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Activity and participation among stroke survivors

-Towards a self-management intervention supporting
travelling by bus

EMMA CARLSTEDT

DEPARTMENT OF HEALTH SCIENCES | FACULTY OF MEDICINE | LUND UNIVERSITY



Activity and participation among stroke survivors

- Towards a self-management intervention
supporting travelling by bus

Emma Carlstedt



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DOCTORAL DISSERTATION

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Author: Emma Carlstedt	Date of issue: 21 November, 2018
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Title: Activity and participation among stroke survivors - Towards a self-management intervention supporting travelling by bus	
<p>Abstract</p> <p>Aim: The overall aim of this thesis was to study prerequisites for activity and participation among stroke survivors. A first goal was to gain new knowledge of factors important for participation in society for people with stroke in a long-term perspective. A second goal was to further the development of complex interventions targeting participation among stroke survivors, and investigate feasibility aspects of a new self-management (SM) intervention to support outdoor mobility including travelling by bus, targeting stroke survivors with cognitive impairments.</p> <p>Methods and Results: The four papers included represent different samples (N=145, N=34, N=5, N=128, respectively), including data of stroke survivors aged 19-102 years, >6 months to <10 years post stroke. Study I was a longitudinal cohort study showing that Driving a car, Ability to walk a few hundred meters and Social anchorage had a positive effect on social and leisure activity 10 years post stroke. Study II was a test-retest study aimed to identify an instrument (General self-efficacy scale, GSE) for evaluation of the new intervention and evaluate its psychometric properties. The results showed acceptable levels of psychometric properties. For example, the internal consistency was high (0.92) and the test-retest reliability acceptable ($ICC_{2,1}=0.82$). There were no significant mean differences and the SEM was 2.97 (SEM%; 9.40). Study III targeted feasibility aspects of the new intervention and showed that the group format was appreciated; skilled leaders and motivated participants are important; the session material was adequate but need minor revision; and that homework is valuable but also that reflective group discussions must be supported. Narratives of the five participants showed that they all made some progress in outdoor mobility and travelling by bus. Study IV was a cross-sectional survey study to identify important factors for recruitment of stroke survivors to research. The results showed that the majority were interested, in particular younger persons and those closer to stroke onset. Contribution to research, opportunities to try new rehabilitation interventions and meeting others in the same situation were reasons for being interested. Group-based programs and those focusing on regaining lost physical and cognitive functions were preferred. The majority wanted to be contacted through postal mail.</p> <p>Conclusions: The overall conclusions are that there are several important aspects regarding long-term frequency of social and leisure activities to consider after stroke. Stroke survivors, who are able to walk a few hundred meters, driving a car, have a broad social network and who are <75 years are more often engaged in such activities ten years after stroke. To support stroke survivors to be more active and participate in society long-term, the new SM intervention has potential to support outdoor mobility and readiness to travel by bus among stroke survivors with cognitive impairments. While recruitment difficulties appeared as a noteworthy challenge, the SM approach as well as the content and format of the intervention match the preferences of stroke survivors. This is promising for future evaluations and subsequent implementation of the intervention.</p>	
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Activity and participation among stroke survivors

-Towards a self-management intervention
supporting travelling by bus

Emma Carlstedt



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To my family

List of papers

This thesis is based on the following papers, which all have been reprinted with permission from the publishers.

- I. Norlander A, **Carlstedt E**, Jönsson AC, Lexell EM, Ståhl A, Lindgren A, Iwarsson S. (2016). Long-term predictors of social and leisure activity 10 years after stroke. *PLoS One*, 11(2), 1-16.

- II. **Carlstedt E**, Lexell EM, Pessah-Rasmussen H, Iwarsson S. (2015). Psychometric properties of the Swedish version of the General Self-Efficacy Scale in stroke survivors. *International Journal of Rehabilitation Research*, 38(4), 333-337.

- III. **Carlstedt E**, Iwarsson S, Ståhl A, Pessah-Rasmussen H, Lexell EM. (2017). BUS TRIPS - A self-management program for people with cognitive impairments after stroke. *International Journal of Environmental Research and Public Health*, 14(11), 1353-1368.

- IV. **Carlstedt E**, Lexell EM, Ståhl A, Lindgren A, Iwarsson S. Stroke survivor's preferences of participation in rehabilitation research. Submitted.

Preface

In June 2007, I attained my bachelor degree as a registered nurse. I knew I wanted to work on promoting health and preventing illness, but more on a structural level than traditional clinical work. Therefore, I applied for a two-year MSc specializing in public health. Public health attracted me, because of its interdisciplinary approach and opportunities to work on different levels (individual, group and society). My interest in this field is broad, but I have a special interest in methodological development on how to promote health and the ability to live actively and independently no matter who you are.

In summer 2012, I saw a PhD student job posting with the headline “*Can the possibilities to travel by bus improve participation? – A Self-management intervention for people with cognitive impairments after stroke*” The subject of the project including a new intervention with a behavioral orientation in an interdisciplinary research context attracted me. I was hooked and eventually I was selected for the job.

Ever since, it has been an interesting journey. When I look back, I have been enriched with multiple experiences, met people with stroke and heard their stories, collaborated with people from different professional and disciplinary backgrounds, at different academic levels, struggled with recruitment of study participants, travelled around Skåne to collect data, and finally gathered enough material to create this thesis.

The first version of the intervention (BUS TRIPS) studied in this thesis was developed before I was accepted as a PhD student. Although an initial plan for the four sub-studies was set before I was assigned, the project has been developed during the process. For example, it led to a new study with close collaboration with another PhD student (Study I) and new research questions related to recruitment to rehabilitation research (Study IV). I have taken an active role throughout this work. I was involved in the design, I collected all the data, I performed the analyses and took the role as first author of the papers reporting Studies II-IV. For Study IV, I also held the leading position of planning, designing and writing the application for ethical approval. In Study I, both I and the other PhD student took an active part in designing, analyzing, writing and critically revising the paper. However, as the other PhD student had an extra overarching responsibility and wrote more of the introduction and discussion parts, I assumed the role of second author.

This thesis was carried out within the Active and Healthy Ageing research group, Faculty of Medicine, and the interdisciplinary Centre of Ageing and Supportive Environment (CASE), Lund University.

Lund, December 2018

Emma Carlstedt

Svensk sammanfattning

Bakgrund

Att kunna förflytta sig till fots och med hjälp av olika transportmedel är viktigt för att kunna vara delaktig i samhället. Delaktighet är något som tidigare forskning har visat är av betydelse för hälsan. Skador och sjukdomar kan leda till olika typer av funktionsnedsättningar. Stroke är ett exempel på en sådan sjukdom. Efter stroke är det vanligt att man drabbas av både fysiska och kognitiva funktionsnedsättningar, men också av till exempel depression. De olika konsekvenserna av stroke kan påverka förmågan att hantera vardagsaktiviteter och leda till aktivitetsbegränsningar och minskad delaktighet. Internationellt drabbas över 10 miljoner av stroke varje år, medan siffran i Sverige ligger på omkring 21 000. På grund av medicinska framgångar har förekomsten av stroke minskat samtidigt som överlevnaden och prognosen för dem som insjuknat har förbättrats. Det faktum att allt fler överlever stroke i kombination med en allt äldre befolkning ställer stora krav på samhället som måste se till att även personer med funktionsnedsättningar kan leva ett aktivt och självständigt liv.

För att kunna stödja den allt större skara personer som lever länge med stroke, behövs kunskap om faktorer som har inverkan på aktivitet och delaktighet i ett långtidsperspektiv. Sådan kunskap är viktig för att kunna främja hälsa och erbjuda rätt stöd redan tidigt. Många personer med stroke upplever dessutom svårigheter att ta sig ut i samhället samtidigt som stroke-relaterade funktionsnedsättningar kan innebära att man inte längre får köra bil. Rätten till färdtjänst är hårt reglerad och många hänvisas därför till att resa med kollektivtrafik eller med familj och vänner, vilket begränsar resmöjligheterna. Tidigare forskning har visat att stroke-relaterade funktionsnedsättningar, men också en nedsatt tilltro till sin egen förmåga är relaterat till ett minskat resande med kollektivtrafik. Även om möjligheten att kunna resa är en viktig aspekt för delaktighet efter stroke är det ovanligt med interventioner inom detta område. Att förbättra förmågan att resa med kollektivtrafik är således viktigt, inte minst för de personer med kognitiva funktionsnedsättningar - en grupp som ofta exkluderas i forskning.

