From department of Neurobiology,
Care Sciences and Society
Karolinska Institutet, Stockholm, Sweden

PARTICIPATION IN EVERYDAY LIFE AFTER STROKE:

DEVELOPMENT AND EVALUATION OF F@CE – A TEAM-BASED, PERSON-CENTRED REHABILITATION INTERVENTION SUPPORTED BY INFORMATION AND COMMUNICATION TECHNOLOGY

Martha Gustavsson

Karolinska Institutet

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Participation in everyday life after stroke:

Development and evaluation of F@ce – a team-based, person-centred rehabilitation intervention supported by Information and Communication Technology

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By

Martha Gustavsson

Principal Supervisor:
PhD Susanne Guidetti
Karolinska Institutet
Department of Neurobiology, Care Sciences and Society
Division of Occupational Therapy

Co-supervisor(s):

PhD Charlotte Ytterberg
Karolinska Institutet
Department of Neurobiology, Care Sciences and Society
Division of Physiotherapy

Kerstin Tham
Malmö University
Department of Care Science
Faculty of Health and Society

Uno Fors
Stockholm University
Department of Computer and Systems Sciences
Division of Interaction Design and Learning

Magnus Andersson
Karolinska Institutet
Department of Clinical Neuroscience
Division of Neuro

Opponent:
Professor Birgitta Bernspång
Umeå University
Department of Community Medicine and Rehabilitation
Division of Occupational Therapy

Examination Board:
Associate Professor Ingvar Krakau
Karolinska Institutet
Department of Medicine
Division of Neurology

Associate professor Helena Lindgren
Umeå University
Department of Computing Science
Division of Occupational Therapy

Professor Maria Larsson-Lund
Luleå University of Technology
Department of Health Sciences
Division of Health and Rehabilitation

Till kärleken i mitt liv, Kim och de finaste gåvor Gud gett mig,
mina älskade barn Saga och Anton. Ni är det bästa jag har!

ABSTRACT

AIM: The general aim of this thesis was to generate knowledge about how Information and Communication technology (ICT) could be used in the rehabilitation process after stroke in order to develop and evaluate the feasibility of F@ce- a person-centred, team-based intervention, supported by ICT, to enable performance of daily activities and participation in everyday life for people after stroke.

METHODS: Studies I and II were qualitative grounded theory studies that were performed to generate knowledge on people after stroke and health care professionals working with rehabilitation after stroke, regarding the experiences of using ICT. The third study was a secondary analysis of a previously performed randomised controlled trial, evaluating a client-centred activities of daily living (CADL) intervention, to analyse factors of importance for a positive outcome in participation after stroke. The knowledge generated in studies I-III combined with previous research was used to develop F@ce, a team-based, person-centred intervention for rehabilitation after stroke, that was supported by ICT. Study IV was an evaluation of the feasibility of using F@ce, and the study design, in terms of the recruitment process, outcome measures used, fidelity, adherence, acceptability and potential harms.

RESULTS: People after stroke in study I described their drive to integrate ICT in their everyday lives after stroke. They used their mobile phones to feel safe, to stay connected to friends and family, and to improve physical and cognitive functions. They also used their computer for social networks, to manage daily occupations such as paying bills, online shopping and searching for information. The healthcare professionals in study II did not use ICT to any greater extent outside their office, however, they had a vision that ICT could be used as a platform for sharing information and collaboration within the rehabilitation process. The results from study III showed that within the control group (receiving usual ADL interventions) those with mild stroke and home-based rehabilitation had a better outcome in perceived participation compared to the intervention group, however, in the intervention group the difference between stroke severity and context of rehabilitation were not significant. This would indicate that the CADL intervention were specifically useful for those with moderate to severe stroke and those receiving rehabilitation at an in-patient unit. The feasibility testing of the newly developed F@ce intervention in study IV showed that it was feasible to use, and that the fidelity, adherence and acceptability of the intervention were good. The participants had positive outcomes in performance (n=4) and satisfaction with the performance (n=6) of daily activities according to Canadian Occupational Performance measure (COPM) and several participants had clinically significant improvements in different domains in the Stroke Impact Scale (SIS).

CONCLUSION: The studies within this thesis enabled the development and evaluation of a new rehabilitation intervention, F@ce, using ICT which is relevant in this time, with the rapid digitalization in the society, healthcare and rehabilitation. The knowledge from the previously developed CADL study, along with the experiences of people after stroke and healthcare professionals' use of ICT, and the modelling of F@ce together with stakeholders created a strong foundation for the new intervention. Using a team-based, person-centred intervention with the support of ICT seemed to enable people to perform daily activities and thus increase their participation in everyday life.

LIST OF SCIENTIFIC PAPERS

I. **Martha Gustavsson, Charlotte Ytterberg, Mille Nabsen Marwaa, Kerstin Tham & Susanne Guidetti.** Experiences of using information and communication technology within the first year after stroke – a grounded theory study. Disability and Rehabilitation, 2016 (40) 561-568

II. **Martha Gustavsson; Charlotte Ytterberg; Susanne Guidetti.** Exploring future possibilities of using Information and Communication Technology in multidisciplinary rehabilitation after stroke – a grounded theory study. (Submitted)

III. **Martha Gustavsson; Susanne Guidetti; Gunilla Eriksson; Lena von Koch; Charlotte Ytterberg**. Factors affecting outcome in participation one year after stroke: a secondary analysis of a randomised controlled trial. Journal of Rehabilitation Medicine, 2019 (51) 160-166.

IV. **Martha Gustavsson; Charlotte Ytterberg; Kerstin Tham; Magnus Andersson; Uno Fors; Susanne Guidetti.** A single group feasibility study of F@ceTM, a team based, person-centred intervention for rehabilitation after stroke supported by Information and Communication Technology. (In manuscript).

CONTENTS

LIST OF ABBREVIATIONS

ADL	Activities of daily living
CADL	Client-centred activities of daily living intervention
CMOP	Canadian Model of Occupational Performance
COPM	Canadian Occupational Performance Measure
FAI	Frenchay Activities Index
FSS	Fatigue Severity Scale
GT	Grounded theory
HAD	Hospital Anxiety and Depression Scale
I-ADL	Instrumental activities of daily living
ICF	International Classification of Functioning, Disability and Health
ICT	Information and Communication Technology
IVO	The Swedish Health and Social Care Inspectorate
MoCA	Montreal Cognitive Assessment
MoHO	Model of Human Occupation
MRC	Medical Research Council
MSW	Medical Social Worker
OGQ	Occupational Gaps Questionnaire
OT	Occupational therapist
P-ADL	Personal activities of daily living
PT	Physiotherapist
RCT	Randomized Controlled Trial
SALT	Speech- and Language Therapist
SIS	Stroke Impact Scale
WHO	World Health Organization

PROLOGUE

Working in research is a creative process, just like painting a picture. You start out with a plan, but then have to adjust to the conditions and the surroundings, and the end result is at first unclear. When I was at the starting point of this thesis, it was hard to imagine what the finished product would be; all I had was a just a rough sketch with a few lines. But I knew that person-centredness, ICT (information and communication technology), and stroke would be some of the important features. Based on that, I started interviewing people after stroke and professionals about their use of ICT. This stage reminded me of my work as an occupational therapist – working with people, talking, listening, and analysing. However, the working process was quite different from before, and the tools and knowledge I was accustomed to had to be left behind and new techniques, materials, and tools had to be introduced. At this stage, the painting started to take form, but no clear pattern of the finished painting was yet to be seen.

I soon realised that my painting was just one piece of a larger puzzle, a puzzle that had been started on years ago within the research group I now was a part of. Looking at the previous pieces was confusing; how would my contribution fit in? Were my pieces ever going to fit in to this large and beautiful puzzle? Then I had to look closer at those pieces, what were they made of? I started getting to know the puzzle, not just as a spectator, but as a co-constructer. Working with those experienced puzzle-builders was daunting at times, and I was still unsure where I could contribute. But my smart, clever, and inspiring colleagues generously invited me to be a part of their team, sharing their knowledge and guiding the way.

When trying to figure out the bigger picture, I learned a lot, but mostly I realised how much I still did not know – the missing pieces, the blank canvas still to be filled with colours, shapes, and meaning. During this process, the true creation began when modelling the new intervention. The intervention had some pieces from the bigger picture and some new pieces created together with the others researchers. The shapes and colours were added by all of the people participating, including people with stroke, healthcare professionals, health informaticians, and researchers. This creative process of working closely with people in clinical settings and taking part of people's life stories was exciting. And helping people who have suffered a stroke and who are trying to find new paths in their lives has made the struggle worth all the effort.

Looking back, I feel proud of my accomplishments and my small contribution to the bigger picture and to the larger puzzle we are putting together. This work has been a struggle, and has been one of the hardest things I have ever done, forcing me out of my comfort zone and making me work harder than ever before. Patiently placing each piece carefully, ripping it out, deconstructing, improving,

doing over, finishing something today and then the next day doing it over, over, and over again. Sometimes the improvements and progress feel so small, almost non-existent, but when taking a step back they come together, all those imperfect lines have a kind of beauty, still not perfect, but good enough.

The puzzle will never be fully finished – some parts will be cut off when losing importance, and others that are completely new and different will be added. It's a beautiful picture we are creating, and looking closely you will see the all-important everyday life of people, the core of human life, activity, and participation – the colours of life. This is my small contribution to the picture, my hard work squeezed in between the covers of this book. Look closely and you will see imperfections, human mistakes, and missing words and thoughts, but step back and hopefully you will enjoy the whole picture, painted with love and care.

1 INTRODUCTION

The overall aim of this thesis was to develop and evaluate a team-based person-centred intervention to enable people's performance of daily activities and participation in everyday life after stroke using Information and Communication Technology (ICT). The development was performed in line with the Medical Research Council (MRC) guidelines for complex interventions [1]. The development process included developing an evidence base, modelling the procedures, and finally testing the intervention in a feasibility study. The components of the intervention, called F@ce, were based on the previously developed and tested client-centred activities of daily living (CADL) intervention [2, 3]. The F@ce intervention was developed in collaboration with professionals working within multidisciplinary neurological rehabilitation teams, health informaticians, and researchers and was evaluated in a feasibility study.

