroke and their families comes from various physical, cognitive and emotional disabilities [17]. As stroke related burden is assumed to increase over the coming decades, without a new and effective medical treatment, post-stroke care will remain reliant upon rehabilitation interventions [17, 18].

## Everyday life after stroke

### *Short-term perspective*

Having a stroke is a serious disruption of daily life, both for the individual and for their next of kin. More and more persons with stroke now arrive to a hospital within three hours from onset, and most of the stroke patients (91 %), receive care at a stroke unit at some point during their hospitalization [13].

In Sweden around 75 % are discharged to their own homes and 25 % to special housing after acute care [19]. The initial time at home with one's family is mainly about finding ways to handle activities of daily living (ADL) such as self-care, getting in and out of bed, eating, walking outside etcetera. Subsequently, and

depending on the state of the individual, most persons will try to regain as much as possible of their pre-stroke life [20].

In the most favorable situation, the person with stroke and his/her family are assisted by a multidisciplinary stroke team [18], including physiotherapists occupational therapists, nurses, and speech therapists, assisting and helping the person to get back to their lives. In the county of Västra Götaland, 27% received some sort of rehabilitation in their home with the aim to facilitate their transition to everyday life [19]. One study showed that persons who received assistance in their homes early after stroke, so called Early Supported Discharge (ESD), had improved functional outcomes and their length of stay in institutions were reduced compared to a traditional stroke unit care [21]. It is probable that the social and physical milieu of one's home creates a good arena for relearning pre-stroke abilities [22].

Readjusting to pre-stroke life, as soon as possible is beneficial for the person with stroke and his/her next of kin. Without a supportive team however, people with stroke living at home may have a harder time accessing therapists, leading to a potential worse recovery, and an increased burden on their caregivers [23]. In Sweden, one in five people with stroke reported unmet rehabilitation needs one year after stroke [24].

Coming back home and trying to figure out life after stroke is complicated for many individuals. After a few days the majority have realized that some pre-stroke activities are challenging to perform, which might lead to feelings of depression [25]. The person with stroke can, preferably together with professionals, recognize and try to reduce hindrances in order to resume their most valued pre-stroke activities [26].

The Swedish National Stroke Register [19] has issued a report on Swedish stroke outcomes three months after onset which showed that 71% reported persisting problems. Almost 30% specified that they had resumed pre-stroke activities, and the remaining 36% reported that activities were carried out in a new way, or not at all (35%). According to The National Board of Health and Welfare,

61% depended on help from family members after three months [27]. Even though many people needed some sort of assistance at this stage, an average of almost 80% of people with stroke in Sweden reported a “pretty good” or a “very good” overall health [19].

### *Long-term perspective*

Stroke is acknowledged as a long-term condition, however most studies concerning participation after stroke are short-term or cross-sectional, and less is known about outcomes many years after onset [28]. Previous studies showed that people with stroke might experience a participation and activity restriction in the chronic phase, sometimes despite a relatively good physical recovery [28, 29]. It was shown that the most frequently reported restrictions were in leisure and social activities [25]. Participation restrictions can be a consequence of long-lasting physical, cognitive or emotional problems. Common examples of such consequences are; mobility limitations, attention or memory deficits, anxiety, depression or fatigue [30-32]. Previous research has also shown that walking ability and mobility are important factors for long-term participation after stroke [28, 33].

In a long-term perspective, participation in new, or altered activities, and acceptance of a somewhat different lifestyle, are important factors for enhancing quality of life after stroke [34].

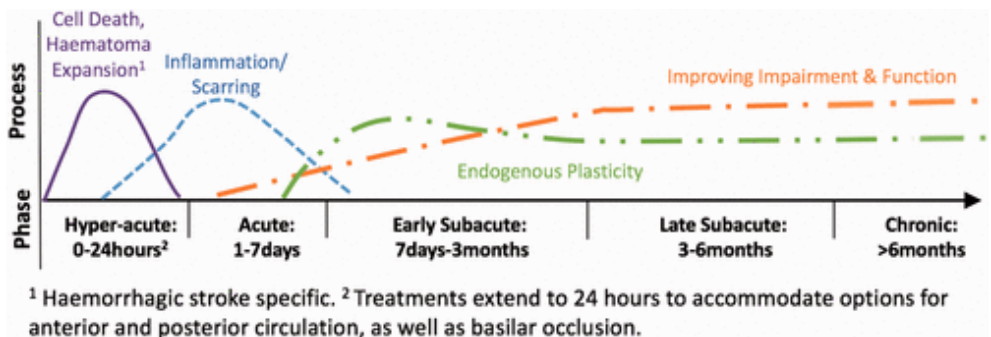
Refocusing on other aspects of life and accepting long-term consequences after stroke may be seen as parts of the human capacity to deal with life-shattering events in the longer term [35]. This process of getting used to a chronic condition and, through trial and error in daily life, finding the best response to deal with the consequences of a condition has been described in the literature as a process of self-management [36]. Self-management seem to be easier for some persons, while more difficult for others. In a long-time perspective it would be valuable with interventions, preferably in groups, to teach persons with stroke about self-

management strategies that could be valuable to enhance participation in daily living [36].

## Recovery after stroke

The greatest recovery after stroke occurs during a limited time window, of which the exact duration is not yet known, but takes place within the first three months or so [37, 38]. This timeframe is commonly referred to as the acute to sub-acute phase [39]. The person becomes more and more medically stable, and focus shifts from shock and chaos to an organized rehabilitation and mobilization of lost functioning [39]. The brain reorganizes and allows functions that were previously controlled by the now damaged areas, to be taken over by other regions of the brain [40]. See Figure 1.

Figure 1. Source: Book, Warlow's Stroke: Practical Management (2019), page 869.



Long-term consequences after stroke will most likely be manifested when the person has entered a more stable phase of recovery and gone back to routines in everyday life [20].

## Rehabilitation

The purpose of stroke rehabilitation is to restore some, or all of the person's physical, sensory and cognitive functions. Rehabilitation includes assisting the

person with stroke to compensate for deficits that cannot be reversed medically [41, 42]. A vast majority of all persons with stroke will need rehabilitation to regain autonomy and to manage their everyday lives in a way that they can eventually accept [17].

It is important to note that this process is described as something that occurs within the individual. Professionals should preferably contribute with knowledge and expertise, and also be emotionally supportive in the rehabilitation process. However, it is ultimately the persons own journey, and therefore it is meaningful to let the person set his/her rehabilitation goals, with guidance and advice from professionals [43].

The constructions of rehabilitation cited above, also includes participation that are relevant in later stages post-stroke. Aims in later stages are focused on providing the individual with opportunities for full participation and inclusion in society. These areas include for example; study, work, healthcare and access to services on the same basis as other citizens in society.

### *Rehabilitation in an early stage*

Optimal functional recovery is the main goal of rehabilitation after acute stroke [44]. Early rehabilitation mainly concerns itself with functioning in muscle movements and mobility [45]. Other common areas of rehabilitation include; speech and language training, as well as interventions directed towards swallowing, vision, sensation, cognition and fatigue.

Early rehabilitation takes place during the acute and sub-acute phases, when the time-window for spontaneous recovery is at its peak [46, 47]. It is therefore of high importance to use intensive rehabilitative interventions, aimed to help increase the degree of recovery that now takes place naturally [37, 48]. The assessment battery for patients included in the SALGOT- study group, which represented participants in study I and II of this thesis, started at day 3. All patients of the SALGOT- study group underwent early rehabilitation training at the hospital.

Initial stroke rehabilitation commonly takes place at a stroke unit. Working a multidisciplinary manner, with specialized professionals, is important to achieve high qualitative individualized rehabilitation in an early stage [49]. Apart from the actual rehabilitation program, aspects of psychological, cognitive and social consequences for the patient and his/her next of kin need to be taken into account when forming an optimal early rehabilitation. When the person with stroke and their closest relatives are motivated and engaged in the training, it is likely that a better outcome will be achieved [49].

The number of persons with stroke who receive care at a stroke-unit have increased, and during the same time the length of stay in inpatient care has decreased [50]. At Sahlgrenska University Hospital in Sweden the median length of stay in acute and inpatient care was 7-10 days in 2017, which is a little less compared to previous years [50]. In Sweden around 75 % of all people with stroke are discharged to their homes [50], and the percentage of people with stroke living at home has increased in Sweden and most other high-income countries [49].

### *Rehabilitation in later stages after stroke*

The most common health consequences for people with stroke and their families comes from various physical, cognitive and emotional disabilities [17]. The stroke related burden in Sweden and other high income countries is increasing. More people are living longer, and the incidence of stroke under the age of 65 is increasing. Therefore, stroke care in later stages will probably continue to rely upon rehabilitation interventions [17, 45].

Successful rehabilitation after stroke depends on the person and that his/her rehabilitation needs are acknowledged and addressed by an interdisciplinary team of specialists [51]. Long-term stroke rehabilitation is included in the discipline of Rehabilitation medicine, and is focused on persons with long lasting, often complex disabilities [49]. It's aimed towards helping create a meaningful life for the person, and integrating people of working age into the labor market.

A person's active involvement in long-term rehabilitation processes is recommended [52], and according to person-centered care; persons with stroke should act as partners in forming their own rehabilitative interventions [53]. Being actively engaged in rehabilitation, and particularly in goal-settings and decision making have been described as important for rehabilitation [54, 55].