En möjlig inriktning på en sådan intervention skulle kunna vara att stärka tilltron till den egna förmågan hos personer med stroke. Tilltro till den egna förmågan är en viktig komponent i self-management. Self-management är ett engelskt begrepp som innebär att personer får lära sig strategier för att hantera uppgifter man upplever som

svåra. Metoden används vanligen för att lära personer med kroniska sjukdomar att hantera sin sjukdom och det finns studier som tyder på att den kan ha gynnsamma effekter för personer med stroke.

Övergripande syfte

Det övergripande syftet med den här avhandlingen var att studera förutsättningarna för aktivitet och delaktighet för personer med stroke. Ett första mål var att öka kunskapen om faktorer för delaktighet i samhället för personer som levt länge med sin stroke och på så vis bidra till evidens som motiverade utvecklandet av ett nytt rehabiliteringsprogram. Ett andra mål var att vidareutveckla förutsättningarna, samt undersöka genomförbarheten av en första version av ett nytt self-management-program med syfte att stödja personer med kognitiva funktionsnedsättningar efter stroke och deras förmåga att ta sig ut och resa med buss.

Då detta self-management-program är komplext krävs en rad olika studier innan det kan anses robust nog för utvärdering i större skala och på sikt implementeras i klinisk praxis. Som stöd i denna process användes etablerade riktlinjer för utveckling och utvärdering av komplexa interventioner. Studie I, II och IV ingår i riktlinjernas utvecklingsfas, medan studie III tillhör genomförandefasen.

Studie I-IV

I studie I undersökte vi faktorer som kan förutsäga frekvens av delaktighet i sociala- och fritidsaktiviteter 10 år efter stroke. Huvudfyndet var att förmågan att kunna gå några hundra meter, att köra bil och ett brett socialt nätverk hade en positiv inverkan, medan en ålder av 75 år eller äldre hade en negativ inverkan. Resultatet indikerar att mobilitet utanför hemmet är viktigt och bör därför få större utrymme i rehabiliteringen efter stroke.

Kunskapen från studie I samt tidigare forskning om personer med strokes begränsade möjligheter att ta sig ut i samhället och resa med kollektivtrafik var grunden till ett nytt rehabiliteringsprogram baserat på self-management. Programmet riktades mot att stödja personer med kognitiva funktionsnedsättningar. För att undersöka om programmet gör någon nytta behöver man göra mätningar både före och efter programmet för att se om det blivit någon skillnad. Eftersom self-management handlar om att stärka personers tilltro till den egna förmågan behövdes ett instrument som mäter detta. Vi valde instrumentet "Generell self-efficacy skala" (GSE). Innan det kunde användas i rehabiliteringsprogrammet behövde vi dock undersöka om det var tillförlitligt att användas bland personer med stroke. Detta gjordes i studie II. I studien studerade vi flera olika aspekter och trots att inte alla var helt optimala ansågs resultaten vara acceptabla för att vi skulle kunna använda instrumentet i vårt nya rehabiliteringsprogram.

Syftet med Studie III var att testa det nya rehabiliteringsprogrammet i liten skala (fem personer). Vi undersökte programinnehållet och genomförandet samt om

programmet kunde påvisa eventuella förbättringar avseende deltagarnas förmåga att ta sig ut i samhället inklusive och resa med buss samt generell tilltro till sin egen förmåga, delaktighet och livstillfredsställelse. Rehabiliteringsprogrammet var format som ett grupprogram, där deltagarna träffades 5 gånger i grupp och 1-2 gånger individuellt. Under det individuella tillfället hade deltagarna möjlighet att träna att resa med buss tillsammans med en av programledarna. Resultaten av studie III visade att materialet i programmet fungerade bra, men behövde viss revidering för att matcha deltagarnas behov. Hemläxor som genomfördes individuellt mellan grupp-sessionerna sågs som värdefulla, men reflekterande uppföljande diskussioner av dem behövde utvecklas. Att programmet var utformat som en grupp-intervention uppskattades av deltagarna. Tiden för gruppträffarna behövde dock förlängas för att hinna med allt innehåll utan att stressa igenom det eller avstå från inplanerade pauser. Avseende genomförandet belystes även vikten av kompetenta ledare och motiverade deltagare. Samtliga deltagare förbättrade sin förmåga till utomhusmobilitet. Tre av fem reste med buss tillsammans med någon av ledarna. Särskilt två av dem beskrev det som att de kände sig säkrare på att klara det samt kunde sätta mål och hantera problem som uppstod längs vägen. De två som inte reste med buss gjorde andra framsteg. Den ena klarade att självständigt gå till ett möte, vilket är en del i ökad förmåga till utomhusmobilitet och också en potentiell del i resekedjan. Den andra personen hade egentligen inga svårigheter att ta sig ut i miljöer som han var motiverad att vara i, men efter programmet beskrev han att han nu såg fördelar med att resa med kollektivtrafiken vilket är ett förstadium till att faktiskt ta steget att resa.

När vi arbetade med studie III upptäckte vi svårigheter att rekrytera deltagare till programmet. Vi ville därför närmare undersöka intresset för att delta i strokeinriktade rehabiliteringsstudier och vad personer med stroke själva föredrar vad gäller den typen av studier. Detta utgjorde syftet för studie IV. Resultaten visade att intresset för att delta i strokeinriktad rehabiliteringsforskning var stort, inte minst bland yngre personer och bland dem där det inte gått så lång tid sedan insjuknandet. Deltagarna belyste dock att det även var viktigt att inkludera personer lång tid efter stroke. Vanliga orsaker till att vilja delta i rehabiliteringsforskning var att bidra till forskning och utveckling, att få prova nya rehabiliteringsprogram och att få träffa andra i samma situation som en själv. Hjälp med transport mellan hemmet och lokalen där det tänkta studien skulle genomföras var också en orsak kopplat till intresse av att delta. Den rehabiliteringsform som flest verkade intresserade av var grupp-baserade program och program som fokuserade på att träna upp förlorade eller nedsatta fysiska eller kognitiva förmågor. Deltagarna verkade föredra att bli inbjudna till att delta i studier via brev på posten. Deltagarna beskrev att personliga karaktärsdrag (såsom motivation, självförtroende och kommunikativa förmågor), att det tas hänsyn till individuella behov (utifrån till exempel funktionsnedsättning, ålder och livssituation) samt kompetenta ledare, som särskilt viktiga komponenter

för forskare att tänka på vid rekrytering av personer med stroke till rehabiliteringsforskning.

Avslutningsvis

Sammanfattningsvis visar den här avhandlingen att det finns flera viktiga aspekter avseende delaktighet i sociala- och fritidsaktiviteter på lång sikt efter stroke. Personer med stroke som kan gå några hundra meter, köra bil, har ett brett socialt nätverk och är yngre än 75 år var mer engagerade i sociala- och fritidsaktiviteter 10 år efter stroke. För att stödja personer med stroke att bli mer aktiva och delta i samhället på lång sikt utvecklades ett nytt rehabiliteringsprogram baserat på self-managementmetodik. Programmet har potential att öka förmågan till att ta sig ut i samhället och resa med buss för personer med kognitiva funktionsnedsättningar efter stroke. Programmet behöver dock revideras något. Dessutom behövs ytterligare överväganden göras kring vilka instrument som ska användas för att utvärdera programmet. Trots att det var svårt att rekrytera personer till programmet var metoden för programmet samt innehåll och form i linje med stroke överlevares preferenser. Detta är positivt inför det fortsatta arbetet med programmet.

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Definitions

Activity	Execution of a task or action by an individual (WHO, 2001).
Activity limitations	Difficulties an individual may have in executing activities (WHO, 2001)
Disability	An umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between a person's health condition(s) and that individual's contextual factors (environmental and personal factors). (WHO, 2001).
Impairment	Reduction in body function or body structure such as significant deviation or loss of psychological or physical functions or anatomical structures (WHO, 2001).
Mobility	In health science and rehabilitation, mobility is about moving by changing body position or location or by transferring from one place to another, by carrying, moving or manipulating objects, by walking, running, or by climbing, and by using various forms of transportation (WHO, 2001).
Outdoor mobility	The motion of persons and goods in outdoor space to surmount distances (EC, 2006). This includes transportation to get access to desired places and people (destination-dependent) or just to move around (destination-independent) (Metz, 2000).
Participation	Involvement in a life situation (WHO, 2001).
Participation restrictions	Problems an individual may experience in involvement in life situations (WHO, 2001)
Rehabilitation	A set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments (WHO, 2011, p 96).