1.1 Participation

Participation in everyday life can promote health and life satisfaction and is often expressed as the overall goal in occupational therapy rehabilitation [4]. There are several different definitions of the concept of "participation", and this highlights different aspects of participation from a global, societal level to an individual, personal level. The International Classification of Functioning, Disability and Health (ICF) developed by the World Health Organization (WHO) includes a personal as well as a societal level connected to equal rights. The ICF defines participation as being influenced by the environment and as "involvement in a life situation". The involvement can include "taking part", "being included", "being accepted", "engaging in an area of life", and "having access to needed resources" [5].

In this thesis, participation is viewed as something more than just being present or performing an activity. Participation includes having access to environments and situations where meaningful activities can be performed as well as having the ability and desire to perform those activities. In occupational therapy, the definition of participation in everyday life usually highlights personal factors such as the individual's performance capacity, volition, and habituation [6]. Participation in everyday life is influenced by environmental factors (social and physical environment) that can either hinder or facilitate occupational performance [6]. Feeling included, being in charge, and being a part of the team by making decisions in daily life can be as important when it comes to participation as the actual performance of the activity.

1.2 Everyday life from an occupational perspective

In this thesis, the performance of activities in everyday life for people after stroke has been of interest, mainly by exploring the use of ICT in everyday life and by trying to improve the performance of activities and participation in everyday life for people after stroke through the development of a new intervention. The term "everyday life" is used to describe the daily activities, routines, and roles that shape people's daily lives [6]. The Canadian Model of Occupational Performance (CMOP) [7] has developed a taxonomy of occupational performance describing and defining occupations, activities, and tasks. Performance of a task includes a set of purposeful movements and mental processes, for example, cutting vegetables for dinner. An activity is defined as a wider concept that includes performing a set of combined tasks, for example, cooking. Occupation would then be an even greater concept that includes a set of activities, for example, making dinner for your family. Occupation could include anything that people do in their everyday lives such as self-care, leisure, and productivity [7].

Within occupational therapy, it is important not to view occupational performance as something purely objective, and we also need to acknowledge the subjective experience [6]. Having the capacity, the volition, and habituation, as well as knowing how to, are all important for the performance of an activity or occupation [6]. The lived body is a concept from philosophy that describes the human being as a combination of body and soul and highlights the subjective experience of doing [8]. The person experiences the world through the body and through performing activities, and each person's experience of their lived body is unique [6].

While performing their daily occupations, people's everyday lives are intertwined with all of the physical, social, cultural, and economic/political aspects of their environment [6, 7]. The physical environment includes both the spaces people exist within and the objects they use, including technical devices such as mobile phones and computers [6], which from an occupational perspective could even be seen as parts of ourselves [9].

1.3 Rehabilitation process after stroke

The rehabilitation process after stroke is crucial for the person in order to regain functions and to be able to perform daily activities and to manage one's everyday life [10]. A stroke is caused by a haemorrhage or a blood clot that obstructs the blood supply to an area of the brain. Depending on the location and the magnitude of the damage, the consequences for each person vary. The acute treatments of stroke include removal of the clot or stopping the haemorrhage, and time is of the essence to reduce the damage [11]. The symptoms of stroke might include

one-sided paresis, fatigue, and impairments in speech, memory, vision, and/or cognition [11, 12]. Some of the acute symptoms might disappear immediately with treatment, while some are reduced within days when the swelling goes down, and some of the recovery is due to the plasticity of the brain [13]. Having a stroke is usually a shocking life event and is experienced as a chaotic time for the person and their significant others [13, 14, 15, 16, 17]. Some people might return to daily life as it was before their stroke; however, it is not unusual to experience long term, sometimes lifelong, consequences of stroke in daily life, including reduced life satisfaction and participation in everyday life [18].

National guidelines for the care and rehabilitation process after stroke are available in different countries to guide the professionals in providing evidence-based practice [19, 20, 21, 22]. Rehabilitation after stroke usually starts at an acute unit at hospital, although because early discharge is recommended to reduce time spent in hospital the continued rehabilitation needs to be performed elsewhere. Sometimes there is a need for continued hospitalisation at a rehabilitation unit, and when discharged home the primary care units are in charge of rehabilitation [19, 20, 21, 22].

Rehabilitation after stroke is usually focused on enabling the person to regain lost abilities and to be able to experience participation and to perform activities with purpose and meaning in daily life [22]. Research has shown that people one year after stroke often report restrictions in participation in everyday life and in performing daily activities [23], and there are those who report having unmet rehabilitation needs one or two years after stroke [24, 25]. When rehabilitation is carried out at home, the person's motivation has proven to be a key element for success, and one study showed that 2/3 of the participants needed more supervision at home or needed rehabilitation at an in-patient unit in order to keep their motivation high and to reach their rehabilitation goals [26].

The multidisciplinary teams working within stroke rehabilitation usually include occupational therapists, physiotherapists, speech therapists, medical social workers, and dieticians who often work in close collaboration with physicians and nurses [27]. Professionals working together as a team around the person need to contribute with their knowledge and to collaborate in goal-setting and planning of the rehabilitation in order to achieve good care quality [22, 28]. Multidisciplinary teams have proven to improve function in people with stroke and other diagnoses by identifying the persons' needs and goals and by communicating, coordinating, and sharing knowledge [29].

1.4 Person-centred rehabilitation

Within this thesis, the concept of person-centredness has been used to highlight the importance of viewing the person with stroke within rehabilitation as the most important person on the team. The theoretical foundations of the concept are grounded in the client-centred approach as described in the occupational therapy models Model of Human Occupation [30] and CMOP [7]. These models emphasise the holistic view of the person, which includes paying attention to the person's whole situation and not just their medical needs [7, 30].

Person-centred is a concept used within healthcare and has been described by Carl Rogers, who specified that the therapeutic relationship should consist of a warm, understanding, and safe environment where the person is the expert and the therapist is a tool to support the person in finding their own answers [31]. To have a person-centred approach is in line with the WHO guidelines that state the following goal for community-based rehabilitation: *"People with disabilities and their family members make their own decisions and take responsibility for changing their lives and improving their communities."* [32].

The concepts of person-centred, patient-centred, client-centred, and other similar concepts have been used as interchangeable concepts in health care research and practice. Because this thesis builds on a multidisciplinary approach, the concept of person-centredness was used because it is a concept that different professionals are familiar with. Thus the person-centred approach used in this thesis is based on client-centredness [6, 7] as well as person-centredness as described by Ekman [33], which is widely used in Swedish healthcare.

To enable a successful outcome of the rehabilitation, the use of a person-centred approach in goal-setting is important by actively involving the person [34, 35] and by providing rehabilitation continuously during the first year [25]. Using strategies such as problem-solving, decision-making, and goal-setting within rehabilitation soon after stroke improves the ability to perform activities of daily living (ADL) and reduces the risk of a poor outcome [36]. To include significant others, i.e. spouses, parents, adult children, and close friends, is also recommended in the national guidelines [22].

During the qualitative evaluations of the CADL study, two important concepts connected to a client-centred approach emerged, namely sharing [37] and transparency [38]. The concepts derived from the experiences of those who received and provided the CADL intervention, which had an enhanced client-centred approach. The concept of sharing is described from the views of professionals as an important part of the client-centred intervention that includes working close to people after stroke [37]. The professionals noticed that sharing the same understanding of the person's abilities and experiences and building a therapeutic

relationship are important foundations for the rehabilitation process. Additionally, sharing experiences, knowledge, and goal-setting based on valued activities enables the person to regain lost abilities and enables agency in daily activities [37]. The concept of transparency has been described from the view of people after stroke as being able to have a clear vision of the intervention process, giving them a structure, and providing insights into their own abilities [38].

1.5 ICT Interventions in stroke rehabilitation

The development and use of information and communications technology (ICT) is rapidly increasing in society as well as in healthcare and rehabilitation. In line with this, the Swedish government has a vision to be a world leader in the use of e-health by the year 2025 [39]. Digitalisation is seen as a valuable tool for increased participation in society for people with disabilities [40]. There are a variety of concepts within research addressing different aspects of digitalisation such as e-health, tele-rehabilitation, and health informatics. The term ICT has been used in this thesis and includes technological devices used for providing information and for communicating such as mobile phones, tablets, and computers as well as the applications and software used on those devices [41].

The use of ICT within rehabilitation is increasing, and monitoring and supporting recovery from a distance has been tested with good results within home rehabilitation and has proven, for example, to increase the level and intensity of physical exercise [42], improve communication skills for people with aphasia [43, 44], support memory [45], improve balance [46], increase activity level, and create opportunities for socialisation [47] for people after stroke. One of the benefits of using ICT-based interventions is that they might be cost effective by reducing the number of home visits and thereby saving time and travel costs, especially in rural areas, without compromising with the results of the rehabilitation [46, 47, 48].

The use of ICT solutions has been proven to enable communication and feedback from health care professionals [47, 48, 49, 50, 51] and to facilitate person-centred care [52]. One study showed that participants were satisfied with using videoconferencing as an alternative to phone calls in their contact with professionals and felt that it was equivalent to or better than home visits, and they were also able to achieve their goals to a greater extent than when using regular home visits [48]. ICT-based solutions might also be used by significant others by providing a network for support and for exchanging experiences with others in the same situation and as a source of information about their family member´s diagnosis [53]. Using ICT-supported systems for reminders and for creating routines can support the significant others in letting go of the responsibility of always reminding about and maintaining routines [45]. One concern in using ICT among people with stroke might be their ability to manage the technology. Research has shown that people

might experience a variety of difficulties in handling technology after acquired brain injury [54, 55, 56]. However, there are other studies showing that persons with acquired brain injury can learn to use technology in their daily activities and that memory aids can support participation in everyday life [57]. ICT has been successfully introduced and used within rehabilitation after acquired brain injury and regardless of age or earlier use [47]. ICT can even be considered to be a "lifeline" in everyday life for people after stroke in order to be able to continue performing daily activities [58], although support is often needed, especially when using a new device or when something unexpected happens [53]. Still, knowledge about the possible benefits and obstacles for using ICT within a person-centred rehabilitation intervention for people after stroke is unexplored.

1.6 Complex interventions

The Medical Research Council (MRC) guidelines for the development and evaluation of complex interventions has been used throughout this thesis [59]. The MRC guidelines define a complex intervention as one consisting of several components that interact with each other [59]. The complexity of the intervention might arise because behavioural changes are needed among those receiving or delivering the intervention, because the intervention includes a variety of possible outcomes, or because the intervention must be flexible or individually tailored [59].