Some persons benefit from rehabilitation a long time after stroke, and their needs might therefore also be reviewed in later stages [56, 57]. It has also been shown that engaging persons with stroke in multimodal interventions in late stages after onset enhanced the general life situation of their close relatives [58]. In addition, it has been argued that stroke rehabilitation is not only about regaining functions and working against loss, but also learning to bear and deal with consequences [59].

### *ICF – The International Classification of Functioning*

The ICF constitutes a foundation for the understanding of health, functioning and disability [60]. The main ambition when constructing the ICF was to provide a basis for an integrative understanding of the human experiences of functioning and disability, where the body and the overall physical, social and attitudinal environment are inseparably linked to one another [61]. The ICF is integrative, and does not follow the medical or the social model, but take both views into account when understanding the management of disabilities [61].

The components of ICF can be summarized as follows: 1) body functions are psychological functions of the body; 2) body structures are anatomical parts of the body; 3) activities refer to the execution of tasks or actions by individuals; 4) participation implies the involvement in a life situation; 5) environmental factors are the physical, social and attitudinal situations in which people live and 6) personal factors are the background of peoples life and living situation and are features that are not part of a health condition [62]. The impact of these factors is important to acknowledge, since they can be either facilitators or barriers for functioning in daily life [62].

Disability is commonly seen as an umbrella term for impairments, activity limitations and participation restrictions [63]. Disability refers to negative aspects of the juncture between individuals with a health condition (such as stroke related impairments or depression) and personal or environmental factors (such as negative attitudes, inaccessible public spaces or limited social supports). The World Health Organization works towards establishing an inclusive and enabling society in which people with disabilities can flourish [63].

### *Rehabilitation research*

Rehabilitation research is preferably based on the integrative model of human functioning [64, 65] and placed to integrate the advances of science into benefits for people and society [65]. In this context rehabilitation research is an interdisciplinary mix of natural, human, behavioural and social sciences, as well as engineering research and other related fields [64]. Therefore human functioning and rehabilitation research has the potential to be a multifaceted, although coherent research area, where researchers from various disciplines and backgrounds share knowledge and work together to improve functioning and quality of life for people experiencing disability [64]. When research fields collaborate and learn from each other it is possible to create well-functioning clinical and community practices and rehabilitation policies [64].

## Participation

Participation is a key concept of this thesis, and is often a main outcome in the field of rehabilitation [66, 67]. Participation has a positive influence on health and is considered to bring meaning to daily life [20, 25, 68]. Levels and quality of participation in everyday life are often affected after stroke, regardless of severity [69, 70]. Despite access to rehabilitation services and a general focus on stroke care many people with stroke experience limited participation [27].



Scientific consensus about factors of importance for successful participation is partly missing [66, 71]. It has been discussed that participation is difficult to measure, because it is influenced by many interfering factors. Physical autonomy, cognitive and emotional health, life satisfaction and environmental components, are examples of factors that may influence on the perception of participation in everyday life [71, 72]. How participation is perceived also depends on personality as well as cultural factors [73].

In the ICF, participation is described as “involvement in a life situation”, which assumes active engagement in real life environments and activities [74]. It has been discussed that the ICF provides a rather brief and imprecise definition [75], which is open for interpretation and also insufficient when used on its own [72, 75, 76]. For example; people are involved in life situations all the time, so what is required for a situation to be classified as a “life-situation”? Is the answer defined by the individual or by someone else? The ICF classification may also be inapplicable when trying to distinguish between participation that is either more positively or more negatively perceived [75, 77]. When disregarding the subjective perspective on quality of participation, the measurement might lose its meaning [66, 78]. The ICF uses two qualifiers; capacity and performance, to evaluate participation [79]. The capacity qualifier describes an individual’s ability to execute a task, in a uniform or standardized environment, while the performance qualifier describes what a person does in his or her current environment [79]. Contextual factors are either “environmental” or “personal” factors [79].

The ICF acknowledges participation as an increasingly important outcome for rehabilitation, but does not clearly define or distinguish it from activity and/or performance [75]. It was argued that creating only one classification scheme for both activity and participation might have been an oversimplification [80, 81]. Performance per se does not mean participation, and not performing does not mean not participating. For example, a person who is physically very dependent on others, but who lives according to his or her wishes, might consider him/herself as highly participant, without performing, nor being especially active. In such

cases, opportunities for choice and co-decisioning, or being respected and listened to may be factors of higher importance for the subjective participation, than for example performing activities.

Mallinson and Hammel stressed that an observer cannot know how activities are experienced by its practitioners if they are not asked [72]. For example; an act of cooking does not tell us if the person in question likes to cook, needs to cook or if he/she would have loved to spend their time and energy on something different [72].

In this thesis, the understanding of participations was taken from Mallinson and Hammel [72], who concluded that participation “occurs at the intersection of what the person can do, wants to do, has the opportunity or affordances to do, and is not prevented from doing by the world in which the person lives and seeks to participate”, page 30. Furthermore, they emphasized that participation is something that is created at the nexus of the person-task-environment [72]. From this definition we can understand participation as a result of interactions between the person, activity and the actual context in which he/she lives. This definition also includes an aspect of the individuals own will, which ensures some degree of quality in participation, rather than just quantity or activity alone.

### *To assess participation*

Participation is a concept that should be determined subjectively by the person in question, who is the only one that can tell how successful his/her participation is [79]. Bergstrom et al. [68] found a way to assess participation that is based on a person’s like and dislike for different pre stroke activities. The authors named these activities “participation in everyday occupations” and claimed it to be a useful way to measure perceived quality in participation. The questionnaire is called the Occupational Gaps Questionnaire (OGQ), and is based on the choice and performance of activities desired by the person in question [82].

It has generally been proven difficult to design a measurement of participation that includes all important components. An attempt to develop a questionnaire that

considers personal preferences, social, environmental and economic factors has been made [83]. The authors emphasized that the new generation of participation measurements should correspond to well established definitions of participation, evaluating the subjective experience of people with disabilities and seek to build on previous measurement theories. It was also argued that both objective and subjective forms of assessment should be used [66]. In this thesis, experienced or self-perceived participation has been studied, which may generate results closer to the “truth” compared to when participation is objectively measured alone.

## Daily living and upper extremity impairment

The study groups of study I and II consisted of persons with an impaired arm-hand function at day three after stroke [84]. Previous research showed that more than two-thirds of all stroke patients had an arm paresis on admission that resulted in reduced upper extremity function [85]. According to a follow-up study four years after stroke, 67 % still experienced non-use or disuse of the affected arm as a major problem [86].

Upper extremity dysfunctions post-stroke showed to significantly impact on a person’s ability to perform an activity, using the upper limb, and have a negative impact on quality of life [49]. A Swedish study concluded that tasks including manual sleight of hand were perceived as difficult or impossible for a majority of participants, four months or longer after stroke [87]. As upper limb recovery is important for autonomy in activities of daily living, it is one of the main goals in stroke rehabilitation [88].

The fact that a study group with detected impaired arm-hand function was used for study I and II was not without relevance for the results. As participants scored very widely within the hand function domain it was possible to visually display its clear association with participation in boxplots, as shown in study I. Thanks to the wide range of hand function capacity within the study group, the association with participation was clear, even though the study group was rather small (n=92).

In study II the domain of hand function strongly correlated  $p > 0.7$  with the Strength, Mobility and ADL domains and was therefore merged with all these domains into a “composite Physical” domain. Because of this procedure, the final multiple logistic regression did not show hand function alone as one of the predicting domains for perceived level of participation. However, the level of hand function (SIS) was significantly associated with perceived participation at both 1, 6 and 12 months in the univariate logistic regressions. The results of study I and II indicated that the level of hand function seemed to be important for perceived participation during the first year after stroke.

## Culture and Intersectionality

This thesis was conducted in a Western socio-cultural context (Sweden), with Swedish authors. It cannot be ignored that the cultural context has had its influence over results generated by this thesis. As physical and social environments are formed by culture, and interpreted through cultural preunderstandings, it needs to be taken into account when studying matters that will influence a person's interactions with his/her environment. Culture can be defined as the beliefs and perceptions, customs and behaviors, values and norms that are shared by a society (or a group) and are passed from one generation to the next, both consciously and unconsciously [89]. In this thesis, especially results of the qualitative studies have been affected by participants' interactions with their environment, which is characterized and shaped by a Swedish culture. What this may be about, in more concrete terms, is for example that individuals chose activities and behaviors from what is possible within their specific culture. Also how individuals recognize and value societal functions are formed by cultural views. Having a stroke in an individualistic society, with a strong belief in the healthcare sector and other societal bodies, may contribute to certain expectations that might differentiate from persons coming from more collectivistic and family orientated societies.

Intersectionality, is an important approach when trying to understand power structures that produce and sustain health outcomes [90]. Cardiovascular disease

(stroke or other) and differences in its distribution by socioeconomic status, or ethnicity, and sex are well documented [90]. For stroke, an American study showed that US born Mexicans or Puerto Ricans were significantly more likely to have a stroke, compared to non-Latino white Americans [91]. Another study showed that among Arab immigrant women in Canada, barriers to engaging in stroke prevention came from life stressors, lack of health literacy, and limited financial resources [92].