Reliability	The authenticity of a measurement. The extent to which scores have not changed are the same for repeated measurement under several conditions: for example, using different sets of items from the same health-related patient-reported outcomes (internal consistency), over time (test-retest), by different persons on the same occasion (interrater) or by the same persons (i.e. rater or respondents) on different occasions (intrarater) (Mokkink et al., 2010).
Self-Efficacy	A person's belief or confidence in his or her capability to realize a specific task (Bandura, 1997).
Self-management	An individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition (Barlow et al., 2002)
Travel chain	The chain of activities during an entire trip starting with planning the trip to the arrival at the final destination (Ståhl, 1997; Wretstrand & Ståhl, 2008).
STS	Special Transportation Service that is, a special service offered for people with difficulties in using official public transportations.
Stroke unit	An inpatient unit that mainly treats patients with stroke. The care is organized and performed by a multidisciplinary team specialized in stroke care (Socialstyrelsen, 2018).

Introduction

The ability to move around in society using different modes of transportation, for example walking, car driving and public transportation, is required in order to be active outside the home and participate in society (Haak et al., 2008; Broome et al., 2009). Being mobile in the community enables participation in for example, leisure and social activities (Unsworth, 2012) and social participation improves health and well-being (Rosso et al., 2013). However, diseases and injuries can cause disabilities, that is, impairments, activity limitations and participation restrictions (WHO, 2018a). Today, around 15% of the world's population live with some sort of disability (WHO, 2015). As Sweden and countries globally are facing an ageing population with an overall increased life expectancy, more people survive and are living and ageing with implications for a long period of their life due to their illness. This is positive, but watching it from a health care and economical point of view, it is an increasing public health issue (Grady & Gough, 2014). In parallel with this, there is pressure from global and national policies that declare goals for sustainable health and participation in society for everyone (United Nations, 2015; Kommissionen för jämlik hälsa, 2017; prop. 2002/03:35; WHO, 2015). One tool to support people with disabilities to be active and participating in society is rehabilitation. Rehabilitation is "a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments" (WHO, 2011, p 96). To cover all those aspects, the international classification of functioning, disability and health (ICF) can be used in research and as a clinical tool during the rehabilitation process. ICF includes both functions and disabilities (body functions and structures and activity and participation) as well as contextual factors (environmental factors and personal factors) (WHO, 2001). Still, traditionally, physical aspects have been prioritized in many rehabilitation programs. Watching it from holistic point of view, rehabilitation interventions need to include the whole person and the context where he/she lives. It is also important to let the person affected take an active role in the rehabilitation process. Although rehabilitation in Sweden has advanced concerning interdisciplinary teamwork involving the person affected and his/her relatives (Lexell & Rivano Fischer, 2017), there is still need for improvement. Today development of care still mainly focuses on health care for patients and much less with them (Myndigheten för vård- och omsorgsanalys, 2018). Taken together, there is an expanding group of people living with long-term disabilities, global pressure

on sustainable health and participation in society for everyone as well as a financially strained health care. Therefore, there is a need to develop long-term sustainable rehabilitation interventions supporting people with long-term disabilities to live active lives outside their homes although different impairments with focus on their own defined goals. Such interventions are often complex, involve extensive work and different types of studies are required to develop a robust intervention that can show actual positive outcomes.

The four papers in this thesis are parts of the development of such a complex intervention (named BUS TRIPS) supporting outdoor mobility and travelling by bus for a group, in which long-term disabilities are common, namely stroke survivors.

Background

Stroke

- Stroke is a common disease in Sweden and internationally, with an annual global incidence of more than 10 million strokes and with high prevalence of disabilities as a consequence.
- Despite a decreased incident rate due to primary prevention, better outcome due to acute medical treatment, a combination of population growth, an increasingly ageing population and the fact that more people survive and are living and ageing with implications of stroke for a long period of their lives speak for an increased burden from stroke.
- This imposes great demands on health care and social service to create conditions for active and healthy ageing for stroke survivors.

Stroke is the second most common cause of death and the third most common cause of disability internationally (Feigin et al., 2017). Stroke occurs because of inadequate blood flow usually caused by a blockage (ischemic stroke) or rupture or leakage of blood vessels (hemorrhage) supplying blood to the brain (WHO, 2018b). Ischemic stroke is the most common type, 67% (Feigin et al., 2017). Regardless of stroke type, it leads to lack of oxygen that causes injuries to the brain tissue (WHO, 2018b). On a global level, there were 10.3 million new strokes, 25.7 million stroke survivors and 6.5 million deaths due to stroke in 2013 (Feigin et al., 2017). In Sweden, the incident rate for acute stroke was about 21,000 in 2017 including both first-ever onset and relapse (The Swedish Stroke Register, 2018). According to a population-based study from the UK, the prevalence of disability five years post stroke was estimated to almost 40% (Luengo-Fernandez et al., 2013). Typical risk factors for stroke are hypertension, hypercholesterolemia, carotid stenosis, atrial fibrillation, diabetes mellitus, cigarette smoking and other lifestyle factors (Feigin et al., 2017; Hankey, 2017). Acute symptoms of stroke are, for example, sudden weakness of one side of the body, numbness, language difficulties, visual loss, non-orthostatic vertigo, and severe headache (Hankey, 2017).

The mean age for acute stroke in Sweden are 75 years (women: 78 years and men 73 years) (The Swedish Stroke Register, 2018). However, at an international level,

two out of three are <70 years at stroke onset (Fergin et al., 2017) and the positive trend of an overall decreased incidence of stroke in Sweden is not seen among the age group below 45 years (Aked et al., 2018). Medical treatment for atrial fibrillation is an important primary prevention action for reduction of the stroke incident rate (Johnson et al., 2017). Medical progress has not only contributed to the prevention of stroke, but also to a positive outcome if stroke occurs. Acute medical treatment with thrombolysis and endovascular thrombectomy have improved the prognosis and decreased disabilities post stroke (Hankey, 2017). In addition, mortality and Disability-Adjusted Life Years (DALY) related to stroke have declined globally during 1990-2013. However, a combination of a population growth, an increasingly ageing population and the fact that more people survive and are living and ageing with implications of stroke for a long period of their lives speak for an increased burden from stroke (Feigin et al., 2017). Above and beyond primary prevention and effective acute therapies, rehabilitation and long-term follow-ups are needed to reduce the burden of stroke. This imposes great demands on health care and social services to create conditions for active and healthy ageing for stroke survivors. As an example, lifetime costs for all first-ever stroke survivors in Sweden with onset during 2009 was estimated to more than 16 billion SEK (Ghatnekar & Steen Carlsson, 2012). Rehabilitation and other care interventions in the post-acute phase comprise about 40 percent of the total costs for stroke (Persson et al., 2012). That is, beyond the importance of offering effective methods that support activity and participation after stroke although long-term disabilities, there are economic incentives to offer long-term sustainable rehabilitation interventions.

Activity and participation after stroke

- Many stroke survivors experience remaining impairments after stroke that can lead to activity limitation and participation restrictions.
- Participation in social activities and hobbies are important for subjective well-being after stroke, but research on how to promote such activities in a long-term perspective has not gained sufficient attention.
- Outdoor mobility is a prerequisite for being active and participate in society, but transportation opportunities for stroke survivors are often limited since many are not allowed to drive a car, Special Transportation Service is highly regulated and stroke related impairments and low self-confidence reduce the use of public transport.
- Rehabilitation interventions that support outdoor mobility and the ability to use public transport among stroke survivors would be one way to support the ability to be active and participate in society.
- However, such interventions are rare, not the least for those with cognitive impairments. Therefore, development of such interventions are warranted.

Despite medical progress and sufficient rehabilitation in the early phase, many stroke survivors experience physical and cognitive impairments for a long time after stroke onset. Such impairments can often lead to restrictions in activity and social participation (Skolarus et al., 2014; Jansen et al., 2012). For example, physical impairments, such as hemiparesis and reduced balance can influence the individual's ability to move around (Michael et al., 2005). Stroke survivors has also reported the importance of walking capacity for activity and participation (Combs et al., 2013). Further, cognitive impairments has been documented to be prevalent among 50-80% of people with stroke (Kapoor et al., 2017; Delavaran et al., 2017; Jokinen et al., 2015; Mellon et al., 2015). Cognitive functions comprise the capacity to absorb and process information as a base for taking actions. Cognitive impairments include, for example, difficulties with attention and memory, processing information and executive functions (i.e., planning and deciding how to perform a task) (Björkdahl, 2015). Cognitive impairments can be particularly difficult for other people to comprehend, since they often are hidden (i.e., not visible on the outside of a person). In addition, stress, fatigue, emotions and environmental factors affect the cognitive capacity, meaning that the capacity can vary depending on the context. Cognitive impairments are associated with decreased participation (Adamit et al., 2015; Spitzer et al., 2011) and can result in social participation avoidance (Patchich et al., 2015). In addition, depression is prevalent in around one third of the stroke survivors (Hackett & Pickles, 2014) and is also associated with decreased participation (Rozon & Rochette, 2015).