Rehabilitation interventions after stroke can be complex, especially in the early stages from the acute to the rehabilitation phase [10]. The successful implementation of a complex intervention in stroke rehabilitation relies on having collaboration among the healthcare professionals, having a good organisational structure, and having a clear goal [60]. In the evaluations of the CADL study, the occupational therapist who had delivered the intervention described the positive factors that impacted the implementation as collaboration with the researchers, acquisition of evidence-based knowledge, and opportunities for discussions and reflections in the workshops arranged by the researchers [61].

1.7 Rationale of this thesis

In summary, the rationale for this thesis is to meet the need for increased participation after stroke by developing a person-centred rehabilitation intervention. After a person has had a stroke, multidisciplinary teams, both at hospital and then in primary care, should provide the rehabilitation [22]. The evidence shows that team-based rehabilitation in which team members collaborate with each other and the person by having a clear goal-setting strategy forms the best foundation for a successful rehabilitation [34, 35]. According to the national guidelines for stroke care, there is a lack of evidence-based rehabilitation interventions after stroke [22].

Previous research has shown that sharing [37] and transparency [38] are key aspects of person-centred rehabilitation after stroke, and the hypothesis is that ICT can be used to enable transparency and sharing of knowledge, goals, and plans. However, before developing and implementing ICT tools there is a need to develop knowledge about the potential benefits and obstacles for people after stroke in order to use ICT in everyday life and within the rehabilitation process. Additionally, any new intervention needs to be carefully tested on a small scale before performing large-scale testing and implementation [59].

2 AIMS

The general aim of this thesis was to generate knowledge about how Information and Communication Technology could be used in the rehabilitation process after stroke in order to develop and evaluate the feasibility of F@ce- a person-centred, team based intervention supported by ICT to enable performance of daily activities and participation in everyday life for people after stroke.

The specific aims were:

I. To identify how people 6–12 months after stroke were using and integrating information and communication technology (ICT) in their everyday lives.

II. To explore how multidisciplinary teams used and could potentially use Information and Communication Technology to enable a person-centred rehabilitation process after stroke.

III. To explore the importance of client characteristics (age, sex, stroke severity and participation before stroke), rehabilitation context (inpatient or client's home), and approach (enhanced client-centeredness or not) on participation in everyday life one year after stroke.

IV. To evaluate the feasibility of the study design in terms of recruitment and outcome measures used. An additional aim was to evaluate the feasibility of using F@ce within in-patient and primary care rehabilitation after stroke in terms of fidelity, adherence and acceptability.

3 METHODS

The focus of the research in this thesis was to develop a rehabilitation intervention using ICT to enable performance of daily activities and participation in everyday life for people after stroke. In order to develop the new intervention, there was a need to generate knowledge on the experiences of using ICT within the rehabilitation process after stroke and to explore factors impacting on participation for people who have had a stroke. The four studies in the thesis were all parts of the development and evaluation of the F@ce intervention. Both qualitative and quantitative methods were used, and an overview of the studies and methods are presented in Table 1.

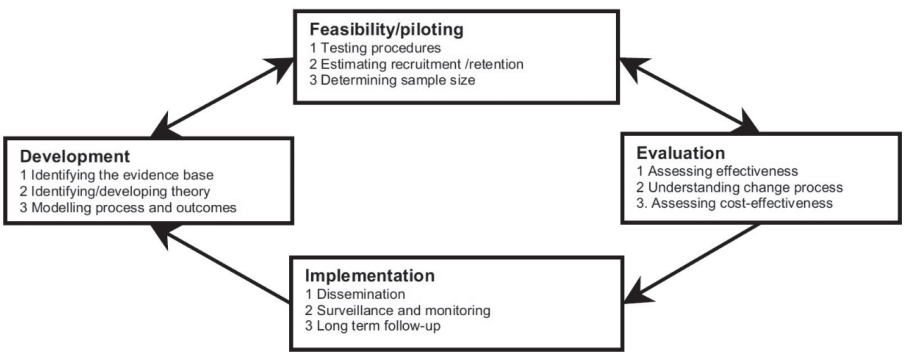
Table 1. Overview of the studies included in this thesis following the MRC guidelines

	Study I	Study II	Study III	Study IV
MRC guidelines, key elements	**Development**			**Feasibility/ piloting**
Focus	Experiences of using ICT in everyday life after stroke	Experiences of using ICT in rehabilitation after stroke	Factors impacting on participation in every-day life after stroke	Development and evaluation of F@ce, an ICT-based multidisciplinary intervention for rehabilitation after stroke
Design	Qualitative, Grounded theory	Qualitative, Grounded theory	Secondary analysis of a previous RCT	Feasibility study
Participants	18 people 6–12 months -after stroke	18 professionals working in rehabilitation after stroke	237 people ≤3 months after stroke.	Six professionals from three neurological rehabilitation teams and 10 people 0–32 months after stroke
Data collection	Individual and focus group interviews Demographic data: Age, sex, months post-stroke, living conditions, Stroke Impact Scale	Individual and focus group interviews Demographic data: workplace and profession	Outcome measures: Stroke Impact Scale, Frenchay Activities Index, Occupational Gaps Questionnaire Independent variables: Age, sex, months post-stroke, rehabilitation type, Frenchay Activities Index, Katz, Barthel	Outcome measures: SIS, Frenchay Activities Index, Canadian Occupational Performance Measure, Life Satisfaction Checklist, Self-Efficacy Scale, Hospital Anxiety and Depression Scale, Fatigue Severity Scale. Feasibility outcomes: Recruitment, outcomes, fidelity, adherence, acceptability, and harms Demographic data: Age, sex, months post-stroke, employment before stroke, cohabitation, use of ICT, Barthel, Montreal Cognitive Assessment

3.1 STUDY CONTEXT

The MRC guidelines for the development and evaluation of complex interventions (Figure 1) were used as a framework for the development of the new F@ce intervention. The first stage of the development was to identify the evidence base by reviewing previous research. The previously developed and evaluated CADL intervention was used as a point of departure and then further developed and modelled in close collaboration with stakeholders in the care trajectory after stroke. As preparation for the feasibility testing, several ICT tools were developed, and a series of workshops was arranged for the teams that were going to provide the intervention.

Figure 1. MRC guidelines. Key elements of the development and evaluation process



Craig et al. Developing and evaluating complex interventions: The new Medical Research Council guidance. International Journal of Nursing Studies. 2013; 50: 587, with permission from Peter Craig.

3.1.1 The CADL intervention

The F@ce intervention was further developed as a continuation of the CADL intervention [2, 3]. The CADL intervention was used by occupational therapists working in rehabilitation after stroke with the aim of enabling agency in daily activities and participation in everyday life for people after stroke. The person´s lived experiences were used as a point of departure, and goals were set based on activities the persons needed and wished to perform and included problem-solving strategies. The CADL intervention was evaluated in a randomized controlled trial (RCT) [2, 3] and in qualitative studies exploring the experiences of people after stroke [38] and occupational therapists participating in the CADL study [37]. Even though the results from the RCT showed no difference in participation between

the intervention group and the control group, there was a positive trend towards a clinically meaningful positive change in participation in favor of the intervention group receiving the CADL intervention [3]. One of the limitations described in the CADL study was that it was only directed to occupational therapists and not the whole team [3]. In the qualitative studies, both the participants with stroke and the occupational therapists described how they valued the client-centred approach and how it enabled them to share information and knowledge [37, 38].

3.1.2 The development of F@ce

The results from evaluations of the CADL intervention were used to further improve and model the F@ce intervention. One of the alterations included the addition of a multidisciplinary approach in line with national guidelines [62]. Additionally, using ICT as support was seen as an opportunity for the teams and persons with stroke to share information and knowledge and to be transparent, which had been emphasised in the qualitative evaluations of the CADL study [37, 38].

Still, there was a knowledge gap and a need for knowledge about the use and possibilities to use ICT within rehabilitation after stroke. Therefore, as a part of the development of the theory base for the F@ce intervention, three studies were performed. Two qualitative studies were performed to explore the use of ICT among people after stroke (study I) and among professionals within neurological rehabilitation teams (study II). Study III was based on quantitative data from the previous CADL study [2, 3] that were analysed to explore which factors might be important for participation in everyday life after stroke. The results from these studies were also used when modelling the F@ce intervention. Studies I and II confirmed that people after stroke use ICT in everyday life and that it could be used more within rehabilitation for communication, collaboration, and monitoring from a distance. Studies I and II also highlighted that people might experience difficulties with using ICT due to impairments and lack of experience and that support might be needed. The results from Study III showed that people receiving rehabilitation at an in-patient unit might benefit from a person-centred approach, and thus an in-patient unit was included in study IV.

The basic principles and components of the F@ce intervention were established by the researchers in a series of meetings. In order to ensure the relevance and to model the intervention, a workshop was arranged where the F@ce intervention was presented. The participants in the workshop included two rehabilitation team members, a representative from the Swedish stroke association, a health informatician from Stockholm University, and four researchers from Karolinska Institutet. Based on the discussions in the workshop, the components of F@ce were finalised and several ICT solutions were developed to support the delivery and the monitoring of the intervention.

3.1.3 The F@ce intervention

The F@ce intervention aimed to enable the performance of daily activities and participation in everyday life for people with stroke and included a Face-to-face meeting, Assessments, Collaboration, and Evaluation. The F@ce intervention was designed to be used by a team of professionals working within rehabilitation after stroke.

The content of the F@ce intervention includes different components providing a structure to support the rehabilitation teams and a person-centred rehabilitation, and it should not be seen as chronological but rather as an on-going process. The content of F@ce is based on previous research within stroke rehabilitation, a person-centred approach, and occupational performance as described in Figure 2.