Adopting an intersectional view in stroke research means framing questions and data analysis, paying attention to social, economic and cultural factors that shape individual experiences and influence how life after stroke can be managed. Even though intersectionality was not the main focus in the present studies, study IV showed that stroke management in a long-term perspective could partly be attributed to intersectionality. The study design of paper IV made it possible to dig a little deeper into the participant's lifeworlds, and thereby gain a richer understanding about how their lives were perceived. Results showed that economic and social vulnerability, due to an experienced exclusion, long-term unemployment, a history of ill health, low income or social loneliness, worked as dimensions that influenced how stroke consequences were perceived and managed.

# Aims

The overall aim of this thesis was to investigate perceived participation at different timepoints after stroke, with the means of quantitative and qualitative designs. A further aim was to develop knowledge that can be used both in rehabilitation and in the development of interventions for promoting participation in daily life after stroke.

Specific aims were:

I. To describe self-assessed physical, emotional, and cognitive impact of stroke and to investigate associations with participation and stroke severity in an early stage (1 month) after stroke.

II. To investigate perceptions of participation and how this related to background characteristics and self-assessed rehabilitation outcomes, at 1, 6, and 12 months after stroke.

III. To understand how participation was experienced in everyday life, by individuals of working-age, 7–8 years after stroke. The aim was to obtain a deeper understanding of how participants coped in everyday life, and how they reflected upon their own participation.

IV. To explore the experience of everyday life after stroke and potential aspects of participation through the photovoice method

# Patients and Methods

The study design of this thesis is a combination of different quantitative and qualitative methods aimed to build broad knowledge regarding short and long-term participation with persons after a stroke. When approaching a phenomena with both quantitative and qualitative designs, the methods can complement each other, and thereby a deeper understanding is achieved [93].

Study I and II showed descriptively how the study group performed within areas that have been considered important and meaningful in everyday life after stroke (SIS) [94]. They also showed factors that were associated with the level of perceived participation during the first year after stroke. Study III complemented with participants own unique expertise regarding experiences of daily living with stroke. These narratives provided a great contribution to knowledge when it came to understanding how post stroke processes and concerns can be experienced [95]. The photovoice method used in study IV encouraged participants to be engaged in active forms of reflection about their daily lives and circumstances.

## Participants

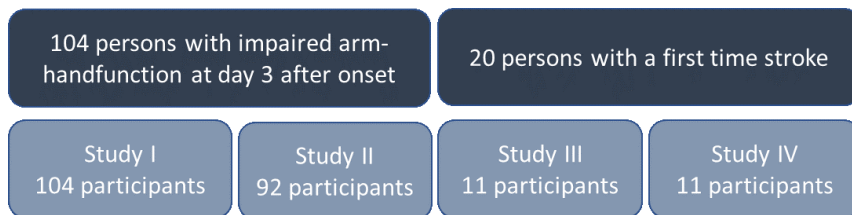
Study I and II are parts of a larger project that is called the Stroke Arm Longitudinal Study at the University of Gothenburg (SALGOT-study) that was conducted at Sahlgrenska University Hospital. Study participants were consecutively recruited to the SALGOT-study between the 4th of February 2009 and the 2nd of December 2010, from the largest of three stroke units at Sahlgrenska University Hospital. Patients were identified through hospital records: International Statistical Classification of Diseases and Related Health Problems - Tenth Revision (ICD 10), code I61 and I63 as first or second diagnosis. All persons, screened with a first stroke and admitted to the stroke unit within 72 hours were included in the SALGOT-extended study group [96, 97]. See Table 1 and Figure 2 for more information.

Table 1. Overview of Studies I-IV

	Study I	Study II	Study III	Study IV
Study design	A descriptive quantitative study with consecutive selection	A longitudinal study with cross-sectional analyses	A qualitative study based on thematic analysis	A qualitative, photovoice method
Participants	Persons (n=104) at 1 month after stroke	Persons at 1 (n=92), 6 (n=79) and 12 (n=78) months after stroke	Persons (n=11) at 7-8 years after stroke	Persons in a long-term phase after stroke (n=11)
Data	SALGOT-data (n=117)	SALGOT-data (n=117)	SALGOT-extended data (n=281)	Stroke organisations in Gothenburg and persons with contacts in the research group
Data collection (Instruments and time-points)	NIHSS at admission, SIS at 1 month	NIHSS at admission, SIS at 1, 6 and 12 months	Interviews with open-ended questions held 7-8 years after stroke	Focus group interviews held at least 2 years after stroke
Methods of analysis	Descriptive statistics and non-parametric statistics for differences between groups	Multiple logistic regressions and descriptive visualisations of data	Inductive thematic analysis with an element of deductivism	Inductive thematic analysis



Figure 2. Study population and number of participants included in Study I-IV. Observe that two individuals partook in both Study III and Study IV. All participants in Study II partook in Study I.



The initial purpose when extracting a group from the SALGOT-extended study was to investigate the recovery of physical function generally, and more specifically upper extremity function, as well as ADLs in a non-selected sample of patients diagnosed with a first time clinical stroke and admitted to a stroke unit [98]. The SALGOT- study group is therefore distinguished from the larger SALGOT-extended group by only including persons with an impaired upper extremity function. For detailed information about how the impaired upper extremity function was defined the SALGOT protocol is referred to [84].

### *Study I*

The SALGOT study included 117 people, from the 763 people that were screened [99]. Completion of the SIS was an assessment criteria for being included in study I, and this included 104 participants. For inclusion and exclusion criteria see Table 2.

### *Study II*

Participants in study II were also extracted from the SALGOT- study group. Additional criteria for inclusion in study II were: measured with the NIHSS [100] at admission to hospital, completion of the SIS participation domain 8 at 1, 6 or 12 months [94]. The final samples included 92 persons at 1 month, 79 at 6 months and 78 at 12 months.

### *Study III*

In 2014-15, a document with stroke specific questionnaires named “Your daily life after stroke” were sent out to all persons still alive (457 persons) amongst the SALGOT- extended study group. There were 281 persons who answered the questionnaires. Inclusion for study III was made amongst those who had answered the questionnaire (partly or fully), and who hadn’t explicitly said that they didn’t want to be contacted for research purposes again. The idea was to only ask persons who we thought could be interested in participating. To obtain broad and rich interview data, participants were purposively selected with varying age, gender, stroke severity and stroke subtype.

From this list, persons were contacted by telephone and asked if they wanted to take part in an interview about their lives after stroke. At this point, 15 persons were interested, and were sent a letter with information about the purposes of the study. One week later, we rang back to invite participants for an in-depth interview and subsequently four persons had withdrawn their interest. Hence, the 11 participants in study III were included from these 281 persons, and the inclusion was made in 2016. Upon accepting, participants were informed both verbally and in writing about their participation. Baseline characteristics, stroke outcome and other personal information were collected retrospectively from the SALGOT – extended database.

### *Study IV*

We chose a selective, convenient recruitment procedure in order to attract enough participants for study IV. The inclusion was undertaken from the 14th of October 2018 to the 15th of November 2018 and began with contacting individuals who had some previous connection with researchers at our department. Fourteen persons were contacted through this snowball selection procedure that took place amongst researchers at our department. Seven individuals, one with aphasia, agreed to participate, four persons did not return phone calls or did not answer e-

mails, and one person declined. Two persons wanted to send in photos, but were not willing to participate in a focus group due to unpaid leave from their personal businesses. These two persons were “kept” to be a part of the upcoming photo-exhibition.

Local organizations, such as “Strokeföreningen Västra Götaland”, the Aphasia Association in Gothenburg, and “Dalheimers Hus” were visited with the aim to recruit more persons to the focus groups. At “Dalheimers Hus” three persons were initially interested to participate, but two of them changed their minds after a few days, leaving only one more person to be a part of the study. At “Strokeföreningen Västra Götaland” one person wanted to participate and was included. All persons who showed an initial verbal interest were sent further general information about the study, which included; persons responsible for the study and their contact information, the aims, the course of action, ethics about photographing and a consent form. They were then contacted by phone to confirm their willingness to participate, and as written above, only two persons resumed their interest at this stage.

A disadvantage with the snowball recruitment is that it is quite impossible to validate to what extent the sample is biased by what they have in common (what binds them together). In the case of study IV, we aimed for a mix in age, gender, stroke severity and subtype. The snowball procedure was started amongst persons with a connection to our research group, previous study patients or persons who had expressed an interest in research participation. Hence, this group of people can be alike in ways that we cannot anticipate, nor be certain about. To compensate for that potential pitfall, several different local organizations (named above) were also contacted, but we were only able to recruit two persons this way. Information about the study was also put on the wall of two Facebook groups with members that have acquired brain injuries (stroke or other), “Hjärnkraft” and “Stroke Mitt i Livet” (SMIL) (Stroke in midlife). One person from SMIL and two persons from “Hjärnkraft” contacted us with a phone call and agreed to participate.

Finally, 11 persons chose to participate, 5 men and 6 women. Half of the study group was represented by persons with prior experience of participating in a research study. It could be speculated that persons with this background may believe that research is more important compared with a general stroke population. However, we cannot know if or how these persons differentiate from an average study group in a late stage of stroke.