Social and leisure activity

Research has shown that there is a need for strategies to reduce the risk of long-term activity limitations (Wolfe et al., 2011) and that social activities and hobbies are essential to subjective well-being in a long term perspective after stroke (Brunborg & Ytrehus, 2014). Such activities are also related to improved health, functional recovery and survival after stroke (Boosman et al., 2011; Sveen et al., 2004; Venna & McCullough, 2015). However, social activities decrease after stroke (Blömer et al., 2015) and are less frequent among stroke survivors than among healthy controls (Schepers et al., 2005), also in a long-term perspective (Jansen et al., 2012). Nevertheless, research on how to promote such activities in a long-term perspective has not gained sufficient attention. Several factors has shown to be negatively related to participation in social activities and hobbies in the early phase up to the first years after stroke. Age (Schepers et al., 2005; Desrosiers et al., 2008, Gadidi et al., 2011), motor and cognitive impairments (Desrosiers et al., 2008), depression (Desrosiers et al., 2006), emotion regulation difficulties (Cooper et al., 2015), transportation difficulties (Walsh et al., 2014) and driving cessation (Liddle et al., 2009) are examples of such factors. Exercise (Obembe & Eng, 2016), walking ability (Desrosiers et al., 2008), supportive networks (Woodman et al., 2014; Walsh et al., 2014) and available health and rehabilitation services (Anderson & Whitfield, 2011) are instead examples of factors related to higher activity levels or constitute facilitating factors for activity. There is increasing attention being paid to needs for long-term sustainable stroke service. Thus, long-term studies about participation has been listed among the ten top priorities for stroke research (Wolfe et al., 2007). To catch stroke survivors at risk of activity limitation and participation restriction and to create sustainable support, we need to learn more about the impact of such factors in a long-term perspective. Such information would constitute a knowledge base for the development of individualized rehabilitation and new interventions.

Outdoor mobility

Being able to move around in society is a prerequisite for being active and participating in activities outside the home. Outdoor mobility (EC, 2006) usually includes a combination of walking, cars and public transport and can be either destination-dependent to get access to desired people or places, or destination-independent, meaning just moving around (Metz, 2000). New research has shown that about 20% of stroke survivors experience problems related to outdoor mobility and mode of transport five years after stroke (Persson & Selander, 2018). In Sweden there are governmental directives on accessibility and usability in public spaces, including for those with limited mobility or orientation capacity (Boverket, 2013; Boverket, 2011). Removal of physical barriers in the outdoor environment has

shown to be a potential effort to increase outdoor mobility among people with functional impairments age ≥ 65 (Wennberg et al., 2010). However, additional actions are needed to make society accessible to everyone.

After a stroke, it is common that one are not able to drive a car due to for example physical or cognitive impairment (Tan et al., 2011; Finestone et al, 2009) and especially older stroke survivors cease to drive after stroke onset (Person & Selander, 2018). In Sweden, advice on car driving on discharge from hospital was lacking for more than a fifth of the stroke survivors (The Swedish Stroke Register, 2018), although laws (Körkortslag, SFS 1998:488) and recommendations regarding medical requirements for driving (Transportstyrelsen, 2010) regulate the possibility of starting to drive again after illness such as stroke. In Sweden, the general recommendation is driving cessation the first three months after onset, although this period can be extended (SKL, 2016). At the same time, driving after stroke is associated with reintegration in the community (Finestone et al., 2010) and alternative solutions for travelling are important to consider.

In Sweden, special transportation service is regulated by law (Lag om färdtjänst, SFS 1997:736) and only those with significant, long-lasting disabilities have the right to this mode of transportation. At the same time, there are laws regulating public transportation (Lag om kollektivtrafik, SFS 2010:1065) which should also be accessible on people with impairments (Lag om handikappanpassad kollektivtrafik, SFS 1979:558). This allows wider restrictions of the right to special transportation. Consequently, to a large extent stroke survivors have to rely on friends and family to travel or use public transportation. However, in a Swedish study it was shown that only a minority (21%) travel by bus after stroke, even if as many as 45% said that they wanted or needed to do so (Asplund et al., 2012). Additional studies support the idea that fewer travel with public transportation after a stroke (Wendel et al., 2010; Logan et al., 2004). Challenges to travel with public transportation are related to physical impairments (Asplund et al., 2012; White et al., 2012; Wendel et al., 2010), fear of falling (Logan et al., 2004), cognitive impairments (Risser et al 2012; Asplund et al., 2012; Rosenkvist et al., 2009) as well as depression (Wendel et al., 2010) and loss of self-confidence (Ståhl & Lexell, 2018; Barnsley et al., 2012; White et al., 2012; Logan et al., 2004). Fatigue and anxiety might also explain difficulties to travel with public transport (Ståhl & Lexell, 2018) In addition, using public transportation does not only include the actual ride, but a chain of activities (Ståhl, 1997; Wretstrand & Ståhl, 2008) (e.g., planning the trip, walking to the bus stop, buying tickets, getting on and off the bus). Difficulties in one or more of those areas implies an inaccessible travel chain (Risser et al., 2015; Wretstrand & Ståhl, 2008) which complicates the ability to travel even further (Ståhl & Lexell, 2018).

Although travelling is an important aspect for participation after stroke (Bergström et al., 2015), interventions in this area are rare. There are only a few studies that

target how rehabilitation interventions can improve the ability to use public transportation (Logan et al., 2004, Logan et al., 2014). In the most recent study (Logan et al., 2014), the intervention resulted in increased journeys among the intervention participants compared to controls. However, this was related to a therapist effect (some therapists were more successful), and the satisfaction with outdoor mobility participation was not higher among the intervention participants compared to controls. Meeting transportation needs to support a continued active life outside the home after stroke is a challenging task and needs to be examined further. All this suggest that there is a need to develop rehabilitation interventions that facilitate the ability to move around in society and thereby increase participation (Ståhl & Lexell, 2018; Wendel et al., 2010).

Rehabilitation after stroke

- It is recommended that people with stroke are treated at specialized stroke units, where individual rehabilitation should start immediately parallel with the medical treatment and care.
- For those with mild to moderate strokes, transition from hospital to the home can be accelerated by early supported discharge (ESD).
- Rehabilitation traditionally focuses on functional capacity and basic activities of daily living and there is less attention to for example cognitive aspects and complex activities to promote participation and reintegration into society. In addition, long-term unmet rehabilitation needs are prominent.
- There is a lack of knowledge on rehabilitation interventions to support complex activities and reintegration to society. A self-management approach for such an intervention might be promising.

To support people with stroke in recovering as well as adapting to potential remaining impairments, a chain of care and rehabilitation is needed. To start with, according to current international and national guidelines for stroke, care at specialized stroke units are recommended (Hebert et al., 2016; Socialstyrelsen, 2018). Stroke units have adequate multidisciplinary teams consisting of physicians, nurses, occupational therapists, physiotherapists, speech therapists, psychologists and counsellors. In addition, dietitians should be accessible (Socialstyrelsen, 2018). The vast majority (90%) of those affected by stroke in Sweden are treated at an inpatient stroke unit at some point in their hospital stay (The Swedish Stroke Register, 2018). To prevent prevailing consequences of stroke, individualized rehabilitation needs to begin immediately during the inpatient period, in parallel with medical treatment and care (Hebert et al., 2016).

In Sweden, most stroke survivors (75%) are discharged from hospital to ordinary housing (The Swedish Stroke Register, 2018). For those with mild to moderate disability after stroke early supported discharge (ESD) from hospital are recommended. This means that the hospital offer and coordinate further rehabilitation in the persons home environment (Hebert et al., 2016). ESD has shown to be associated with reduced dependency (Hebert et al., 2016; Fearon & Langhorne, 2012) and an appreciated form of rehabilitation among stroke survivors (Lou et al., 2016). In Sweden, the proportion of ESD coordinated by the hospital was planned for about a fifth (The Swedish Stroke Register, 2018).