Figure 2. The F@ce intervention

Content of the intervention		Evidence base/theory
Face-to-face meeting	Have an initial face-to-face meeting with the person in order to build a relationship and provide relevant information.	Creating a therapeutic relationship [63] with the person, using a person-centred approach [33], and having transparency throughout [38] supports the rehabilitation process.
	Let the person describe his/her abilities, roles, and habits before stroke.	Having a person-centred approach includes using the person's unique life-experiences[8] and narrative stories [33]about previous performance of daily activities [6] and participation in everyday life as a point of departure.
	Make contact with family/significant others in order to provide relevant information, including contact information.	Involving significant others by providing information and support has proven to be beneficial for the rehabilitation process [14, 64].
Assessments	Let the person describe his/her current occupational performance.	The person's current daily activities and environment need to be explored in order to plan the rehabilitation [7]. Listening to the person's narrative and sharing the same view of the person's abilities is important in a person-centred approach [37].
	Record an activity on video, view it together, and let the person score his/her performance.	After a stroke, the person needs to get to know their new body [65] and needs to have sufficient support from the team in doing so [63]. Sharing the view of the person's performance creates a common ground for planning the rehabilitation [6].
	Use COPM [7] as a base in order to create goals.	COPM is a person-centred measure based on the person's description of important issues in everyday life as scored for performance and satisfaction with performance [7].
Collaboration	Set three goals and create a clear plan with strategies to work with individually and together with the team, and document this in the F@ce web platform.	Enable change through setting goals and formulate strategies. Make sure that the person is actively involved in goal setting and planning of the rehabilitation [6, 7, 66].
	Daily reminders are sent out through the F@ce web platform every day, and the person rates their performance, and the researcher monitors the ratings and offers feedback and support.	It is important to maintain the therapeutic relationship and to be transparent in the communication and information in order to achieve a person-centred rehabilitation [38].
Evaluation	Review the goals and strategies regularly.	It is important to have realistic and achievable goals in order to maintain motivation and to support the person's discovery process and problem-solving strategies in order for them to use these in the future.
	Evaluation through COPM at the end of the 8 weeks of intervention.	COPM is useful in order to evaluate progress.
	Plan continued rehabilitation by revising the goals or by referring to another unit or to other professionals.	The consequences of stroke and the needs for rehabilitation often remain for a year or more [16, 67], and thus planning for the person's future rehabilitation is essential.

3.1.4 ICT support

Several ICT tools were developed by the researchers in collaboration with health informaticians, and these tools were used within the project to support the delivery and the monitoring of the intervention.

A *webpage* was created to support the teams, to serve as a structure for the workshops (described below), and to provide information, references, and contact information. The aims and content of each workshop were available on the webpage at any time to enable the rehabilitation team members to prepare and reflect on the content of the intervention and to share the theoretical basis before and after each workshop.

The F@ce *web platform* allowed the teams to register the three goals that were formulated based on activities the person needed and wanted to perform in their everyday lives. The web platform sent out daily reminders to the participant's mobile phone or tablet each morning regarding their goals and strategies and a short survey each afternoon asking them to score their performance of the activities on a scale from 1 (did not perform) to 5 (performed the activity very well). Low ratings (1-2) were marked with red in the system, a medium rating (3) was marked with yellow, and high ratings (4-5) were marked with green.

An online database for collecting the measurements was developed to collect, store, and sort the data. This enabled the researcher and the person that had a stroke to fill out the assessments together on a tablet. The results were then stored on a secure server that enabled easy transfer to Microsoft Excel for analysis.

3.1.5 Workshop for the participating teams

As preparation for initiating the feasibility study (study IV), the teams participated in a series of three workshops (about 2 hours each). The aims for the first workshop were to exchange experiences and knowledge within the group regarding successful rehabilitation and to discuss and reflect upon person-centeredness and participation. At the second workshop, the F@ce intervention was introduced and discussed, and the rehabilitation teams had the opportunity to try out the F@ce web platform. The third and final workshop was focused on preparation for the feasibility study (study IV) and aimed to develop the teams´ ability to set person-centred goals and strategies together with the person. After the workshop, the teams included participants with stroke currently enrolled in their rehabilitation teams to be a part of the feasibility study

3.2 Procedures

The procedures for recruiting participants, collecting data, and analysing the results are described below. In order to develop the new intervention, it was important to include people with stroke and professionals working in rehabilitation after stroke in the studies. To generate knowledge, an explorative approach was used where previous and new research were explored and used as a basis for the new intervention.

3.2.1 Recruitment and participants

Study I included 18 people from Sweden and Denmark who had had a stroke 6–12 months prior to data collection, lived at home, had been involved in out-patient rehabilitation, owned and used a mobile phone, and were able to participate in an interview. The participants had passed the acute stage of rehabilitation and returned to life at home and thus were able to describe their use of ICT in everyday life after stroke. The participants were identified through the Swedish Stroke Register and through a gatekeeper at a community rehabilitation centre in Denmark.

Study II included 18 professionals working within multidisciplinary rehabilitation teams. The participants were identified by a person working at an acute stroke unit who recommended participants with a variation of professions and workplaces. These participants included one occupational therapist (OT), one physiotherapist (PT), and one medical social worker (MSW) from an acute stroke unit and one OT, one PT, and one speech and language therapist (SALT) from a primary care rehabilitation team, and these participants were interviewed individually.

In addition, two focus group interviews were held with a total of 12 participants, including seven OTs, four PTs, and one SALT from nine different primary care rehabilitation teams. The participants in the focus group interviews were informed and asked to participate while attending a seminar, and the focus groups were held at the end of the seminar with two researchers present in both interviews.

Study III included 237 participants, including 123 participants from the intervention group who participated in the CADL intervention and 114 participants from the control group who received usual ADL interventions. The participants were included by trained data collectors (occupational therapists) at 16 rehabilitation units in Sweden participating in the study.

Study IV included 10 persons at 0 to 32 months after they had suffered a stroke and who had on-going rehabilitation within one of the participating teams, who were able to participate in the 8-week F@ce intervention, and who were able to express themselves in Swedish.

3.2.2 Data collection

Study I was performed in collaboration with the University of Southern Denmark. Among the 18 participants, 8 were interviewed in Sweden and 10 were interviewed in Denmark (in six individual interviews and one focus-group interview).

In study II, six professionals in Sweden were interviewed individually, three of whom worked within acute stroke rehabilitation and three of whom worked within primary care neurological rehabilitation teams. To further deepen the categories that emerged in the initial analysis, 12 professionals working in primary care neurological rehabilitation teams were interviewed in two focus group interviews.

The individual interviews in studies I & II were performed at the preferred place of the participant, usually the person's home or workplace. The focus groups were held at a convenient location, and the people with stroke were interviewed at the rehabilitation centre while the professionals at the Karolinska Institutet were interviewed in conjunction with a seminar they were attending. The focus group interviews were performed with one facilitator and one observer present. Interview guides with open questions were developed to guide the data collection and were especially important when different researchers collected data in order to ensure that all of the themes of the interviews were covered. The interviews were audio recorded, and the researchers used memos to capture emerging thoughts, reflections, and analyses.

In study III, the data had been previously gathered within the CADL study and had been collected at inclusion to the CADL study and at 3 and 12 months after inclusion by trained data collectors [2, 3]. This study was performed at 16 different rehabilitation units in Sweden where people with stroke were enrolled (including medical, geriatric, and home-based units).

In study IV, the F@ce intervention was given over the course of 8 weeks, and data were collected at inclusion, at 4 weeks after inclusion, and at follow-up after the 8 weeks of intervention. All demographic data and outcome measures were collected by a researcher using a tablet. Data used to evaluate the feasibility of using F@ce were collected through the F@ce web platform, the teams' logbooks, the researchers' field notes, and the follow-up survey filled out by the participants with stroke.

3.2.3 Demographics

In order to describe the participants' characteristics, demographic data were gathered in studies I, III, and IV regarding the participants' age, gender, and months post-stroke. Data on the participants' workplace and profession were gathered in study II. Additional data were gathered on living conditions (i.e. rural/urban) in study I, cohabitation in studies III & IV, and employment status before stroke and

use of ICT in study IV. Data regarding use of ICT were gathered in a survey filled out by the participants, and the participants' ICT use was graded as basic (sending and receiving text-messages on a mobile phone), moderate (calling, texting, and searching for information on the Internet on a smartphone or a tablet), or advanced (in addition to calling, texting, and Internet searches, also being able to install apps, play games, and perform other more advanced activities on a smartphone, tablet, or computer).

Stroke Impact Scale (SIS) 3.0 [68] was used in study I to describe the participants' perceived impact of stroke.

The *Barthel Index* [69] was used in studies III and IV to describe stroke severity. The scale ranges from 0 to 100, and a score of <15 = severe stroke, 15–49 = moderate stroke, and 50–100 = mild stroke [70].

The *Katz extended index of independence in ADL* [71] was used in studies III and IV as a demographic measure of dependency in personal ADL (P-ADL) and instrumental ADL (I-ADL). Six activities in PADL and four activities in IADL are included in the index, and the results are categorized into dependent in both P-ADL and I-ADL, dependent in P-ADL or I-ADL, or independent in both P-ADL and I-ADL.

The *Montreal Cognitive Assessment* (MoCa) [72] was used in study IV to measure cognitive function. The score ranges from 0 to 30, and a score of <26 indicates signs of cognitive impairment.

3.2.4 Outcome measures

Studies III and IV were both evaluations of interventions, and according to the MRC guidelines it is often more appropriate to use a range of measures than one single primary outcome measure when measuring the outcome of a complex intervention [59]. Thus a variety of outcome measurements were used in order to evaluate the outcomes of the CADL [2, 3] intervention (study III) and the F@ce intervention (study IV) (Table 2).

Table 2. Overview of outcome measures used within this thesis

Measurement	Objective	Used in
Canadian Occupational Performance Measure [73]	Performance of and satisfaction with activities in everyday life	Study IV
Stroke Impact Scale 3.0 [74]	Perceived impact of stroke	Study III and IV
Frenchay Activities Index [75]	Frequency of participation in social and domestic activities	Study III and IV
Occupational Gaps Questionnaire [76]	Gaps between performed/not performed activities and the desired/not desired activities.	Study III
Self-Efficacy Scale [77]	Confidence in performing activities	Study IV
Life Satisfaction Questionnaire [78]	Satisfaction with life in general	Study IV
Hospital Anxiety and Depression scale [79]	Anxiety and depression	Study IV
Fatigue Severity Scale [80]	Fatigue	Study IV

The *Stroke Impact Scale* (SIS) 3.0 [68] was used in studies III and IV to measure the impact of stroke within the domains of strength, hand function, ADL/IADL, mobility, communication, emotion, memory and thinking, and participation. The SIS is one of the five most commonly used measurements for participation in stroke research [81] and was used in study IV to evaluate the F@ce intervention. In study III, the SIS domain of participation was used as an outcome measure together with the FAI and OGQ to cover different aspects of the complex concept of participation.