Table 2. Inclusion and exclusion criteria for Study I-IV

	Inclusion	Exclusion
Criteria, Study I and II	<ol style="list-style-type: none"> <li>1. First time clinical stroke, defined according to WHO criteria by imaging or clinical assessment<sup>[3]</sup></li> <li>2. Impaired upper extremity function at day three after stroke onset</li> <li>3. <math>\geq 18</math> years old</li> <li>4. Admitted to the stroke unit within 72 hours</li> <li>5. Living in the Gothenburg urban area (within 35 km from the hospital)</li> </ol>	<ol style="list-style-type: none"> <li>1. Upper extremity impairment prior to stroke</li> <li>2. Expected lifetime of less than 1 year, due to severe illness</li> <li>3. Not Swedish speaking prior to stroke</li> </ol>
Additional criteria Study I	<ol style="list-style-type: none"> <li>6. Having completed the SIS at 1 month</li> </ol>	
Additional criteria Study II	<ol style="list-style-type: none"> <li>7. Measured with NIHSS at admission</li> <li>8. Having completed the participation domain (SIS) at 1, 6 or 12 months</li> </ol>	
Criteria, Study III	<ol style="list-style-type: none"> <li>1. First time clinical stroke, defined according to WHO criteria by imaging or clinical assessment [3]</li> <li>2. Admitted to a stroke unit or a neuro intensive ward at SU</li> <li>3. Living in the Gothenburg urban area (within 35 km from the hospital)</li> <li>4. 18-65 years old</li> <li>5. Sufficient verbal and memory ability to take part in an interview</li> </ol>	No exclusion criteria
Criteria, Study IV	<ol style="list-style-type: none"> <li>1. Having had an ischemic or a haemorrhagic stroke, according to medical charts.</li> <li>2. Residing in the Gothenburg urban area.</li> <li>3. Being <math>\geq 18</math> years of age.</li> </ol>	No exclusion criteria

## Data collection and procedures

### *Quantitative methods*

#### Instruments

To capture experienced functioning and participation, the SIS was performed in studies I and II [94]. The SIS was developed with input from persons with stroke, their caregivers and healthcare professionals. The SIS consists of 59 items, grouped into 8 domains, ranged from 0-100 (the higher the score, the less stroke impact): Strength, Hand function, Mobility, Activities of Daily Living (ADL), Memory and thinking, Communication, Emotion, and Participation, see Appendix. There are five to twelve separate questions in each domain, and all questions are rated on a five point scale. All domains were individually scored [101]. The four domains that measure physical functions (Strength, Hand function, Mobility and ADL) are often highly correlated and can be merged into a composite Physical domain. This composite Physical domain was used in the regression models for study II. The last question in the SIS, consists of an analogue visual scale from 0-100 that measures self-perceived stroke recovery. This question was assessed but not used in any of the current studies.

The SIS has been found sensitive in identifying motor deficits for persons with stroke who have been classified by standard clinical outcome tools as having minimal or no disability [94, 101]. The SIS has also been proved valid, reliable and useful when assessing the impact of stroke [94].

Domain 8 in the SIS measures participation. This domain showed to be sensitive to change over time and was the one domain of SIS with the most reported problems at one-year after stroke [102]. The questions of domain 8 are, because of their character, not recommended to be assessed before four weeks after stroke [101]. The physiotherapist conducting the SIS reflected upon question 8f, about spiritual and religious activities, as not being particularly relevant in a Swedish context, as Sweden has a highly secularized culture.

## *Data analysis*

### Statistical analysis

Study I and II adheres to the guidelines for reporting observational studies; Strengthening the Reporting of Observational Studies in Epidemiology (STROBE). Baseline characteristics are presented as number, mean and percent. The SIS and NIHSS are presented as median, quartiles 1 and 3, mean score and standard deviation. To test for differences between levels of participation and SIS scores; non-parametric tests (Mann-Whitney U tests) were used. We chose this because the data were not normally distributed, and because ordinal data with a rather small sample size was used. When data were dichotomized, chi-square tests were performed. For calculating differences between groups in study I and II, two means of dividing were used: according to different levels of participation (domain 8, SIS), as suggested previously [76]. This was classified as follows; a score below 50 indicated a limited participation and a score of 50 or more corresponded to participating partly or fully. NIHSS was divided so that a score of <5 indicated mild impairment, 5-14 moderate impairment and <14 severe impairment. In study I, the top ten items that were experienced as either problematic or unproblematic were classified as; response option 1-3 = problematic and 4-5 = unproblematic. The possible scores ranged from 1 to 5 and were encoded on a scale from 0-100.

For study II, multiple logistic regressions were performed at 1, 6 and 12 months. Logistic regressions were performed due to the intrinsic characteristics of the outcome variable (Participation domain) which was not normally distributed, and nor was it possible to obtain a normal distribution through a commonly used equations.

### Statistical software

Statistical analyses were performed in the IBM Statistical Package for Social Sciences (SPSS version 22.0, for Windows) (Armonk, NY, USA). For study III NVivo 12 for Windows was used. NVivo is a software program to structure, organize and separate qualitative interview data [103].

## *Qualitative methods*

In study III, the data was collected through interviews, and in study IV results were based on a combination of photographs and focus groups interviews – using the photovoice method [104].

When the aim is to reach a better understanding of, or to obtain deeper knowledge about, lived experiences a qualitative approach is preferred. Sometimes research questions cannot be answered in a satisfying way by the means of a questionnaire. For example, if the aim is to explore how people view their participation in everyday life, answers might best be understood through conversations. In an interview setting the researcher has the opportunity to ask follow-up questions, which can enrich the content of the interview, and clarify the meaning of specific answers. Qualitative studies can also be very important in areas that are not yet thoroughly investigated, to achieve understanding of subjects or issues important to the study group. To obtain deeper knowledge about participation in a long-term perspective among persons with stroke, we chose to use a qualitative approach for study III and IV.

### Individual interviews

For study III, in-depth individual interviews were used as the basis for knowledge. Relationships with others, and also with ourselves are conversational. Our inquiring and interpreting selves are conversational and have been constituted by the numerous relationships we have had with others [105]. An interview is literally an inter-view, an interchange of views between two persons, conversing about a subject of mutual interest [105].

The interview guide should preferably be constructed with easier and light-hearted questions first, and more serious or sensitive matters in the middle or near the end. A good basis for the conversation is founded by active listening, showing interest, understanding and respect, and that the interviewer is clear about what he or she wants to get out from the interview [106]. One tip about how not to lose the main focus during an interview, is to write down the main research questions next

to the themes that will be up for discussion. If the conversation starts to go astray from the research questions, the researcher can glance at the broader aims and evaluate if this discussion could be valuable [105].

Using meaning-clarifications during the interview is important for two main aspects: through clarifications the interviewee feels encouraged and listened to, which may lead to additional thoughts being brought up. It is also a good way to check that meanings are understood correctly, which will be important for the validity later on [105]. Something that I have noticed (as an interviewer) is that meanings are sometimes vague or misunderstood, and that explanations given as response to a clarification are very useful in the analysis.

An advantage with more openly constructed interviews (study III and IV) is that participants can relatively freely give their interpretations within each subject. However, this is more challenging for the interviewer, who needs to be quick-witted when it comes to finding the right questions for probing further. The interviewer needs to be present in the moment and concentrating on what is being said. In some cases the interviewer needs to understand what the interviewee wants to say, but is not saying explicitly, in order to ask relevant follow-up questions [105].

Sometimes it is the conversation around or far from the topic that answers your research questions. An example of this from study III was from one of the first interviews when the interviewee kept talking about details at work, and I was trying to find a polite way to interrupt, what I thought of as extensive information. After a couple of more interviews, and when listening to the recordings I realized that this part of the interview had been important. The interviewee presented himself as competent by explaining about difficult situations at work that he had solved, and was proud of. I also realized that, working life seemed to be important for the feeling of participation.

In study III the data was assessed by conducting eleven in-depth interviews that lasted between 36-65 minutes. When developing the interview guide, I was inspired by a previous review about important factors for social participation after



stroke [81]. A few themes were highlighted there, as being especially important for people after stroke; to engage in activities with personal meaning and having the freedom to choose such activities. Conclusions made in this review [81] were considered when formulating questions for the interview guide. Hence, questions about meaningfulness, self-chosen activities and social relations were posed. The interview guide was designed to include areas that are most often considered important in a person's life; Family and Social life, Health (associated with the stroke), Leisure and Culture Hobbies, Employment/Work (housework). The open-ended questions aimed to gain rich data, in order to fully understand participants' daily lives.

In the first two interviews, participants explained that they had begun to see their lives in a new light and that they now approached daily life with a certain reassurance. This change of mind came from having had a serious disease that had eventually been well adapted to. These arguments came across as very interesting to me, and therefore two questions were added to the interview guide: Do you think differently about your life after stroke? and Has it changed over time, i.e. how you think about your participation after stroke?

### Focus group interviews

Social interaction and conversations are the sources of information in a focus group, and the idea is that knowledge is created in social contexts. Hence, participants' comparisons of experiences and thoughts in a group produces knowledge that cannot be attained through individual interviews. The participants will comment on and ask each other questions based on something they have in common, that the researcher is not a part of. The group dynamics can therefore be used as a means to create further and more complex knowledge, compared to what would be possible through individual interviews [107]. However, an obvious risk is that social effects of being part of a group (often accompanied with strangers) might suppress the variation and freedom with which participants choose to talk about their experiences [108].