In a review of randomized controlled trails of stroke rehabilitation interventions, nearly 60% focused on improving motor outcomes (McIntyre et al., 2014). Results from another study showed that most interventions in occupational performance use a biomechanical approach (Ahn, 2016), while rehabilitation care with a focus on psychosocial consequences receives less attention (Jones et al., 2013; Jones, 2006). Functional capacity and the ability to perform basic activities of daily living are also the primarily focus in rehabilitation after discharge from hospital, where rehabilitation often is transferred to primary care and the local municipalities. However, stroke survivors has expressed that physical needs have been the focus to the detriment of non-physical needs (Peoples et al., 2011). Healthcare professionals has also expressed that there is more attention to physical aspects and that it can be difficult to bring up cognitive impairments with the stroke survivors (Tang et al., 2017). Nevertheless, due to the high proportion of such impairments (Kapoor et al., 2017; Delavaran et al., 2017; Jokinen et al., 2015; Mellon et al., 2015), rehabilitation interventions within this area deserve more attention. In addition, while physical aspects and basic activities of daily living have traditionally been prioritized, interventions supporting more complex activities that promote participation and reintegration into society need to gain more attention (Logan et al., 2014; Wendel et al., 2010).

Although many stroke survivors are in need of ongoing rehabilitation for many years (O'Neill et al., 2008), access to rehabilitation in the later phases varies (Socialstyrelsen, 2011) and research is lacking on benefits from interventions more than the first years after stroke (Aziz et al., 2008). Research has shown that rehabilitation offered today does not match the needs of stroke survivors. In a study including nearly 40,000 stroke survivors in Sweden, unmet rehabilitation needs were found among more than a fifth of survivors one-year post stroke (Ullberg et al., 2016). Further, McKevitt et al. (2011) showed high proportions of long-term needs up to five years after stroke, including needs related to a wide range of aspects such as information and social participation (e.g. work, leisure activities and negative change in relationships). To sum up, there is evidence of how rehabilitation should be performed in the early phase after stroke (Hebert et al., 2016; Socialstyrelsen, 2018; Young & Foster, 2007). However, there is a need for

rehabilitation interventions that match stroke survivor's needs of more complex activities and reintegration into society (Logan et al., 2014; Wendel et al., 2010). Rehabilitation interventions that focus on such aspects for people with chronic diseases, largely deals with behavioral changes. Since the nature of chronic conditions, such as stroke, where there is lack of effective cures, a self-management (SM) (Holman & Lorig, 2004) approach might be promising. SM interventions are typically used within health care to support people with chronic diseases and has been shown to be cost-effective (Lorig & Holman, 2003).

Self-management and social cognitive theory

- Self-management (SM) is defined as “an individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition”
- Social cognitive theory includes a set of core determinants that are important while working with health promotion. One of those determinants targeted by SM interventions that is of particular interest is self-efficacy (SE) which means a person's belief or confidence in his/her capability to realize a specific task.
- SE is important to evaluate in SM interventions.
- Many SM interventions for stroke survivors are focusing on the nature and effects of stroke as well as lifestyle factors for reducing the risk of new stroke events, while there is a lack of studies showing in what way SM interventions can enhance participation.
- Such an intervention is complex and a chain of studies with different research questions is needed to create a robust intervention.

The term SM derives from Creer and colleagues, who emphasized the active role of a person in his/her treatment. Everyone has a responsibility for his/her own health, and it is impossible not to manage it, the question is how one does it (Lorig & Holman, 2003). Barlow et al. (2002) defined SM as “An individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition”. According to a SM approach, it is important to focus on problems perceived by the participants themselves. Regarding SM interventions for people with chronic disease, three task has been emphasized as important; medical management (e.g., compliance to medications), behavior/role management (making new and maintaining old) and emotional management (handling emotions related to having a chronic illness) (Lorig & Holman, 2003). The key in SM is to teach skills instead of providing ready solutions. Lorig & Holman (2003) suggest five core skills: 1) problem-solving, 2)

decision-making, 3) resources utilization, 4) partnership with health care providers and 5) taking action.

Social cognitive theory is a suitable theory to improve SM behaviors of patients with chronic diseases. The theory includes a set of core determinants that are important while working with health promotion and prevention of illness (Bandura, 2004). One of those determinants that is of particular interest targeted by SM interventions (Lorig & Holman, 2003) is self-efficacy (SE) (Bandura, 2004; Lorig & Holman, 2003). SE is a person's belief or confidence in his/her capability to realize a specific task (Bandura, 1997). This determinant stands out in the sense that it both affects health behaviors directly and have impact the other core determinants that is, knowledge, outcome expectations, goals, perceived facilitators and social and structural impediments (Bandura, 2004). Supporting improvement of SE among stroke survivors is an important task since decreased confidence is common after a stroke (Logan et al., 2014). SE is also considered as important in the management of everyday activities post stroke (Korpershoek et al., 2011) and is related to cognitive function as well as depression (Lewin et al., 2013). Improved SE seems to reduce health care use among people with chronic diseases (including stroke) (Lorig et al., 2001). There are four factors that affect SE; 1) Mastery experience, that is, the level of success (if you are successful in performing a task, self-efficacy increases, while failing has a negative effect). 2) Vicarious experience, that is, comparison with others similar to yourself ("If she can, - I can"). 3) Verbal persuasion, that is, encouragement or dissuasion from others. 4) Physical and affective states/physiological feedback, that is, perception of the physical or emotional conditions in stressful situations (Bandura, 1997).

To ensure improvements in SE, reliable and valid assessments of this core determinant should be used when evaluating SM interventions. There are different instruments available, for example those that measure specific SE, such as the Stroke Self-Efficacy Questionnaire which capture stroke survivors confidence in functional performance (Jones et al., 2008). There are also instruments which capture general self-efficacy, such as the widespread General Self-Efficacy scale. This instrument has been translated into 32 languages, including Swedish (Schwarzer, 2014). The scale is valid (Löve et al., 2012) and reliable when used in samples with different characteristics (Scholz et al., 2002). However, it has only been used occasionally in a Swedish context (Nilsson et al., 2015; Löve et al., 2012) and no study has investigated the psychometric properties of the Swedish version (Koskinen-Hagman et al., 1999) in a stroke population. Accordingly, further psychometric evaluation is warranted prior to considering for use in a stroke SM intervention.

Many SM interventions directed at stroke survivors focus on for example prevention of new strokes, and the nature and effects of stroke (Huijbregts et al., 2008; Kendall

et al., 2007; Rodgers et al., 1999). Warner et al. (2015) concluded that although research is still not sufficiently clear to draw any overall conclusions, some stroke-specific SM interventions show significant positive effects. The results of a recent SM intervention study showed positive effects on participation in everyday life activities, although it was a small study (Wolf et al., 2016). However, in summary, there is a lack of studies showing in what way SM interventions can prevent social isolation and enhance participation in society (Jones & Riazi, 2011), not the least for those with cognitive impairment (Jones et al., 2013) and interventions targeting the ability to move around in society. Development and evaluations of such interventions are warranted and using a SM approach seems to be effective. However, such interventions are complex and to establish an actual positive improvement and a robust intervention, a chain of studies with different research questions is needed.

Development of complex interventions

- Interventions including several interactions of mechanisms are complex.
- The Medical Research Council (MRC) guidelines offer a framework to support development and evaluation of complex interventions.
- The MRC guidelines includes four key elements; development, feasibility, evaluation and implementation of complex interventions.
- The MRC guidelines have been used in this thesis to support the process of developing and evaluating a new SM rehabilitation intervention.

Rehabilitation interventions such as a SM program that targets support for improving participation in society and outdoor mobility ability among people with cognitive impairments typically comprise numerous interactions between mechanisms and are therefore complex. The complexity also lies in for example different behaviors of those performing and receiving the intervention and the need for flexibility due to local prerequisites (Craig et al., 2008, Craig et al., 2006). In 2000, the Medical Research Council (MRC) published a first version of guidelines for developing and evaluating complex interventions for randomised controlled trails. The background to the guidelines was based on the fact that most randomised controlled trails do not evaluate the effect of only a single intervention and are therefore complex (Campbell et al., 2000). Such interventions should still be evaluated in the same way as pharmacological trials (Buchwald, 1997; Stephanson & Imrie, 1998), but their complex nature would benefit from a pragmatic approach

(Stephanson & Imrie, 1998). In other words, there was a need for good practice in developing and evaluating complex interventions (Campbell et al., 2000). The MRC guidelines have been used extensively, but criticisms have also been raised related to, for example, the linear process, insufficient focus on the development phase and initial piloting and the absence of focus on the context of the interventions. Therefore, the guidelines were updated (Craig et al., 2006) and summarized by Craig et al., (2008). The guidelines includes elements for development, feasibility, evaluation and implementation of complex interventions. A process is required where the researchers need to move back and forth frequently between the different elements before the intervention can be implemented. The guidelines should be seen as a tool for making proper decisions related to practical and methodological nature when developing and evaluating complex interventions (Craig et al., 2008, Craig et al., 2006). This is how they are used in this thesis. The papers included and their positions within the MRC model are described in the methods section.