The SIS ranges from 0 to 100 (with 0 being the greatest impact and 100 being no impact from the stroke). Reaching the maximum score or improving by ≥15 points at follow-up was seen as a positive outcome [74]. SIS version 2.0 has been tested and shown to be valid, reliable, and sensitive to change [74]. In the improved SIS 3.0 version that was used in this thesis, five items were removed. In a validation of the SIS, the physical domains (ADL/IADL, mobility, and strength) as well as participation were found to be the most robust domains and therefore the most suitable for use as outcome measures [68].

The *Frenchay Activities Index* (FAI) [75] is commonly used in stroke research to measure participation [81] and was used in studies III and IV. FAI is a self-reported retrospective measurement that measures frequency of participation during the previous 3 or 6 months. It has good validity [82] and inter-rater agreement [83] and is suitable for use with people with stroke [81]. The scale ranges from 0 to 45 (where 0 = inactive and 45 = very active). A return to pre-stroke level or activity level within normal age and gender values [82] was considered to be a positive outcome.

The *Occupational Gaps Questionnaire* (OGQ) [84] measures the discrepancy between the activities the person can perform and the activities they want to perform. The OGQ includes 28 activities that are rated according to performance (yes/no) and desire to perform (yes/no), and the discrepancy between the performance and desired performance is defined as an occupational gap. Having no gaps or a reduction of gaps to a normal level according to age [84] was considered to be a positive outcome. Even though the OGQ is not primarily designed to be an outcome measure, but rather to be used for guide goal setting and for planning the rehabilitation [85], it was used in study III as a complement to the SIS and FAI.

The *Canadian Occupational Performance Measure* (COPM) [73] was used in study IV and was added as a part of the intervention to capture the activities the person experienced as being most important to be able to perform and was used as a basis for goal-setting. In the COPM, a maximum of five activities are selected by the person that are important in everyday life. Each activity is then rated by the person on performance from 1 "not able to do it at all" to 10 "able to do it extremely well", and satisfaction is rated from 1 "not satisfied at all" to 10 "extremely satisfied". A mean difference of 2 points from the first rating to follow-up is considered to be clinically significant [73]. The COPM has been tested for validity among people with stroke and has shown good validity for the performance and satisfaction scales, and it has been concluded that the COPM captures issues that are not captured in other measurements [86]

The *Life Satisfaction Checklist* [78] item "life in general" was used in study IV to measure satisfaction with life in general. The score ranges between 1 (very dissatisfying) to 6 (very satisfying), and a score >5 indicates being satisfied with life in general. The measurement has good validity [87] and an acceptable sensitivity and test-retest reliability [88]; however there are a large number of variables that might affect life satisfaction [78, 88].

The Self-Efficacy Scale [77] was used in study IV to capture the confidence in performing activities. The Self-Efficacy Scale includes 18 activities that are scored from 1 to 10, and a score of >5 indicates that the person is confident in performing daily activities. The Self-Efficacy Scale was developed based on the guide

from Bandura [77] and was adapted to people with stroke and has been used in previous stroke research [89].

The *Hospital Anxiety and Depression Scale* (HAD)[79] was used in study IV to measure levels of post-stroke anxiety and depression [90, 91]. The HAD includes an anxiety subscale and a depression subscale, and the score ranges from 0 to 21. Having a score of >4 implies signs of anxiety/depression. The HAD has been shown to have good validity among different samples such as primary care and within the general population [92].

The *Fatigue Severity Scale* (FSS)[80] was added in study IV because fatigue is common after stroke [93] and might affect the person's participation in activities in everyday life[94, 95, 96]. The scale ranges from 1 to 7, and a score of ≥4 implies having fatigue that impacts daily life. The FSS has shown good validity and reliability when used in people after stroke [97].

3.2.5 Feasibility outcome measures

In order to evaluate the feasibility of using F@ce in study IV, a number of feasibility outcome measures were used. The MRC guidelines recommend thoroughly evaluating the feasibility in terms of, for example, acceptability, fidelity, and recruitment in order to be able to plan and perform a full-scale evaluation [59]. Using a mix of quantitative and qualitative measurements is recommended for evaluating the implementation of a complex intervention [98].

The *recruitment process* was evaluated through the teams' logbooks and researcher's field notes. The feasibility of using the *outcome measures* was evaluated through the researcher's logbooks and by analysing the results of the outcome measures at follow-up. The teams' *fidelity* to the intervention was evaluated by comparing the notes in the teams' logbooks and researcher's field notes with the components in F@ce. The participants' *adherence* to the intervention was evaluated by analysing the number of scorings made in the F@ce web platform. The participants' *acceptability* of the intervention was evaluated through a follow-up survey filled out by the participants at the end of the intervention. Potential *harms* were evaluated by analysing the number of falls before and after the intervention.

3.2.6 Data analysis

The qualitative studies (I and II) were based on individual and focus group interviews that were audio recorded and transcribed verbatim. To facilitate the analysis, the computer software NVivo [99] was used to store and sort the data. Grounded theory according to Charmaz [100] was used in studies I and II in order to explore the experiences of the participants. Grounded theory is a flexible method

that allows the researcher to add data during the analysis when needed in order to saturate the emerging categories [100]. Memos were written throughout the process to capture the thoughts, feelings, and initial themes and categories that came up, and the memos were then used as part of the analysis [100].

Descriptive statistics were used in study III, and univariate and multivariate logistic regression analysis was performed to identify factors that might impact on participation in everyday life after stroke. In study IV, descriptive statistics were used along with content analysis [101] of the teams' logbooks and the researcher's field notes.

4 RESULTS

The results in this thesis are a synthesis of the results from the four studies and include the use of ICT among people that had a stroke and professionals in rehabilitation after stroke, factors that are important for participation in everyday life and rehabilitation after stroke, and the outcomes of the feasibility testing of F@ce. An overview of the results from each of the four studies is presented in Table 3.

Table 3. Overview of results

Study I: Experiences of using information and communication technology within the first year after stroke – a grounded theory study	
The participants had a drive to integrate ICT in everyday life after stroke	The participants used their mobile phones to feel safe and to communicate and stay connected with others. ICT, i.e. mobile phones, tablets and computers, was used to recreate their everyday lives and to find activities for enjoyment, entertainment, and rehabilitation. They were also using ICT as a tool for managing everyday life, such as grocery shopping online, seeking information, and managing their finances. The participants described stroke-related obstacles for using ICT such as reduced fine motor skills, vision, or cognition and how they overcame these obstacles by, for example, getting support from family and friends.
Study II: Exploring future possibilities of using Information and Communication Technology in multidisciplinary rehabilitation after stroke – a grounded theory study	
The professionals' vision of sharing through ICT	The professionals described their current use of ICT within rehabilitation after stroke as well as their vision for how ICT could be used. They described how ICT could be used for sharing of information and could enable monitoring and collaboration from a distance. ICT could make the documentation transparent within the team and between colleagues as well as for the patients. The professionals also described how it was important to consider the patients' needs and abilities to use ICT before it was incorporated into rehabilitation.
Study III: Factors affecting outcome in participation one year after stroke: a secondary analysis of a randomised controlled trial	
Stroke severity and the context of rehabilitation were associated with outcomes in participation	For all participants, there was a significant association between mild stroke and a positive outcome using FAI. Among participants who had not received the CADL intervention, i.e. the control group, there was a significant association between mild stroke and a positive outcome using SIS 3.0. The context of rehabilitation, i.e. receiving home rehabilitation, was also associated with a positive outcome in FAI for the control group.
Study IV: A single-group feasibility study of F@ce, a team based, person-centred intervention for rehabilitation after stroke supported by Information and Communication Technology	
The F@ce intervention seemed to remind and motivate people to perform activities and to improve participation in everyday life after stroke	It was feasible to recruit a suitable number of participants, but not all of the rehabilitation teams' current patients could be recruited because they had other additional impairments that hindered their participation. The measures were feasible to use, but the follow-up period was too short and the sample too small to draw any conclusions about outcomes. Overall, the rehabilitation teams and the participants with stroke were satisfied with using F@ce, and the adherence and acceptability were high. The teams' fidelity to the intervention needs some improvement in terms of routines for follow-up of the patients.

4.1 The use of ICT among people with stroke and professionals in rehabilitation after stroke

The results from study I and II showed that ICT was used by people after stroke in their everyday lives and that it had the potential to be used more within rehabilitation. The participants with stroke (study I) did not describe having used ICT within their rehabilitation, although they did use it on their own to improve functions such as by memory training, the use of reminders, and for motivation (tracking the distance and speed during walks).

The participants (study I) described how they gradually reclaimed their use of ICT, such as their computer, tablet, and mobile phone, after stroke. Initially after their stroke the use of ICT was difficult or impossible for them, but step-by-step they started to use ICT again for the activities they wished or needed to perform in their everyday lives. These activities could include playing games, watching movies, searching for recipes, and social networking. The participants (study I) usually used ICT to the same extent as before their stroke; however, some ICT took on a new meaning and enabled them to participate in everyday life. Some described that the mobile phone enabled them to feel secure when they were home alone or taking walks, while others found social support through online networks or social media.

Being able to download apps, purchase hardware, and install programs were things mentioned (study I) as tasks they needed support with. The participants with stroke (study I) expressed how they had not received any support in the use of ICT from rehabilitation professionals. Instead, they turned to relatives and friends to support them in their use of ICT. The professionals (study II) also described the need to support the use of ICT in everyday life for people after stroke; however, there were no guidelines available for whom, where, or how to assess a person's ability to use ICT. The occupational therapists were described (study II) to be the ones doing assessments of activities that included ICT; however, there was a lack of tools and routines for these assessments. Previous experience of using ICT before stroke seemed to be important for the ability and interest to use ICT after stroke. The participants (study IV) who had experience of using ICT before they had their stroke were able to understand and manage the reminders and fill in the ratings they received from the F@ce web platform, while those with less experience were not. The teams (study IV) had to support some of the participants in getting a Wi-Fi connection and in using the F@ce web platform.

The professionals (study II & IV) mostly used their computer in their office because most of them did not have access to smartphones, tablets, or laptops within their work. Some of the professionals (study II) mentioned having access to a laptop, but they were not able to use it outside the office due to a lack of Internet

connection and because the medical records and other systems were not accessible due to security reasons. Both in study II and IV the professionals described how their use of ICT within rehabilitation was limited by a lack of resources, time, and equipment. The professionals (study II) described how they used ICT to some extent in rehabilitation; for example, they used their own private mobile phone or the person's mobile phone or tablet together with the person for showing or taking pictures or for searching the Internet.