An advantage with focus groups is that concentrated data about a subject is created in a relatively short amount of time in comparison with for example an observational or a field study [108]. A disadvantage is that persons can feel a little uncomfortable in a group with people they do not know. A focus group setting is therefore less suitable when the aim is to generate knowledge about subjects that can be perceived as personal [107]. The social control of a focus group setting can create statements and opinions that participants perceive as socially accepted and opinions that are generally perceived as less typical might be suppressed. There is a risk that participants aren't willing to be completely honest in a group setting. However, a contradictory reflection was made in another article [109], and authors stressed that participants can feel freer to express themselves in a group with persons with similar experiences, compared to when they are alone with a researcher.

In the process of recruiting participants for study IV the aim was to obtain a variation in age, gender, lesion side and severity of stroke as well as cultural heritage. Purposive selection with maximal variation is a strategy to avoid distortion in qualitative research. However, regarding focus groups, participants shall not be dissimilar to the extent that they have troubles understanding each other or feel intimidated in each other's company. The production of knowledge is, as proposed initially, dependent on the social interaction amongst participants.

The relatively low number of participants (3-5) in the three focus groups of study IV had to do with the extended material that was brought to the table. We wanted to make sure that participants' had time and energy to discuss all the selected photographs and that they did not feel exhausted afterwards. An important issue was to give all photographs and participants' equal attention. Another consideration was that some of the participants' concerns could be of a sensitive nature, and therefore a lower number of participants is preferred [107].

When conducting focus groups for study IV, the small number of participants was shown to be an apparent advantage in the context of combining social interactions with visual presentations. In two groups the numbers were three in

each group. Because one person had aphasia, it was considered important to place this person in a smaller group. One person explicitly wanted to partake in a small group and was placed in another group of three. With the benefit of hindsight, groups of three proved to be a good number, leaving sufficient room for all participants when presenting thoughts and experiences through their photos.

## Photovoice

The photovoice method is recommended to be used as a highly participatory method [110] and comes from the tradition of PAR – participatory action research [111]. PAR is considered to be a methodological approach within a research paradigm that is known as the empirical analytic paradigm (ECP) [112]. According to the ECP, research processes benefit from making participants actively involved, and study persons are not viewed as subjects to be understood [112]. The research process involves working *with* rather than *on* persons, and the power of hierarchy should be genuinely respectful, open and democratic [112]. Such approaches also makes the researcher more of an facilitator, than the sole authority [104].

Initially, research based on photos has mostly been used with groups living in the margins of society [104], who received an opportunity to present community concerns from their own perspectives [113]. The photovoice method is now increasingly popular in the field of disability and rehabilitation research, as it helps to teach policy makers and researchers about unique problems from the view of persons with disabilities [110].

Photovoice is a specific research method used to facilitate the conduct of PAR by displaying visual images and participants discussions about these images as the results [110, 114]. Using the photovoice method in a Swedish context, with persons a long time after stroke is a new and explorative approach.

In study IV participants were asked to take photos of motifs which they considered meaningful in everyday life. Subsequently, they were invited to a focus group meeting to present their photos with associated narratives. An advantage with this method is that participants choose questions and issues that are important

to them. Thereby, data for analysis contain what is most important for participants, who are assumed to be experts of their own lives [104].

In contrast to a regular interview study, where participants are answering to an interview guide, the photovoice method allows participants to freely choose subjects to speak about [110]. Researchers can thereby obtain contents that will be about what matters most to the study group. Participants are also expected to associate further, and to come up with related thoughts when studying their and other participants' photos in the focus group situation [115]. With that in mind we cannot expect participants to share everything about their photos in a focus group setting, some issues might be considered personal or difficult to talk about.

During a regular interview there is often not so much focus on the settings where narrated experiences occurred. An advantage of photovoice is that attention to the milieu of the issues in question are visually presented, and thereby recognized [116]. This is especially important if participants are speaking about "accessibility in the community" or other concerns that are best understood through visual presentation. An example of this, shown during the data collection of study IV was that some everyday problems were quite difficult to grasp without photos. It was only when we saw the narrow stairs down to the basement or the rough path to the bus stop, that we fully realized the impact of having to overcome these hurdles on an everyday basis. The long and slightly tilted duckboard, used as an aid to take a dip in the lake was also quite difficult to imagine before seeing a picture of it. Results of a photovoice study are thereby easy to grasp and understand, even for people who may find academic language somewhat difficult. Through visual representation, results can also be spread more easily, and the knowledge gain may be greater for a general public [117].

By assigning participants to take photos of something that is meaningful to them, they are encouraged to reflect upon their choices and practice explaining them to others. In doing so, a process of reflection will take place, which may enable participants to develop a more active approach in how they reflect about their own lives [104]. These reflective processes may also evoke ways of thinking

that hopefully could be applied to other areas in life. It has also been acknowledged that by letting participants become co-researchers, their self-confidence may increase [115, 118]. These advantages can be acknowledged as potential positive side effects when participants becomes actively involved in research processes.

As described in study IV, the photovoice method requires time from participants, as well as their personal engagement, interest in photographing and in sharing their everyday lives openly with a general public [104]. A limitation is therefore that persons who are attracted to engage to such a high level in research about societal concerns for people after stroke may not be representative of persons with stroke in general.

When recruiting participants for study IV persons who initially wanted to partake, claimed to be interested in everyday concerns for persons after stroke. They also thought positively of research in general and a few had participated in a research study before. In an attempt to reach voices held by persons not accustomed to the world of research, information about the photovoice study was posted on the wall of two Facebook groups for persons with acquired brain injuries (stroke or other), and two local stroke organizations were contacted. Participants recruited outside contacts from academia were thought to contribute with other aspects and further information on everyday life after stroke.

Therefore, some participants were not used to partaking in organized projects of any form. A few experienced health problems on a daily basis after stroke. Despite this starting point, they were interested in the project quite fast and wanted to share thoughts and information about their lives. However, difficulties when executing the project were for example; attending the focus group meetings on the right day and on time or finding the right location. Managing a study group that includes persons who feel more or less socially excluded and live away from the labor market, may be challenging in some aspects.

However, as people live in contexts that vary a lot, it is important to show a wide range of views about life after stroke. For example; people after stroke who

are not anticipated to return to work, early retirement in terms of sickness compensation is a common arrangement [119]. Finding out more about people who lives with this arrangement might be a way to enhance the understanding of their situation that might lead to increase the visibility of this group.

## *Qualitative analysis*

### Thematic analysis

Qualitative methods are diverse, complex, and nuanced and thematic analysis is acknowledged as a foundational method for qualitative analysis [120]. It is one of the most used methods and provides basic skills that are useful for various qualitative methods, for example; thematising meanings [120].

To ensure trustworthiness of a method it is imperative that data analysis is conducted in a consistent and exhaustive manner, so that the reader can evaluate (to a certain degree) whether the process seems credible [121]. Braun and Clarke (2006) have provided an approach to thematic analysis that was used in study III and IV. It is flexible, yet clear and easy to follow, and assumes theoretical and methodological soundness [120].

According to this method [120], researcher judgement is key in understanding what a theme is, and that this evaluation should be driven by research questions rather than prevalence. The flexibility of thematic analysis makes it possible to determine themes in a number of ways. However, the procedure must be consistent within the same analysis [120]. It is also important to consider internal homogeneity and external heterogeneity when themes are created [95].

In study III, themes were not dependent on quantifiable occurrences. Instead, the focus was on whether the themes captured important issues in relation to the research questions or not. The overall aims: “To obtain a deeper understanding of how persons a long time after stroke cope in everyday life, and how they reflected upon their participation”, were seen as an underlying guide during the analysis process.

An inductive approach was undertaken in both study III and IV. This means that themes identified are strongly determined by the data. When coding data inductively, the researcher tries to disregard their own preconceptions as much as possible, and looks at the material as openly as possible [95]. It also means that the researcher does not try to compare data to existing theories or frames of coding [120]. However, no analysis is made without subjectivity and it is not possible for the researchers to place themselves in a theoretical middle of nowhere. The fact is that the researcher takes an active role in the inductive, as well as in the deductive analysis [120].

Thematic analysis can either be done on an explicit/descriptive level or at an interpretative level. An interpretative analysis, is an attempt to give the reader an understanding of the underlying meaning of the results and also what the results might imply for clinical work or future research. When it comes to thematic analysis, the development of themes themselves involves interpretation, and the produced analysis is not just summarized results, but is already theorized [120]. In both study III and IV interpretative analyses were undertaken. The ambition during both analyses were to understand the broader meanings of the results, to see patterns and to be able to put the significance of results in relation to previous literature. The procedure used for the analysis in study III was taken from Braun and Clarke's step-by-step scheme that describes the analysis in six phases [120].

## *Ethics*

Ethical approval for study I and II was granted by the Regional Ethical Review Board in Gothenburg, with registration number: 225-08, in May 2008. Written informed consent was obtained from all participants or a close relative.

Ethical approval for study III was granted by the Regional Ethical Review Board in Gothenburg, with registration number 225-08 and with the additional application for conducting qualitative interviews, registered T801-10. All participants gave informed written and verbal consent prior to the interviews.

Study IV was approved by the Regional Ethics Committee in Gothenburg (EPN) 20181011, Dnr: 800-18. Participants gave written informed consent prior to the focus-group interviews. It was clearly communicated that photos in this study were going to be presented and published in a research article, and that participants had to notify us if they did not want their photos to be made publicly available. Prior to signing the informed consent, participants were informed that no financial compensation would be given for participating in this project. In all four studies the Helsinki Declaration [122] was followed.