Summing up

Stroke is a common disease in Sweden and internationally, with an annual global incidence of more than 10 million strokes and with high prevalence of disabilities as a consequence. Despite a decreased incident rate due to primary prevention, better outcome due to acute medical treatment, a combination of population growth, an increasingly ageing population and the fact that more people survive and are living and ageing with implications of stroke for a long period of their lives speak for an increased burden from stroke. Much rehabilitation research focuses on the early phase of stroke as well as on physical aspects, while studies into a later phase and into interventions supporting reintegration into society have received less attention. However, many stroke survivors experience activity limitations and restriction in participation, such as participation in social and leisure activities. Outdoor mobility, including transportation opportunities, enable activity and participation outside the home, but many stroke survivors cease to drive a car, are not qualified for STS and experience difficulties in travelling by public transportation. Travelling by public transportation, for example by bus, not only involves the actual bus ride, but a chain of activities that require the ability to solve various types of task. Interventions to support outdoor mobility including increasing the ability to manage the entire travel chain are rare, not least for people with cognitive impairments. A self-management approach for such an intervention is promising because it enables people to learn skills to solve different types of problem. However, an intervention of that type is complex and in order to establish if it renders a positive improvement, several questions need to be considered in advance of larger scale evaluation studies. The MRC guidelines are a useful tool to support this process. Spending time and effort

on the development and feasibility phase will create a stronger intervention, easier to evaluate in a larger context and later implement into practice.

Aims

The overall aim of this thesis was to study prerequisites for activity and participation among stroke survivors. A first goal was to gain new knowledge of factors important for participation in society for people with stroke in a long-term perspective, thereby contributing to the evidence base warranted to nurture the development of a new intervention. A second goal was to further the development of complex interventions targeting participation among stroke survivors, and investigate feasibility aspects of the first version of a new self-management intervention (BUS TRIPS) to support outdoor mobility including travelling by bus, targeting stroke survivors with cognitive impairments.

Specific aims

To identify factors that predict participation in social and leisure activities 10 years after stroke (*Study I*)

To identify an instrument for forthcoming evaluations of a first version of a new self-management intervention (BUS TRIPS), and study its psychometric properties. (*Study II*)

To investigate feasibility aspects regarding program content and delivery as well as possible improvements in outdoor mobility and travel by bus as well as general self-efficacy, stroke impact on participation and life satisfaction among stroke survivors by means of a first version of a new self-management intervention (BUS TRIPS) (*Study III*)

To identify important factors when recruiting stroke survivors to participate in rehabilitation research (*Study IV*)

Methods

Since the intervention (BUS TRIPS) developed and tested in this thesis is complex and includes different types of research questions, several studies are needed. The MRC guidelines (Craig et al., 2008, Craig et al., 2006) for complex interventions were used to support the process and the four thesis papers represent different elements within the guidelines. This thesis is based on four studies: The Long-term predictor study (I), the Psychometric study (II), the Feasibility study (III) and the Recruitment study (IV). An overview of the key elements in the MRC guidelines (Craig et al., 2008, Craig et al., 2006) and the studies placement within the framework are visualized in Figure 1.

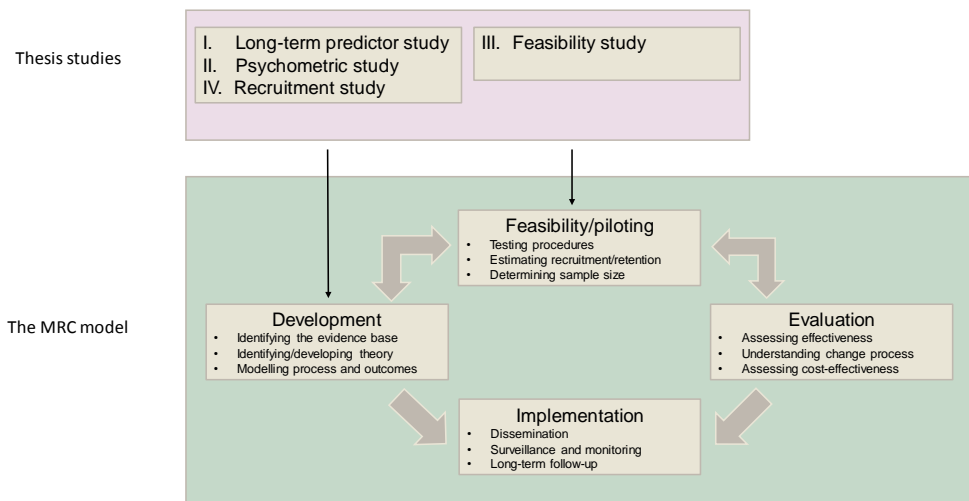


Figure 1. Key elements of the MRC model (after Craig et al., 2008 and Craig et al., 2006) and thesis papers placement within the different MRC elements.

Overall study designs

To cover the target area and to achieve the specific and overall aim in line with the MRC guidelines (Craig et al, 2008, Craig et al., 2006), this thesis includes studies that utilize a variety of designs and methods, where both quantitative and qualitative data are represented. The studies also include different samples. For an overview, see Table 1.

Table 1. Overview of the papers in this thesis.

	Paper I	Paper II	Paper III	Paper IV
Name of study	Long-term predictor study	Psychometric study	Feasibility study	Recruitment study
Participants, N	145	34	5	128
Time since stroke	16 months and 10 years	6-10 months	6-12 months	0-6 months up to more than 5 years (70% >1 year but <5 years)
Mean age (min-max)	68 (19-88) and 76 (28-97)	68 (58-86)	72 (64-82)	71 (34-102)
Research approach	Longitudinal cohort study	Test-retest reliability study	Mixed methods study	Cross-sectional survey study
Data collection methods	Structured interviews at baseline, 16 months- and 10 years post stroke	Structured interviews at baseline and follow-up three (± 2) weeks apart	Structured interviews at baseline, two weeks after intervention finished and three month follow-up, semi-structured group interview, structured phone survey one week after discharge and structured reflection notes during intervention	Self-administered survey
Main analysis	Multivariate linear regression	Targeting, Scaling assumptions, Cronbach's alpha, Intraclass Correlation Coefficient (ICC), Standard Error of Measurement (SEM)	Cross-case and within-case analysis with a mixed methods approach (direct content analysis)	Descriptive statistics, Chi-Square test, Mann-Whitney U-test, thematic analysis,

Development of the first version of BUS TRIPS

To create complex intervention, the developing phase should include identification of evidence to build the intervention. For example, the focus of the intervention should be motivated based on previous research. In addition, to evaluate the effects of a complex intervention, it is important to find suitable instruments that assess core aspects related to the intervention (Craig et al., 2008, Craig et al., 2006). In this

thesis, the first two studies and the fourth study are included in the development element, while the third study is included in the feasibility/piloting element. However, since the process of developing and evaluating complex interventions includes steps backwards and forwards, the first two studies are presented first, followed by the third and last the fourth.

The Long-Term predictor study

Participants

The Long-term predictor study included participants recruited from the Lund Stroke Register (LSR). LSR is an ongoing hospital-based first-ever stroke register covering the catchment area of Skåne University Hospital (Lund) including eight municipalities (Hallström et al., 2007; Jönsson et al., 2005) with 274,239 inhabitants, December 31, 2015) (Aked et al., 2018). For detailed methods used to find patients (including prospective screening methods, regular inquiries to primary care, hospital registers, death and autopsy registers), see Hallström et al. (2007) and Jönsson et al. (2005).

Of the 416 people registered in the LSR for the selected period (March 1, 2001 to February 28, 2002), people from the 16-month follow-up (n=310) as well as all survivors at 10 years after stroke onset (n=145) were included, see Figure 2. Mean age at stroke onset was 66 years (41% women) and a majority lived in ordinary housing with no home care at both the 16-month and the 10 years follow-up.