4.2 Participation in everyday life after stroke

There were several factors that influenced a person's participation in everyday life, including both personal circumstances and environmental factors. Having had a mild stroke, receiving rehabilitation at home, and using ICT were highlighted in the studies as contributing to participation.

The results from study III showed that stroke severity and the context of the rehabilitation could have an impact on a persons' perceived participation in everyday life. Among participants not receiving enhanced client-centred rehabilitation, having had a mild stroke and receiving rehabilitation at home were factors that were associated with a positive outcome in terms of participation. In study I the participants described how ICT was used to increase participation in daily activities after stroke, for example, through online shopping and paying bills. The computer and mobile phone were also used to stay connected to family and friends and in some cases to find new friends.

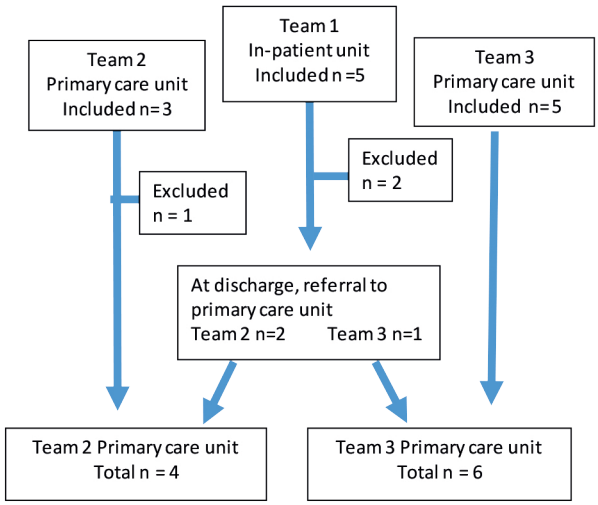
From the professionals' point of view (study II), ICT was considered to enable increased participation in the rehabilitation process by sharing the person's goals and the planning to reach these goals. The professionals (study II) described a desire to collaborate closely and provide information to people after stroke they are working with and to involve their significant others to a greater degree by using ICT tools. In study IV the participants that had a stroke reported increased participation according to COPM when they had participated in the F@ce intervention with daily reminders on their mobile phone. The daily reminders motivated them to perform the activities that they needed and wanted to perform, i.e., to reach the goals they had set.

4.3 Outcomes of the feasibility testing of F@ce

Overall, the F@ce intervention and the study design were feasible to use and were described by the participants that had a stroke as being motivating and as increasing their performance of daily activities. Ten participants were recruited by three different rehabilitation teams during four months (September–December 2017). None of the ten participants that started using the F@ce intervention dropped out.

The in-patient team included participants who could continue their rehabilitation with one of the participating primary care units (Figure 3).

Figure 3. Participants flow-chart



The content of the F@ce intervention included creating a therapeutic relationship with the person, using shared assessments, and introducing a problem-solving strategy where three goals regarding participation in daily activities and participation in everyday life with clear strategies formulated to reach these goals were set. Reminders were sent out daily to the participants regarding their three goals, and the participants were asked to rate their performance daily over the course of eight weeks. The teams were able to monitor the ratings through the F@ce web platform in order to offer support when needed. The teams' fidelity to the content of the F@ce intervention was good, but the follow-up of the participants' scorings could have been more regular and structured.

The *adherence* among the participants, i.e. their use of the daily reminders and ratings in F@ce, was overall high, and they rated 44–100% (mean 78%) of the daily reminders they received. Half of the participants (n = 5) answered 95–100% of the ratings. For three of the participants it took time to start using F@ce because they were in the process of leaving the hospital and returning home, but once they started using F@ce the adherence was high. Two of the participants filled out the ratings partially on paper due to failing Internet connection at home or their inability to handle the ICT.

The *acceptability* was good among the participants who described that using F@ce had been positive and to some degree had been a support for their rehabilitation. The benefits of using F@ce mentioned by the participants in the follow-up survey were that the goals were in front of them and that they were reminded and motivated to perform daily activities. However, two of the participants described how they would have appreciated having a better dialogue with the team in order to have had the possibility to adjust the goals and strategies sooner.

The *outcome measures* were not mainly used to evaluate the outcomes of the intervention but rather to study the feasibility of the study design. All 10 participants showed improvements in COPM, and a clinically significant improvement of >2 was shown in four participants regarding performance and in six participants regarding satisfaction. The results according to SIS were inconsistent, with some participants showing improvements in some of the domains and deteriorations in other domains. Clinically significant improvements of >15 points or reaching the maximum score of 100 were found among the participants regarding strength (n = 3), emotions (n = 3), participation (n = 3), recovery (n = 3), memory and thinking (n = 2), communication (n = 2), and ADL/IADL (n = 2). Significantly lower scores by >15 points i.e. deterioration, were found in the following domains: hand function (n = 4), communication (n = 2), ADL/IADL (n = 2), participation (n = 2), mobility (n = 1), emotions (n = 1), and recovery (n = 1).

5 DISCUSSION

This thesis has generated knowledge about the use of ICT within the rehabilitation process after stroke, which led to the development and feasibility testing of F@ce, a new team-based intervention. This section includes a general discussion on how stroke rehabilitation could be developed for future needs, including how to integrate a person-centred approach with the use of ICT in an intervention to enable participation in everyday life after stroke.

5.1 Developing stroke rehabilitation for the future

The intervention developed within this thesis, F@ce, included a person-centred approach, a goal-setting strategy, and ICT support to enable performance of daily activities and participation in everyday life for people after stroke. When developing rehabilitation interventions, it is important to consider future needs and challenges in order to create sustainable solutions. The world today is changing at a more rapid pace than ever before, and we are facing a wide range of societal challenges such as caring for an aging population, unequal living conditions, illness, poverty, and climate changes [102]. In the sustainable development goals of the United Nation's "Agenda 2030", Goal 3 is to "ensure healthy lives and promote well-being for all at all ages", which includes non-communicable diseases such as stroke [103]. When developing interventions in line with the sustainable development goals, the interventions therefore should be sustainable, promote health, be inclusive, and use environmental, financial, and personal resources wisely. Many of those aspects were considered during the development of F@ce, and the content of the intervention was based on the best available evidence, national guidelines, legislations, previous research, and established occupational therapy models [6, 7].

The F@ce intervention was developed to meet the current and future needs for rehabilitation of stroke. During the latest century, progress within medical research has been greater than ever before in areas such as providing care with high quality and developing medicines and treatments [102]. In several of those areas, Swedish healthcare is ranked as one of the best in the world, for example, in treating cancer, acute care, and vaccination [104]. However when it comes to care for people with long-term illnesses, safe patient care, and patient satisfaction, the Swedish health care system is scored to be among the bottom third among over 40 other countries in the world [104]. The Swedish Health and Social Care Inspectorate (IVO) has reported that there are flaws in the person-centredness and in the coordination of care in the Swedish health care system [105]. This shows that improvements are needed when it comes to providing person-centred care and rehabilitation. Furthermore, the IVO concludes in a report from 2018 that there is a continued need for person-centred care, i.e. to include the person in the care, to

develop digital tools that are simple and usable for communication and follow-ups, and to create a model for inter-professional teamwork [105]. The development of F@ce was in line with those needs of creating a model for team-based work and using ICT as a tool to support rehabilitation, enhance communication, and enable follow-ups from a distance.

In this thesis, people who have had a stroke and the professionals working with them have been involved by participating in the interviews (study I and II) and in the modelling and feasibility testing of F@ce (study IV). This was important in order to ensure that the new intervention would be usable and effective for those who were going to use it. The MRC guidelines [59] describe how this kind of primary research, such as interviewing stakeholders, could be a valuable addition to the theoretical base when developing interventions. In order to develop interventions that meet the needs of people after stroke, it is important that they are involved in research, for example, in the design of studies and by including them as participants describing their experiences [106]. In the development of interventions for the future, it is important to continue to have a sustainable mind-set and to base interventions on the available evidence.

5.2 Using person-centredness in the rehabilitation

In this thesis, person-centredness was included as one of the main concepts in order to reflect the view of a person as being unique and complex [6]. Having a person-centred approach implies that the person is actively involved in planning the rehabilitation, in decision-making, and in goal-setting [33]. Because study III found that receiving a person-centred intervention seemed to be especially beneficial for those receiving rehabilitation at an in-patient unit, the F@ce intervention was developed to support the teams in implementing person-centredness throughout the whole rehabilitation process.

The content of the F@ce intervention guided the teams in being person-centred and included, for example, building a relationship with the person, video recording an activity together, and using COPM as a basis for the goal-setting. The content of F@ce was built on basic theoretical principles such as creating a therapeutic relationship [63]; basing the rehabilitation on the person's performance of daily activities [6], their lived experiences [6, 8], and their narratives [33]; being transparent regarding goals and plans [38] and sharing information and experiences between the person and the rehabilitation team [37]; and making sure that the person is actively involved in the goal-setting [6, 7, 66]. The professionals in study IV seemed to agree with the underlying basic principles and had a high fidelity to the content of the intervention. The F@ce web platform provided an opportunity for the teams to collaborate with the participants by viewing the daily ratings and following up when needed; however, this was not used due to either lack of

time or that going onto the web platform was not yet incorporated into their routines. Instead, they usually followed-up the participants' ratings and progress when meeting them face-to-face. Some of the participants receiving the F@ce intervention expressed how they had wished for better follow-ups and adjustments of the goals. These results highlight the challenges in working with person-centredness within a team, such as the communication and collaboration with the person and within the team, which are key elements in goal-setting and planning the rehabilitation [107].