# Results

In this chapter results from the four studies are presented. Study I showed that participants did not experience extensive problems within the areas of memory and thinking, emotion or communication. An exception was that 34 % of participants reported that they felt sad. Both study I and II clearly showed that perceived participation was associated with perceived performance in all the physical domains during the first year after stroke. Study III showed that participants were able to refocus on other aspects of life and that the impact of consequences post stroke had decreased. Participants still considered, for example, fatigue and cognitive problems were frustrating in some situations, but were accustomed to these issues and didn't pay them so much attention.

Results of the photovoice study showed that the drive and desire to participate in one's society were stronger than all combined worries and fears. Study IV showed that stroke consequences were handled by inventiveness, strategically or in a preventive manner. For example, not taking on more than one assignment per day to avoid fatigue or asking your next of kin when memory failed. Through trial and error many everyday problems had been solved in a way that most participants were rather content. Nevertheless, several participants of study IV reported being depressed. All results will be presented more thoroughly in this chapter.

## Physical functioning

In study I it was shown that scores in the domains of physical functioning varied widely among participants. For example, the median Q1-Q3 were 0-80 for hand function and 25-92 for mobility. However, the study group scored more homogeneously when reporting which everyday tasks they perceived as unproblematic. Participants also answered more similarly when reporting activities that were experienced as more difficult. In study I the top ten items that were experienced as problematic at 1 month included mainly physically heavy

chores and fine motor skills. For example; doing heavy household tasks or carrying heavy objects were difficult for a majority of participants. Around 60 % found it difficult to turn a doorknob, open a can or jar, and to tie their shoe laces.

Figure 3. Activities experienced as problematic at 1 month after stroke (*Study I*)

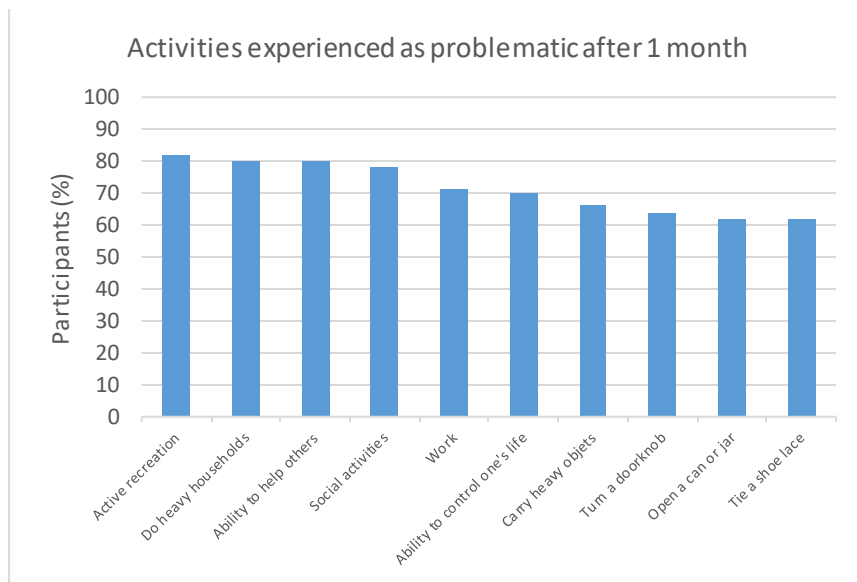
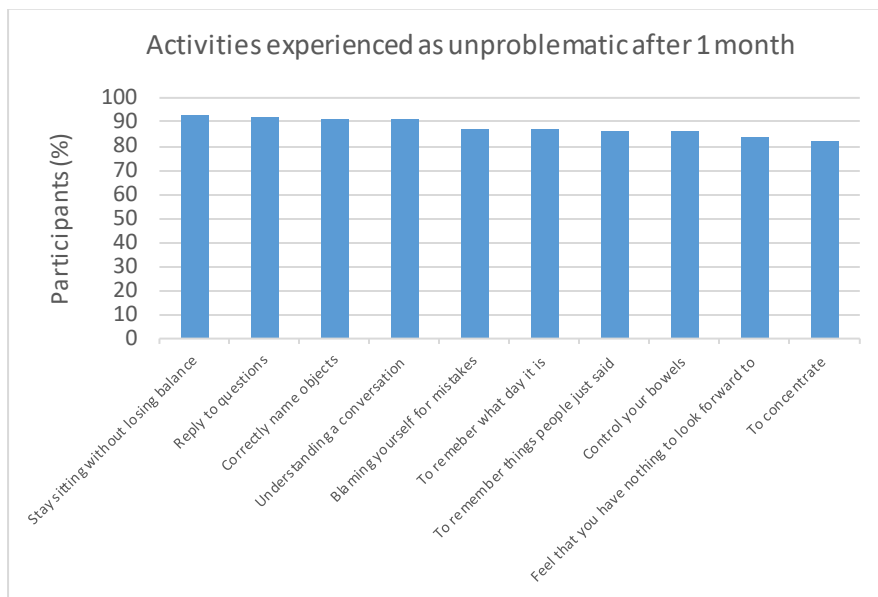


Figure 4. Activities experienced as unproblematic after 1 month after stroke (*Study I*)



Participants with a more severe initial stroke (as measured with NIHSS) perceived more problems within all physical domains of the SIS. For example; the median on the strength domain for persons with a mild stroke was 72, whereas this score was only 25 for those who had a severe stroke. The ability in hand function differed between a median of 0 for individuals with a severe stroke and of 73 for individuals with mild stroke.

In study III the group did not perceive any extensive physical impairments at this late stage. One person still had troubles with the sensation in one hand, and could not differentiate between hot and cold water. A few individuals stressed that stroke-like symptoms, like a tingling or numb sensation in their affected side, were present when they experienced stress or tiredness. Also an increased clumsiness or impaired balance were reported when being tired or highly stressed. These symptoms made participants afraid that they were about to have a recurrent stroke, and were seen as signs that one needed to calm down or rest for a while.

In study IV a majority of participants were still disabled to some extent in their paretic side. They had to deal with stiffness, numbness or problems with coordination and balance. A few reported to be severely disabled in their affected side, to the extent that they could hardly use their hand or arm at all.

## Cognitive and emotional functioning

In study I, items that participants experienced as unproblematic were mainly within the domains of memory, thinking and communication. Around 90 % of participants found it easy to correctly name objects and to follow a conversation at 1 month. A majority also found it easy to remember things that people had just said and to concentrate, see Figure 4. However, around 80% still perceived social activities and their ability to help others, as problematic at 1 month (Figure 3).

When looking at stroke severity (NIHSS); communicative and cognitive skills as well as the emotional state, did not differ greatly between mild, moderate and severe strokes. The median scores were around 80 and 90 for these domains across all levels of stroke severity.

Study II showed that at a group level the scores of the emotion and memory and thinking domains were generally high at 1 month, and more spread after both 6 and 12 months.

Some participants in study III still experienced difficulties with their short-term memory. Some of them wrote notes to not forget tasks on a daily basis. Within the group, problems with fatigue was a pronounced problem, both in social situations and at work. Participants said experiencing fatigue in everyday situations limited their opportunities for participation and affected their feeling of participation negatively.

The results from study III, regarding poor working and short-term memory and fatigue were reproduced in study IV. An additional result of study IV was that some participants felt depressed and reported not having reached acceptance about how their lives had turned out after stroke.

## Participation

Many participants reported that they were restricted in participation at 1 month after onset. After six and 12 months around 30 % reported a somewhat restricted participation.

Study II showed that perceived participation associated with all physical domains at 1, 6 and 12 months after onset. Unfortunately, all regression models had very wide, and thereby uncertain, confidence intervals (see table 3 in article 2 of this thesis). Area under the curve (AUC) tests were used in an attempt to strengthen the results and were obtained between the composite physical domain and participation at all three time points.

It was shown that the reported level of participation varied widely in the study group at all three measurement occasions. When looking at participants who had reported that they were fully participating ( $\geq 80$ ), none of them had a low score ( $< 50$ ) on the Emotion or Memory and Thinking domains.

In study II it was shown that participation scores were widely distributed at all three time points, which showed a heterogeneity within the group. Study II showed that participation scores changed in different directions between the three time points, and that these changes did not follow a typical pattern at a group level. This indicates that the level of self-perceived participation is sensitive to change and probably depends on a variety of factors within an individual's life.