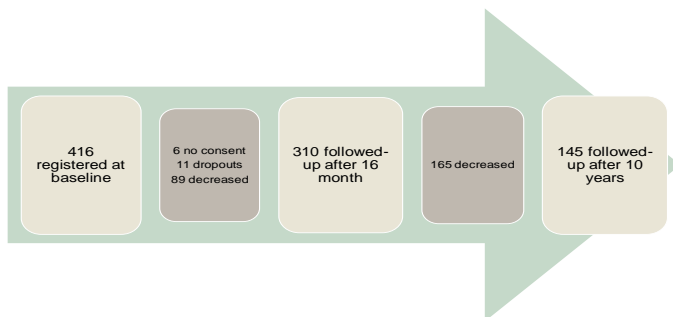


Figure 2. Participant flow-chart from baseline to the 10 year follow-up.

Data collection

Data were collected through interviews, conducted by the same experienced specialist nurse and researcher (AJ). The majority of the 16 month and 10 year follow-up were performed at an outpatient clinic at Skåne University Hospital. The

remaining were performed at primary care centres, nursing homes, the participant homes or a few by phone. If necessary due to cognitive, communicative or health related difficulties, a family member or caregiver who knew the participant well assisted during the interview. For details, see Jönsson et al. (2014) and Jönsson et al. (2005).

Instruments and study specific questions

A subset of the LSR instrument battery, selected at 16-months and 10 –year follow up was included in the Long-term predictor study. Data from well-established instruments: the Barthel Index (BI) (Mahoney & Barthel, 1965), Mini Mental State Examination (MMSE) (Folstein et al., 1975), Geriatric Depression Scale (GDS-20) (Gottfries et al., 1997) and the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36) (Sullivan et al., 1995) and project-specific questions (Hanson & Östergren, 1987; Swedish Stroke Register 2-year follow-up survey (1999) were included from the 16-months follow-up.

At the 10-year follow-up, a Swedish extended version of the Frenchay Activities Index (FAI) (Wendel et al., 2013) was added. FAI is a commonly used instrument as a measure of frequency of social activity among stroke survivors (Jansen et al., 2012; Boosman et al., 2011; Schepers et al., 2005) and has shown good psychometric properties for stroke survivors (Piercy et al., 2000; Wade et al., 1985). However, in a recent ICF-linking study (Norlander et al., 2016), it was shown that only a sub-domain of FAI was related to the ICF chapter “Community, social and civic life”, which is in focus for the present study. Therefore, only this sub-domain of FAI was used. It was named FAI-CSC.

Dependent variable

The dependent variable represented the frequency of social and leisure activities at the ten year follow-up and was assessed by FAI-CSC (Norlander et al., 2016). The FAI-CSC includes three items from the FAI, namely;

- 1) Social outings (frequency of taking part in social activities out of the home, such as going to the theater, dinner with friends or visiting family),
- 2) Pursuing active interest in hobby (activities of interest in or out of the home, such as knitting, caring for houseplants or sports)
- 3) Outings/car rides (coach or rail trips or car rides to some place for pleasure).

The first two items assessed the frequency of participation during the last three months, while the third referred to the previous six months. The maximum total score is nine (0-3 for each item) where a greater score indicates a higher overall frequency of social and leisure activities.

Independent variables

A considerable number of independent variables was collected from the 16-month follow-up due to the complexity of engagement in social and leisure activities. The variables (n=22) were chosen within four categories, using the ICF components body function (n=8), activity/participation (n=6), personal factors (n=2) and environmental factors (n=6) (WHO, 2001). The selection was based on the literature of barriers to participation in social and leisure activities in the acute and the first years after stroke (see the Background section) and through discussions in the multidisciplinary co-author team.

Data analysis

The initial analysis consisted of investigating the relations between the dependent variable (FAI-CSC) and the independent variables separately, using Spearman's rho and the Kruskal-Wallis test. Variables that achieved the predefined statistical significant level of $p \leq 0.25$ qualified for further investigation, where we applied multiple linear regression models for each ICF-category component with the FAI-CSC as the dependent variable. Pre analysis, the independent variables were dichotomized, to create sound regression models. The dichotomizations relied on data distribution and the response categories. During analysis, a stepwise backward manner was used until only significant variables remained that is, $p < 0.05$.

In the final, multiple linear regression model the significant variables from each ICF-category were combined and calculated. The regression model was reduced in a stepwise backward manner until only significant variables remained ($p < 0.05$). Possible confounders that were checked for in the final model were stroke severity and type, cardiac disease and pre-stroke education level of the participants. We used the Shapiro-Wilk test in the final regression model to test the residuals for normality.

The Psychometric study

Participants

In the Psychometric study, the participants were recruited from a local part of the national Stroke Register (Riksstroke) from Skåne University Hospital (Malmö). The process was carried out during October 2012-February 2014. Participants were included if 6-10 months had passed since their most recent stroke, they had reported independent indoor- and outdoor mobility (with/without mobility devices) three months post stroke and were 55 years or older. Those with insufficient language skills were excluded. Potential participants were invited to the study through a postal letter. Of the 192 people that fulfilled the inclusion criteria, 51 (26.6%) were interested in participating and sent in their informed consent. However, 14 were excluded after further screening by a phone call from the author of this thesis due

to: no respond (n=4), change of mind (n=5), no time to participate due to travel (n=1), surgery (n=2) and insufficient language skills (n=2). Another two people were excluded after the baseline data collection (due to travels and could not be reached) and one after the follow-up (due to severe language difficulties that threatened the reliability of the data).

Thirty-four participants (38% women; mean age = 68.1 years) were included and completed the data collection. The sample included people with/without mobility devices, with/without impaired cognitive function and with/without depressive symptoms. All lived in ordinary housing.

Fifty-two people actively chose not to participate in the study (46% women, mean age: 71.4 years). Most common reasons were language difficulties and no energy to participate. In addition, two had not had stroke. A further 89 people (49% women, mean age 72.3 years) did not respond to our invitation.

Data collection

Data were collected on two different occasions, three weeks (± 2 weeks) apart by the same person (author of this thesis) at an outpatient clinic at Skåne University hospital (Malmö). All participants completed the data collection on both occasions with no missing data.

Instrument

In this study the psychometric properties of the General Self-Efficacy scale (GSE) was evaluated. The instrument consists of ten statements with responses scored 1–4, which gives a total score ranging from 10–40; higher scores indicate a greater sense of general self-efficacy (Schwarzer & Jerusalem, 1995). The scale is valid (Löve et al., 2012) and has been translated into Swedish (Koskinen-Hagman et al., 1999).

Data analysis

The psychometric properties, comprising targeting values and scaling assumptions as well as different reliability indices were calculated. Targeting included score distribution, floor and ceiling effects and skewness (Hobart & Cano, 2009). Ideally, the total scale range should be included in the entire sample. In addition, the total mean score should stay close to the midpoint of the scale (in this case 25). Limits of floor and ceiling effects should not exceed 15–20% and skewness should remain within ± 1 (Hobart et al., 2004). The distribution of the mean score and SD of every item was calculated (Hobart & Cano, 2009) as well as the corrected item-total correlations (ideally above 0.3) (De Vet et al., 2014; Nunnally & Bernstein, 1994) to evaluate the scaling assumptions. For reliability, internal consistency (Cronbach's alpha, α) was calculated, which should show a value between 0.7-0.9 (De Vet et al., 2014). In addition, test-retest reliability was evaluated using ICC (Mc Graw &

Wong, 1996; Shrout & Fleiss, 1979). In this case a two-way mixed ($ICC_{2,1}$) single measures with absolute agreement (McGraw & Wong, 1996) (should exceed 0.8 for group comparisons and 0.9 for individual scores) (Nunnally & Bernstein, 1994) was used. Mean difference (\bar{d}) between the two data collection occasions was measured to detect systematic or random differences. Also, the Standard Error Measurement (SEM) [$SD_{baseline} \times \sqrt{1 - \text{reliability}}$] (Streiner & Norman, 2008; Weir, 2005) and the SEM% [$SEM\% = (SEM/\text{mean}) \times 100$] (Lexell & Downham, 2005) was calculated. P-values below 0.05 was chosen as a limit for statistical significance.

Feasibility of the first version of BUS TRIPS

After working with the development element of the MRC guidelines, prior to a larger scale evaluation of a complex intervention, investigation of the feasibility (Feasibility/piloting element of the MRC guidelines) should be performed (Craig et al, 2008, Craig et al, 2006). This includes for example recruitment, compliance and delivery of the intervention. In this thesis, a first version of a new self-management intervention was feasibility tested. Different designs can be used, but methods that include both quantitative and qualitative data are favourable.