To enable the teams to use the F@ce intervention, training was needed to gain knowledge of the underlying basic principles and to practice using the COPM and the F@ce web platform. Because the team needed to participate in the project while still managing their other duties at work, the time spent on preparing for the project was restricted to spending two hours in workshops once a week for three weeks. That was not a lot of time in comparison to other studies performed within the research group; for example, the Occupational therapists (OT) in the CADL study participated in workshops for five full days in one month [2], and in the F@ce study performed in Uganda the OTs had a series of workshops over eight half days [89]. In the evaluations of the implementation of the CADL intervention, the collaborative relationship between the OTs and the researchers was described as one that enabled the fusion of scientific knowledge and practice [61]. Thus, it is important for researchers to spend sufficient time on building a relationship with the professionals and sharing knowledge and experiences. Additionally, successful implementation depends on personal factors such as the professionals being motivated and having sufficient knowledge about the underlying theory and the implementation process [108]. In addition, organisational factors such as having the needed resources and support from management are important [108]. Thus, collaboration throughout the implementation process is important, and this collaboration needs to be flexible and supportive, especially when something unplanned happens. During the implementation of the F@ce intervention, the researchers were present at the units each week while collecting data and were thus able to maintain the relationship with the teams and provide support. However, in future testing and implementation of F@ce it would be beneficial to extend the workshops and to have even closer collaboration between professionals and researchers in order for the teams to have time to implement the new knowledge in relation to the intervention.

5.3 Integrating rehabilitation in everyday life

While participating in the F@ce intervention, the persons were able to integrate and work towards their goals in their everyday lives. The goals were based on daily activities, which the participants had chosen and could perform daily without assistance from the professionals in the team. The performance of daily activities

should create meaning, promote health, and be used as tools in the rehabilitation process [6]. Performing activities is important in the process when trying to get to know the body again after stroke and to be able to take control over the body and the activities one wishes to perform [109]. By participating in the F@ce intervention, several of the participants increased their performance of the chosen activities according to the COPM and the follow-up survey.

In order to integrate the rehabilitation in everyday life, the environment is likely to be important. Previous studies have shown that receiving rehabilitation at home could increase participation in daily activities as well as enhance the involvement in goal-setting and individualisation of the rehabilitation [110, 111]. The results from study III showed that it seemed to be beneficial for the participants' participation in everyday life to receive rehabilitation at home. However, some people need to receive rehabilitation at an in-patient unit due to their medical or rehabilitation needs. Study III also showed that for those receiving rehabilitation at an in-patient unit a person-centred intervention seemed to be especially beneficial for their participation. Therefore, the F@ce intervention was provided and tested both at an in-patient unit and for those living at home who received rehabilitation in primary care units.

Goal-setting was an important component in the CADL intervention as well as in F@ce, and it is also recommended in stroke rehabilitation guidelines in order to enable the person who has had a stroke to be motivated and to be able to see progress in their rehabilitation [10, 19, 20, 22]. Some of the barriers in goal-setting could be that the person often has broad goals such as returning to life as it was before, while the professionals' goals often are more specific [112]. Using individually tailored goals and communication has proven to be important for successful goal-setting [112]. However, the teams might also need support in how to formulate the goals together with the person. In the F@ce intervention, the teams used COPM to guide the goal-setting, and this seemed to have supported the teams and the participants after stroke to set goals based on the activities they wanted or needed to perform in their everyday lives. Some of the goals the participants formulated and used in the F@ce intervention included playing the piano, singing, flipping the pages in a book, dressing, and taking walks. By performing these activities, the participants were able to improve their abilities that had been affected by the stroke and to integrate those activities in their everyday lives and in their new way of living.

Because the participants received reminders by SMS every morning for 8 weeks, their three goals and strategies were always present and integrated as a routine in their everyday lives. Additionally, the follow-up SMS, where the person was asked to rate the performance of the three activities in the afternoon, seemed to be a good way for the participants to keep up their motivation and to receive feedback. However, some of the participants discovered that the goals they had

formulated together with the team were too hard or too easy to perform, and their goals or strategies needed adjustments. There is a need for structured follow-ups and close collaboration with the team in order to keep goals and strategies relevant and motivating. Stroke often has long-term consequences on a person's ability to return to daily life, work, and participation in everyday life [94, 113]. Thus it would be beneficial to be able to integrate a model for using goals and strategies, supported by ICT, that could be used by people in their everyday lives after stroke, even after the initial rehabilitation period has ended. F@ce proved to be beneficial for people both with recent stroke and for those who had a stroke a long time ago.

5.4 Introducing ICT in rehabilitation after stroke

Throughout this thesis, the hypothesis has been that ICT can be used to support a person-centred rehabilitation intervention, and the professionals in study II also had the same vision. There is a clear vision from the Swedish government that the use of ICT within healthcare and rehabilitation should increase [39], and it is seen as a way to enhance participation and inclusion for people with disabilities [40]. In study I, the participants expressed that the computer could be important in order to manage daily life activities such as grocery shopping and paying bills. Some of the participants also used their mobile phone or computer to improve physical and cognitive functions and to improve their performance of ICT-based activities. However, the results from studies I, II, and IV also showed that people might need support in managing their mobile phone, computer, and tablet after stroke. The professionals in study II described how the use of ICT had increased among the people they work with in recent years and has become integrated in their daily activities. With the results from these studies and in relation to societal developments with increased ICT use, we considered it important to move forward and develop CADL in order to be supported with ICT.

One concern when developing interventions using ICT support is whether or not people will be able to use it after having had a stroke. Research has shown that people with acquired brain injuries such as stroke often experience difficulties with using technology, especially when using mobile phones and computers [54, 56]. The participants in studies I and IV reported that they had experienced some difficulties, especially initially after their stroke. Some participants described that their cognitive impairments hindered them in using ICT and that they were not able to handle the more advanced functions. Additionally, the hand function on their affected side could hinder, for example, being able to hold and press the keys on a mobile phone. Getting support regarding the use of ICT could be necessary for anyone when, for example, installing new hardware such as a router, computer, or tablet or software such as applications and programs, or when something unexpected happens. Several of the participants in study I mentioned that they were

getting support from family and friends with more advanced ICT activities that they could not handle themselves. The professionals in study II also described how people might need support in the use of ICT, and, when necessary, the OT assessed and supported them. The OTs in study II viewed the use of ICT as a part of the environment that could impact the person's daily life [6] and thus to be a natural part of their profession. This has also been recognised by the Swedish Occupational Therapy Association by adding a new section regarding digital competence in the updated competence description of OTs [114]. Digital competence includes the use and development of digital systems, tools, and services as well as being able to visualise the potential risks and opportunities that digitalisation implies for an individual's occupational performance [114]. Thus, when developing ICT-supported interventions the OT might have an important role to play in making sure that the person can manage the ICT and in offering support in this area when needed.

Another factor impacting the use of ICT might be age, and even though the daily use of Internet services is increasing in all age groups it is more common for older people (especially those over 76 years) to be a non-user or not a daily user of Internet services and to experience digital exclusion [115]. It has been shown that older people are less likely to use Bank-ID (electronic identification for banks, healthcare sites, companies, and authorities), to use Facebook, or to search for medical information or to read public information on the Internet [115]. The mean age for having a stroke is 75 years, but younger and older persons also have strokes [11]. People of all ages were included in this thesis, and in study I the participants' mean age was 62 years (range 41–79) and in study IV the mean age was 65 years (range 44–78 years). The participants used ICT to different extents, some only used basic functions such as calling and receiving text-messages while others used ICT in a more advanced way. Based on the results from studies I and IV, it seemed that the older participants had less need or interest in using ICT. However, in general, based on the participants in these studies it seems that previous use and interest in the use of ICT are the most important factors for whether or not ICT is used after stroke. There are studies showing that most of those not using the Internet actually have access, but they never used the Internet before and have no interest or find it to be too complicated [115]. The trend has been that the use of ICT is increasing in all age groups, and such development is likely to continue [115]. Thus, it is likely that people having a stroke in the future will be more experienced in the use of ICT and will have a greater need and interest in using ICT in their everyday life and rehabilitation.

In this thesis, ICT has, besides being a part of a person's everyday life, also been used as a tool that could enable sharing and transparency between the rehabilitation team and the person throughout the rehabilitation process and to provide the participants with reminders and feedback. This is fully in line with what a recent scoping review has shown, namely that ICT can be used as an alternative to

face-to-face interventions to improve participation in daily life after stroke [116]. Still, it is important to consider which group of people is being targeted so that no one is excluded from the rehabilitation through the use of ICT. There are some people, especially older people, who might prefer face-to-face interactions or phone calls in their contacts with healthcare professionals, and for these people non-digital alternatives need to be available [117]. Additionally, it is important that sufficient support is provided for people who are inexperienced or who have cognitive or physical impairments as a consequence of stroke that might hinder the use of ICT. However, it is difficult to refrain from using ICT in healthcare and rehabilitation, which is what the future will probably require. Therefore, the development and evaluation of the F@ce intervention contributes in part to such a digitalisation development process.

6 METHODOLOGICAL CONSIDERATIONS

6.1 Design

The general aim of this thesis has been to develop and evaluate a new team-based and person-centred intervention supported by ICT. Developing interventions includes several stages, and the MRC guidelines "Developing and evaluating complex interventions" [59] have been used as a framework and a structure throughout this thesis. According to the MRC, an intervention can be considered to be a complex intervention when several components interact, when several different professions are included, when it entails behavioural change, and when it involves individually tailored and flexible intervention and thus could have a variety of outcomes [1]. The F@ce intervention included those components and therefore the use of the MRC guidelines was suitable as an overall structure for this thesis.

To explore the experiences of people after stroke (study I) and professionals (study II) GT was used according to Charmaz [100]. GT is based in constructivism and includes a inductive and explorative approach [100]. The use of GT has made it possible to capture how the participants in study I and II were using ICT in everyday life and the rehabilitation process after stroke. The constant comparative analysis has been performed simultaneously with the data collection, thus any emerging ideas and categories could be used to guide the continued data gathering, such as the selection of participants and adjustments in the interview guides in the studies [100]. For example in study II the initial analysis revealed the need to conduct a focus group interview to complement the individual interviews that were already performed. The use of GT in these two studies has been suitable in order to gather rich data and to capture the participants' experiences.

6.2 Sample

In this thesis people who had had a stroke and those within the team of professionals working with these people have been in focus. There was variation in the sample regarding gender, age and living conditions among the participants' who had had a stroke. The aim has been to include the participants in the development of F@ce by interviewing them regarding their experiences and inviting them to be a part of the development and modelling of the intervention.

In study II the majority of the participating professionals were OTs and PTs and only one medical social worker (MSW) and two speech- and language therapists (SALT) were included. Because OTs and PTs were considered to be those who would mainly implement and use the new intervention, having participants mainly from those professions suited the aim of the study. However if the intervention will

be used by all professionals in the rehabilitation team, which could include OTs, PTs, MSWs, SALTs, dieticians, and in some cases medical doctors and nurses, their views need to be considered to a greater extent in future studies.