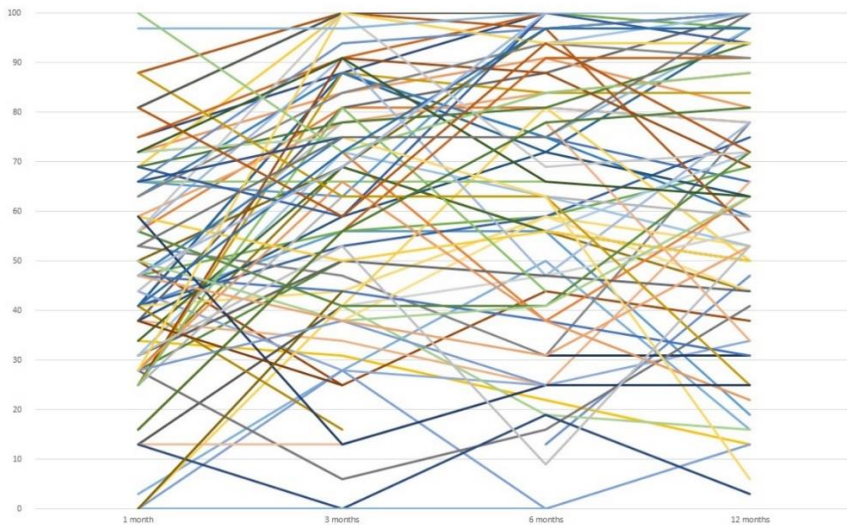
Participation in later stages after stroke (study III) were described as engaging and meaningful, and the settings were often at the workplace or in a social situation. Being part of something meaningful, in interaction with others, were factors that these narratives had in common. These narratives highlighted the multi-faceted nature of participation, but also mirrored a mutual thinking about this concept. A positive result was that none of the participants at 7-8 years after stroke were unhappy with their participation in everyday life.

Participants in the photovoice study (study IV) expressed a personal interest in questions relating to participation after stroke, both on a personal as well as a societal level. Training physical functions persistently, and having a strong will to

solve problems in everyday life had been important factors in the process of achieving a higher level of participation. Engaging in new activities after stroke had contributed to feelings of being positively involved in everyday life for some participants. Others still felt depressed and alienated from society on an everyday basis.

## Participation – unpublished results

Figure 5. Participation - Individual changes over time from 1-12 months



This illustration over perceived participation from 1-12 months shows a heterogenic pattern at a group level. It also shows that the level of participation goes back and forth for many individuals, over the first year after stroke. On a group level, the diagram indicates that perceived participation is sensitive to changes in life, which does not remain on a stable level through the first year after stroke.

## Additional analysis (unpublished results)

When starting this project we were interested in studying a very early assessment (at day 10 after onset) of the SIS. The impact of stroke in a very early stage, and how it is experienced by the persons with stroke, is still not so well understood [123, 124]. An additional aim was to investigate the presumptive improvement from day ten to week four. The question was; could clinically important differences (CID) have occurred during this short period of time?

Previous research [125] showed that spontaneous recovery of body functions is a strong factor during the first weeks after onset, explaining 16-42% of all observed improvements. In later phases, improvements are less frequent and less apparent. Recent research [126] about early processes after stroke has defined and mapped out critical timepoints for improvements of impairments and functions. It was argued that most of the spontaneous recovery takes place during the acute (1-7 days) and the early subacute (7 days to 3 months) phases, even though there are differences among individuals [126].

Figure 6. Changes from day ten to week four on domains 1-4 of the SIS

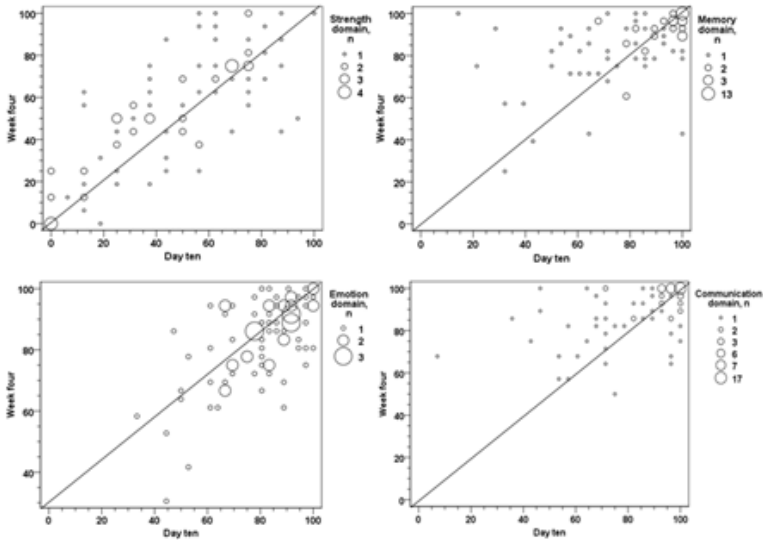


Table 3. Results of domains of the Stroke impact scale (SIS) at 10 days and 4 weeks post-stroke

SIS domain (n)	Ten days			Four weeks		
	Mean (SD)	Median (range)	Q1-Q3	Mean(S D)	Median (range)	Q1-Q3
Strength (91)	46.0 (0.27)	50.0 (0-100)	0.3- 0.7	53.4 (0.28)	50.0 (0-100)	0.3-0.8
Memory(86)	80.9 (0.26)	85.7 (14-100)	0.7- 0.9	86.1 (0.15)	92.9 (25-100)	0.8-1.0
Emotion(85)	80.0 (0.15)	83.3 (33-100)	0.7- 0.8	83.0 (0.14)	86.1 (31-100)	0.8-0.9
Communication (85)	85.4 (0.19)	92.9 (7-100)	0.7- 0.9	90.2 (0.12)	96.4 (50-100)	0.9-1.0

The first four domains of the SIS was collected at day ten and at week four after onset in the SALGOT- study group. Participants showed a general improvement from day ten to week four (see Table 3), although variations within the group were quite high, in all the first four domains that were investigated (see Figure 6).

The results were more heterogenic within the strength domain. At a group level the mean score increase in the strength domain was 7.4 from day ten to week four. As suggested by Lin et al. [127] the score for clinically important difference (CID) for the strength domain (SIS) was estimated to 9.2. In their study, potential improvements (SIS) were studied before and after treatment, during a three-week period, which is approximately the same as our 10 days to four weeks timespan. However, the study was performed in a considerably later phase, at least 6 months after stroke, and therefore it is uncertain whether this score for CID can be used for comparisons with our results or not. Additional research is needed to discover what kind of score changes (on SIS) that can be considered as a CID in a very early phase.



## Discussion

That nearly 60 % of the study group validated their participation as limited at 1 month might appear to be high. However, it is probably a rather good result based on the early timing after onset. As far as we know, there are still no other studies that investigate participation as early as one month after stroke. However, over 75 % of all stroke patients in the Västra Götaland region in Sweden have returned to their homes after one month, and only 24 % were considered to be in no need of rehabilitation at this stage [22]. A majority of persons with stroke have some sort of rehabilitation at one month, and at three months most persons still haven't readjusted to life as it was before stroke, nor resumed all their pre-stroke activities [23]. With this background it seems reasonable that a majority regard their participation as limited at 1 month.

That almost 30% reported to have a restricted participation at 6, as well as at 12 months may be a potentially more problematic result. Although it was not quite the same persons who experienced a lower participation at 6 and 12 months, there was no improvement at a group level during this period. An explanation for this, presented in article II, was that recovery goals might be set higher in a long perspective (12 months), and that participants might demand more of their everyday participation at 12 compared to that of 6 months. Another possible explanation could be the reported lack of rehabilitation at 6 months. Many rehabilitative interventions come to an end after about 3-4 months and persons with stroke are expected to then take care of their own rehabilitation. With time, this might become increasingly difficult to maintain. In an interview study with persons after a subarachnoid haemorrhage, participants highlighted that they missed a planned and well thought-out rehabilitation plan, and it was confirmed that they had to manage rehabilitation on their own after about 6 months [128].

The individual changes in participation scores (Figure 5) might appear as somewhat random over time, but indicates that participation is something that is sensitive to change, and probably depends on various aspects in life. It has been

shown before that self-perceived participation in the first year is sensitive to the impact of stroke over time, both in positive and negative directions [24]. That levels of self-perceived participation seems to be open to change at different time points after stroke, and the fact that different factors may help to increase this level, are positive results both for persons with stroke and for professionals who works to improve participation. For example, that levels of participation decrease between 6 and 12 months might have to do with the fact that many individuals loses their access to rehabilitation services before or somewhere around six months. The main challenge for professionals becomes to target the needs of each individual and to tailor-make interventions based on these needs. Based on the results of this thesis, it doesn't seem to be a question of finding new ways to enhance participation, but rather to find the best ways for each individual.

The scatterplots in study II showed an interesting relationship between perceived emotional health or cognitive ability and perceived participation at 1, 6 and 12 months. In article II it was discussed that a certain level of emotional health and cognitive functions seemed to be required for a person to achieve full participation. Hence, the person's experience of full participation seemed to correlate with a quite high level of perceived emotional and cognitive health. This result could be explained by the nature of perceived participation, being a very personal experience, created in the individual's minds. It is unsurprising that emotional and cognitive health seem to be important for perceived participation [6]. However, these relationships did not work the other way around, i.e. you could perceive your emotional and cognitive health to be good, and at the same time rate your participation level as low. It is possible that the strong association between the level of physical functions and perceived participation plays a role here, or that other factors, that weren't included in the regression models have influenced perceived participation as well. It may seem unexpected that neither the emotional domain, nor the cognitive domain proved to be significantly associated to participation in the regression models. An explanation for this may be that the study group scored homogenously high on these domains, and very few persons

chose a lower score. It is possible that a considerably larger study group would have revealed if emotional or cognitive health could be meaningful for perceived participation or not.

A reflection that I had when compiling the results of study III was that chronic conditions with rehabilitative potentials, shouldn't be neglected in favor of acceptance. For example, rehabilitation with potential to improve a condition shouldn't be overlooked, even if the individual tries to stay positive and ignore their impairments. Thus, it should be important to put both rehabilitative potential and a healthy attitude of acceptance in focus when creating long-term interventions. We do not want to run the risk that individuals become satisfied with a lower level of rehabilitation than what is actually possible for a specific impairment.