When evaluating a complex intervention, such as F@ce, there is a need to generate knowledge regarding the people that will use and benefit from the intervention. In study III the results showed that it seemed to be particularly important within in-patient rehabilitation to use an enhanced person-centred approach. Based on those results participants from both in-patient (n=4) and primary care rehabilitation living at home (n=6) were included in study IV.

Significant others (such as spouses, parents, adult children, or close friends) also play an important part in the rehabilitation process after stroke. In the F@ce intervention, the teams were encouraged to include significant others, if the person gave their permission to do so, by providing them with information. However, in this thesis, the significant others' experiences were not explored as part of the evaluation of F@ce, and instead the focus was on people who had had stroke and the rehabilitation team.

6.3 Instruments

All instruments used in this thesis are instruments that are frequently used in stroke research; their reliability and validity has been tested. In study III, that was based on a previous RCT, three different outcome measures were used to measure participation – the SIS 3.0 [68], the FAI [75] and the OGQ [84]. Having several different outcome measures was beneficial in order to capture the different aspects of participation; however, in this study the OGQ was not able to detect any changes. Most of the instruments used in this thesis were self-reported instruments. This could be seen as a strength, since the F@©e intervention had a person-centred perspective, with the persons' experiences in focus. However, one of the consequences of stroke could be a lack of awareness regarding ones limitations, and in that case self-reported instruments could be difficult to use and might give unreliable research results.

When conducting a feasibility study, one part of the study should be to determine whether an intervention is appropriate for further testing. Another part of a feasibility study is to determine if the different instruments are able to detect possible changes. Participation and life-satisfaction are often affected by a stroke, and self-efficacy, which is a person's confidence in their ability to perform an activity, has been proven to enable the person to achieve their goals [107]. Thus, the outcome measures used were: SIS 3.0 [74], the Self-efficacy scale [77], and LiSat-11 [78]; however, the results of those instruments were inconsistent. When the protocol for study IV was drafted, it was decided that SIS would be used at 4

weeks after inclusion because it might be too early for those in in-patient rehabilitation to be assessed by this instrument at inclusion. However, because half of the participants had their stroke more than 4 weeks prior to the intervention, it might have been possible to use SIS for those participants. The self-efficacy scale was used at 4 weeks after inclusion in order to capture the participants' perceptions of their ability to perform activities. In hindsight it would have been interesting to evaluate possible changes in self-efficacy in the participants from when recently having had a stroke compared to after the intervention.

In addition, the COPM [73] was used in study IV as a part of the intervention, as a basis for the formulation of goals and as an evaluation of the participants' progress. The COPM has previously been shown to enhance the professionals' use of a person-centred practice [118]. In the evaluations of F@ce, the COPM seemed to be feasible to use by the teams in order to set goals together with the person. Additionally, improvements were detected in just 8 weeks on the performance and satisfaction with the performance of the participant's chosen activities. This indicates that the COPM could be used as an outcome measure to evaluate a person-centred intervention.

Because an ICT supported intervention was being developed, the participants' use of ICT had to be explored. This was done through qualitative interviews in study I and through a survey in study IV. One measurement that could have been used is the Everyday Technology Use Questionnaire (ETUQ), which has been developed and used among people with and without cognitive impairments [119]. The ETUQ includes 92 items regarding everyday technology, and 31 of those could be classified as ICT [119]. Thus, parts of the ETUQ, which is a valid and reliable measurement, might have been used to assess the participants' ability of using ICT in study I and IV.

6.4 Generalizability of the results

The results from the qualitative studies, study I and II cannot be generalised to another group of people and, the aim of those studies were not to generalize but rather to generate knowledge. However in qualitative studies the trustworthiness should be discussed. In order to achieve trustworthiness in a qualitative study the methods including the context in which the study was performed and the sample should be clearly described. In study I, the participants' characteristics have been carefully described and also the analysis process, which strengthens the quality of the findings. Additionally using quotes enhances the quality and trustworthiness of the results, which has been used in both study I and II. In these studies the main purpose was to explore the participants' experiences and described their use of ICT within the context, this was only achievable through using qualitative interviews.Study III was a secondary analysis of a previously performed RCT study

with 237 participants in total. The participants' characteristics showed that they varied in age, gender, living conditions and stroke severity. One inclusion criteria was that they had received rehabilitation at an in-patient stroke unit, with continued rehabilitation at an in-patient or primary care unit. Having a varied sample strengthens the generalizability of the results to other people with stroke in that same context.

In study IV, a feasibility study, the sample was rather small with only ten participants, thus the results cannot be generalized. Since the aim was to evaluate the feasibility of using F@ce and the study design, the generalizability was not important in this stage. In this study both qualitative evaluations i.e. the teams' and researcher's logbooks and quantitative measurements and surveys. Mixing qualitative and quantitative measurements in a feasibility study is recommended in the MRC guidelines [59] and while the results are not generalizable they could guide the further testing and implementation of the intervention. The results have to be presented clearly and preferably through several data sources, which they were in the F@ce study.

6.5 Ethical considerations

The participants in all of the studies were informed of the aim and purpose of the study at inclusion and then again before the interview or data collection started. Participants were informed that they could withdraw their consent to participate at any time. Having a stroke can be a chaotic experience and some of the consequences may include cognitive impairments and lack of insight, thus any research including people after stroke has to be carried out with caution. The professionals who selected the participants for the studies judged all of the participants to be able to make a decision about whether or not to participate. When performing qualitative interviews, there is always a risk that emotional reactions might arise, such as feelings of anxiety or sadness. Some of the questions in the outcome measures could be sensitive because they concerned satisfaction with life (including family life and sexual life) and ability to perform personal care (such as continence and managing personal hygiene). However, the researchers collecting the data, i.e. performing the interviews and assessments, were experienced rehabilitation professionals and were aware of any signs of discomfort and/or embarrassment during the interviews and the participants were reminded that they were able to skip questions of a sensitive nature if they wished. However the participants did not choose to skip any of the questions for those reasons and were willing to share their experiences with the researchers. In addition, the participant were offered to choose a place for the interview, to ensure that they felt secure and thus the majority of the participants in study I were interviewed in their homes and most of the participants in study II at their workplace. The studies in this thesis were performed according to the Swedish Ethical Review Law (2003:460), and ethical

approval was obtained for study I and II (2013/1808-31/5) and updated for study IV (2017/1410-32) due to changes in the research plan. Ethical approval for study III (NTCO 1417585) was obtained within the CADL study.

6.6 Conclusions and clinical implications

The results of the studies in this thesis confirm the importance of using person-centredness and goal-setting within rehabilitation in order to enable performance of daily activities and participation in everyday life after stroke. It also provides knowledge on how ICT is used in people's everyday lives after stroke and how it could be used within stroke rehabilitation.

People have a drive to integrate ICT into their everyday lives after stroke and they are often able to handle and use their ICT devices independently or with the support from family, friends (study I), or from OTs (study II). Professionals within stroke rehabilitation view ICT as having the potential to be used in rehabilitation as a tool for sharing knowledge and to communicate throughout the rehabilitation process (study II). The conclusions from study III were that using a person-centred approach could be important in order to increase participation and especially for people receiving rehabilitation at an inpatient unit or those with moderate/severe stroke. Hence, in order to develop person-centred interventions the context has to be considered since different contexts seem to enhance or hinder participation.

The MRC guidelines provided a structure for the development of F@ce and highlighted the importance of building interventions on a solid evidence base. The knowledge generated from study I-III was used in the development of the F@ce intervention along with previous research and theories. The conclusions from the development process were that interventions with a strong theoretical base that are developed together with future users have a good chance of being feasible to be used in clinical practice.

The F@ce intervention seemed to be feasible to use for the professionals and provided a structure for the teams in order to work with people after stroke. Using ICT as a support for person-centred rehabilitation was described as being a reminder and motivated the performance of daily activities for the participants after stroke. By rating the performance of the chosen activities through the web platform the participants received timely feed-back, even though some had wished for more support and adjustments of the goals from the team.

Overall, the gathered knowledge from the previously developed CADL study, experiences of people after stroke and the professionals' use of ICT within stroke rehabilitation, and the modelling of F@ce together with stakeholders created a strong foundation for the new intervention. The studies within this thesis enabled

the development and evaluation of a new rehabilitation intervention, F@ce, using ICT which is relevant in this time, with the rapid digitalization in the society, healthcare and rehabilitation.

6.7 Future studies

In the continued work to improve participation in everyday life after stroke the rehabilitation has to continuously move forward and use the possibilities of new technology. There is a clear vision to increase the use of ICT within healthcare and rehabilitation by developing ICT tools and services [39]. There is still a lack of evidence based rehabilitation interventions according to the Swedish national guidelines of stroke care [22]. However, in order to be able to build strong evidence the F@ce intervention needs to be tested on a larger scale, preferably in a RCT study. Before performing a RCT and implementing a new intervention, it is recommended to perform smaller-scale evaluations such as a pilot study including a control group and continued modelling of the intervention [1]. Additionally the ICT tools - i.e. the F@ce web platform, webpage, and online database - used in the feasibility testing of F@ce were only prototypes and need to be developed further. In order to implement an intervention in health care confidentiality has to be considered and reliable web-platforms and servers used to store data.

The teams that participated in studies II and IV worked with different neurological diagnoses such as stroke, multiple sclerosis, Parkinson's disease, and brain tumours. In study IV, some participants were excluded as they had other neurological diagnoses than stroke, however, because the components in F@ce seem to be generic it could be suitable for different diagnoses. In order to use F@ce for people with those neurological diagnoses it would need some further modelling and testing to be adapted to their needs. As a first step, professionals, people with those diagnoses and their significant others could be invited to give their input regarding the use of F@ce through a qualitative interview study.

Having significant others involved in the rehabilitation process is another important aspect. Being a spouse to a person with stroke can be difficult, and research has shown that their life satisfaction could be reduced for up to seven years after stroke [120]. Six significant others of the participants in the F@ce intervention were actually interviewed after the F@ce intervention ended. Data from interviews with significant others, the participants, and the teams are all part of a qualitative evaluation of the F@ce intervention that needs to be analysed as part of a future study. Those results are important to consider when further developing the F@ce intervention. There could also be a need to develop some interventions for significant others, in order to guide them in their important and difficult role as the main emotional and practical support for the person who has had a stroke.

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