In focus group discussions (study IV) a main emphasis was on personal stories about how one had managed to create an everyday life which could run more smoothly. Participants' narratives were constructed on a timeline, on which they continuously switched focus from the past to the present and back again. An interesting aspect of this was that situations in their current life (photos) were explained through how life had been before stroke, and from stroke onset up to the time of the interview. Participants were also keen to talk about how they envisioned their future; what they hoped for and what they feared. It was previously shown that a sense of coherence plays a vital role as an internal resource in managing life for persons with a chronic disease [129]. Understanding life events as logical parts of a coherent life story is thereby important when trying to create a sense of meaning in life [130]. That narratives of study IV were so focused on processes in time may be explained by this need to make meaning out of a severely disruptive life event. When an individual manages to promote an increased sense of coherence, one's psychological wellbeing may be increased as well [130].

# Conclusions and implications

1. In conclusion, study I and II showed that participants rated their memory and thinking as well as communicative skills as quite good from 1 month and during the first year after stroke. Scores of participation differentiated highly within the group during the first year, indicating that this phenomenon is sensitive to changes in a person's life. This sensitivity to change strengthens the motivation for why measuring participation should be an effective way to acknowledge individuals who don't feel so well adapted to life after stroke. By finding these individuals in an early stage of distress, interventions aimed at improving their situation might be less extensive in comparison to what is needed when persons are very depressed or feel much worse.
2. Physical functioning was significantly associated with perceived participation during the first year after stroke, and it seems that rehabilitative interventions aimed to improve physical functions might improve perceived participation as well. In study III most participants reported not exercising very much in their daily lives. Even though participants knew that exercise would be good for them, they felt that they lack in time or energy for this in daily life. These examples of perceived barriers to physical activity after stroke is well known from previous research, and it has been suggested that individual preferences should be taken into account when physical activities are designed/prescribed [131]. In addition to this it might be necessary to look at how different circumstances in a person's life affect their ability to include physical exercise in a daily schedule. In study III for example, participants mentioned that working many hours made them too tired for physical activities. Therefore, it might be effective to collaborate with employers in finding the best solutions for promoting physical activities

for the person with stroke. This is important to prevent a recurrent stroke, but also to improve a person's overall health and wellbeing.

3. In study III, participants' narratives of their everyday participation were mostly about situations at work or with close friends and family. Situations of participation were described as engaging, meaningful and in relation to others. These results were mostly expected, considering previous research [16], but we did not expect results to be so focused on work situations. Having a job and being able to work seemed highly important to the participants. Facilitating for persons after stroke and preparing them for successful re-entry into the labor market should be an even more strongly emphasized step in the reintegration process.
4. Study IV showed clearly that for some individuals, mental processes of adaptation and acceptance after stroke were hindered by feelings of depression or resignation. These participants felt alienated from society and alone in their struggle towards participation in daily life. These results shed some light on a group of persons after stroke that feel neglected by the healthcare system, or by society as a whole. Long-term healthcare services should place more emphasis on helping persons who feels this way, although new and more flexible methods might be needed to succeed in this.

# Future Research

Conducting this research has contributed with new information regarding participation after stroke, but has also generated several ideas for future research.

These thoughts are described in point format below:

- When conducting study II, clear relationships between all physical domains and participation were found. Due to multicollinearity among the physical domains, these were collated into a main composite Physical domain which were significantly associated with participation at all timepoints in the regression analysis. However, as the confidence intervals for these results were so wide, study II can only contribute with an indication for what might be confirmed in future research, using a larger study population.
- The long-term follow-ups of study III and IV showed results which largely confirmed one another. However, the translatability into other cultural contexts can only be guessed at. Investigating how people manages in a long-term perspective in different types of communities, when it comes to education, jobs and social life, is not well known. It is highly important to investigate these issues further, and from the perspective of intersectionality. Then, challenges in working with reintegration for persons after stroke can be met more adequately and tailored to different societies worldwide.
- Study III and IV showed a need for individualized and more flexible interventions in a long-term perspective after stroke. There is a need for further research regarding how these interventions could be made flexible enough when meeting individuals in their personal preferences.

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## Appendix.

Following are questions of the Stroke Impact Scale 3.0, the Swedish version. These questions was answered on a five-point scale, and have been used for study I and II in this thesis. The Swedish version (Patient version) can be accessed at: (<https://eprovide.mapi-trust.org/instruments/stroke-impact-scale-stroke-toolbox#languages>).

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### **Skala för bedömning av följder efter stroke**

**Syftet med dessa frågor är att utvärdera hur din stroke har påverkat din hälsa och ditt liv. Vi vill utifrån DIN EGEN ÅSIKT veta vilka följder sjukdomen har haft för dig. Vi kommer att ställa frågor om de begränsningar som orsakats av din stroke, samt hur det har påverkat din livskvalitet. Till sist ber vi dig att bedöma hur du återhämtat dig från din stroke.**

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**Följande frågor handlar om de fysiska (kroppsliga) problem som kan vara en följd av din stroke.**

**1. Under den senaste veckan, hur skulle du bedöma styrkan...**

- a. i den arm som har påverkats mest av din stroke?
- b. i gripförmåga i den hand som har påverkats mest av din stroke?
- c. i det ben som har påverkats mest av din stroke?
- d. i den fot/vrist som har påverkats mest av din stroke?

**Följande frågor handlar om ditt minne och din tankeförmåga**

**2. Under den senaste veckan, hur svårt har det varit för dig att...**

- a. komma ihåg saker som folk just sagt till dig?

- b. komma ihåg saker som hände dagen innan?
- c. komma ihåg att göra saker (t.ex. hålla avtalade tider eller ta medicin)?
- d. komma ihåg vilken veckodag det var?
- e. koncentrera dig?
- f. tänka snabbt?
- g. lösa vardagsproblem?

**Följande frågor handlar om hur du känner dig, om humörförändringar och om din förmåga att kontrollera dina känslor efter din stroke.**

**3. Under den senaste veckan, hur ofta...**

- a. har du känt dig ledsen?
- b. har du känt att du inte har någon som står dig nära?
- c. har du känt dig som en börda för andra?
- d. har du känt att du inte har något att se fram emot?
- e. har du anklagat dig själv för misstag du gjorde?
- f. har du haft det lika trevligt som du alltid haft?
- g. har du känt dig nervös?
- h. har du känt att livet är värt att leva?
- i. har du levt och skrattat minst en gång om dagen?



**Följande frågor handlar om din förmåga att samtala med andra människor, samt din förmåga att förstå vad du läser och vad du hör i ett samtal.**

**4. Under den senaste veckan, hur svårt har det varit att...**

- a. säga namnet på en person du haft framför dig?
- b. förstå vad som sades till dig i ett samtal?
- c. besvara frågor?
- d. namnge saker och ting vid dess rätta namn?
- e. delta i ett samtal med en grupp människor?
- f. samtala i telefon?
- g. ringa upp någon samt välja rätt telefonnummer och slå numret?

**Följande frågor handlar om de aktiviteter du kan tänkas syssla med under en vanlig dag.**

**5. Under de senaste 2 veckorna hur svårt har det varit att...**

- a. skära upp din mat med kniv och gaffel?
- b. klä på dig på överkroppen?
- c. tvätta dig (bada, duscha...)?
- d. klippa tånaglarna?
- e. komma snabbt till toaletten?
- f. kontrollera blåsan (så att det inte händer en olycka)?
- g. kontrollera tarmen (så att det inte händer en olycka)?
- h. göra lättare hushållssysslor?
- i. gå och handla?

j. utföra tyngre hushållssysslor?

**Följande frågor handlar om din rörelseförmåga i och utanför hemmet.**

**6. Under de senaste 2 veckorna, hur svårt har det varit att...**

- a. sitta utan att tappa balansen?
- b. stå utan att tappa balansen?
- c. gå utan att tappa balansen?
- d. förflytta dig från sängen till en stol?
- e. gå hundrameter?
- f. gå snabbt?
- g. gå uppför en trappa?
- h. gå uppför flera trappor?
- i. ta dig in och ut ur en bil?

**Följande frågor handlar om din förmåga att använda den hand som har PÅVERKATS MEST av din stroke.**

**7. Under de senaste 2 veckorna, hur svårt har det varit att använda den hand som har påverkats mest av din stroke för att...**

- a. bära tunga saker?
- b. vrida om nyckeln i ett lås?
- c. öppna en konservburk eller syltburk?
- d. knyta ett skosnöre?
- e. plocka upp ett litet mynt?

**Följande frågor handlar om hur din stroke har påverkat din förmåga att delta i de aktiviteter som du brukar göra, saker som är viktiga för dig och som hjälper dig att finna livet meningsfullt.**

**8. Under de senaste 4 veckorna, hur stor del av tiden har du haft begränsningar när det gäller...**

- a. arbete (betalt, frivilligt eller annat)?
- b. aktiviteter tillsammans med andra?
- c. lugna fritidssysselsättningar?
- d. aktiva fritidssysselsättningar?
- e. din roll som familjemedlem och/eller vän?
- f. ditt deltagande i andliga eller religiösa aktiviteter?
- g. din förmåga att ha kontroll över ditt liv så som du önskar?
- h. din förmåga att hjälpa andra människor?