A first version of BUS TRIPS

Eva Månsson Lexell (PhD and occupational therapist) developed a first version of the new self-management intervention, named BUS TRIPS (*BUS* Travel for *Improved Participation in Stroke* survivors) (Lexell 2014, unpublished) to support stroke survivors ability of outdoor mobility and travelling by bus. The intervention was influenced by social cognitive theory (Bandura, 1997) and problem solving therapy (D'Zurilla & Nezu, 2007) and inspired by similar interventions (Shevil & Finlayson, 2009; Shevil, 2008; Londos et al., 2008) and rehabilitation interventions for people with acquired brain injury (Lindén et al., 2011). Stroke survivors and their family members, rehabilitation professionals and researchers have comment a draft of the first version of BUS TRIPS to develop the intervention further before it was used in the Feasibility study.

This version of BUS TRIPS included seven sessions (once a week), five group meetings and two individual meetings of two hours. The group meetings included short theoretical lectures of cognitive impairments after stroke and their consequences in everyday life. The discussions focused especially on travelling by bus and participation in activities in society, problem-solving theories as possible techniques to manage cognitive difficulties as well as possible devices and adaptations. The sessions included practical elements, where the participants

identified difficulties they personally experienced and formulated goals for desired activities that included travel by bus, in an individual rehabilitation plan.

During the individual meetings, each participant had the opportunity to travel together with one of the leaders (experienced occupational therapist or physiotherapist). The sessions started from the participants' individual needs in line with their rehabilitation plan and they had the opportunity to practice tasks such as walking to the bus station, solving problems related to buying tickets or finding the right bus within a real environment.

Between the sessions, the participants did homework individually, related to the topics from the previous group session. For an overview of this first version of BUS TRIPS and its content, see Table 2.

Table 2. Overview of the first version of the BUS TRIPS intervention, targeted skills, content and homework

Session no.	Target skill	Content of session	Homework
1	Self-monitoring	Introduction, cognitive disabilities after stroke, and consequences for daily life – outdoor mobility, bus travels in urban areas	Individual identification of activities problematic for outdoor mobility and bus travels
2	Goal-setting	Reviewing homework Goal plan and goal-setting	Setting goals for the intervention period
3	Problem-solving/Decision making	Problem solving theory (PST) Activity analysis and compensatory solutions (such as travel planner and mobile phones)	Use goals in rehabilitation plan – find solutions, use PST
4 & 5	Problem-solving/Decision making	Individual sessions with PT/OT ^a - use goal plan, practice technical devices walking techniques, etc	Use goals – practice strategies from individual session with PT/OTa in other activities
6	Communication	Share experiences from the individual sessions, communication	Practice communicating problems and asking for help
7	Positive thinking	Conclusion, set long-term objectives	

^aPT/OT= Physiotherapist/Occupational therapist

The Feasibility study

Participants

The Feasibility study included five participants recruited from a local part (Lund Malmö) of the national stroke register, Riksstroke. Information was sent by post to people with stroke onset 6-12 months before, who were ≥ 55 years and who had reported independent mobility indoors- and outdoors three months post stroke (n=280). Of those, 59 (21%) were interested to participate and were further screened by the author of this thesis. At this stage of the recruitment, 48 potential participants were excluded, mostly due to no difficulties in bus travelling. Finally, eleven people were selected, but five of those did not have time to participate, which left us with six people. Further, one person withdrew before the intervention had started due to

lack of energy. Accordingly, three men and two women were included (mean age = 72.2 years).

The 221 people that did not participating in the intervention were slightly older (mean age = 73.9 years) than those included. Some wrote an explanation for not being interested, where the most common reason was that they felt they had recovered from the stroke and were not experiencing difficulties in bus travel.

Data collection

The author of this thesis collected all data before, during and after the intervention. The participants met individually with the author for the baseline data collection before the intervention started. Follow-ups of the same structure were performed two weeks after the intervention had finished and again three month later. At the end of the last intervention session, a qualitative group interview was performed. In addition, data were also collected during an individual phone survey one week after discharge. Parallel with the intervention sessions, the intervention leaders wrote reflection notes after every session regarding the content and delivery of the program (from group sessions) as well as each participant's progress (from the individual sessions).

Instruments and study specific questions

At baseline several well-established instruments were used: Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2005), Craig Hospital Inventory of Environmental Factors (CHIEF) (Lund & Lexell, 2009; Whiteneck et al., 2004), GDS-20 (Gottfries et al., 1997), Timed Up & Go (TUG) (Podsiadlo & Richardson, 1991), as well as study-specific questionnaires focusing on self-rated cognitive impairment (Wendel et al., 2008) and travelling by bus.

In addition, the GSE (Schwarzer & Jerusalem, 1995), Life Satisfaction Checklist 11, item 1 (LiSat-11) (Fugl-Meyer et al., 2002), Stroke Impact Scale, part 8 (SIS) (Duncan et al., 1999) were used on all three data collection occasions (baseline, after intervention had finished and three months later). The individual phone survey consisted of structured study-specific questions about the participant's experiences of the program content and its contribution to improved outdoor mobility and travelling by bus. The group interview and the leaders' reflection notes caught qualitative aspects of the program content, delivery and the participant's progress, Table 3.

Table 3. Data collection sources, of the first version of the BUS TRIPS.

Analysis	Feasibility of content and delivery		Improved ability to travel by bus	
	Cross-case		Within-case (narratives)	
Sample	Participants (N=5)	Leaders (N=2)	Participants (N=5)	Leaders (N=2)
Method (X)	Quantitative data	Qualitative data	Quantitative data	Qualitative data
Demographics			X	
Baseline data (pre-program)				
<i>Activity and participation</i>				
Study-specific questions on walking devices, transfer possibilities, bus travels			X	
TUG ¹			X	
<i>Environmental factors</i>				
CHIEF ²			X	
<i>Cognitive impairments</i>				
MoCa ³			X	
Self-rated cognitive functional limitations ⁴			X	
<i>Depression</i>				
GDS ⁵			X	
Evaluation instruments (pre, post and follow-up)				
SIS, Participation ⁶			X	
GSE ⁷			X	
Lisat-11, item 1 ⁸			X	
Leaders' reflection notes, group sessions (during program)		X		
Leaders' reflection notes, individual sessions (during program)				X
Semi-structured group-interview (end of program)		X		X
Individual structured phone interview (post program)	X		X	

¹TUG (Timed Up and Go Test) (Podsiadlo & Richardson, 1991). ²CHIEF (Craig Hospital Inventory of Environmental Factors) (Lund & Lexell 2009; Whiteneck et al., 2004). ³MoCa (Montreal Cognitive Assessment) (Nasreddine et al., 2005). ⁴Self-rated cognitive functional limitation questionnaire (Wendel et al., 2008). ⁵GDS (Geriatric depression scale) (Gottfries et al., 1997). ⁶SIS, Participation, domain 8 (Stroke impact scale) (Duncan et al., 1999). ⁷GSE (General Self-Efficacy scale) (Koskinen-Hagman et al., 1999; Schwarzer & Jerusalem, 1995). ⁸Lisat-11, item 1 (Life Satisfaction Questionnaire-11) (Fugl-Meyer et al., 2002).

Data analysis

To investigate the feasibility of the procedures of the first version of BUS TRIPS, cross-case analysis as well as within-case analysis resulting in narratives were carried out.

To investigate the feasibility in regard of program delivery and content, a cross case analysis (Yin, 2014) was performed, where the leaders' reflections notes (from the group sessions) and the semi-structured group interview comprised the qualitative material for a deductive direct content analysis (Hsieh & Shannon, 2005). In this analysis, the starting point was taken in the two main categories; program delivery and program content. The material was read repeatedly and text units related to each

of the main categories were first compiled. The data within each of the main categories were then further analyzed into codes and sub-categories. The results were then supported by quantitative data from the phone surveys.

Using a within-case analysis (Yin, 2014), narratives were formed for each participant, embedding quantitative data into the qualitative data (Creswell & Plano Clark, 2011). Pre analyze, data were read repeatedly. All narratives had the same structure, starting by describing the participant's profile before the first version of the BUS TRIPS (baseline data). Then, goals, barriers, concerns and possible solutions during and after the first version of the BUS TRIPS were presented, based on data from the leader's reflection notes (from the individual sessions) and from the group interview. In addition, the quantitative data from the phone survey was merged with the qualitative results to give a rich description. At the end of each narrative, the results from the three instruments were merged and presented.

A step back to the development element

As demonstrated by the MRC guidelines (Craig et al., 2008, Craig et al, 2006), the process of developing and evaluating a complex intervention is not linear, but includes steps backwards and forward. Working with the Feasibility study, new research questions were raised about recruitment issues. This resulted in a step back-to examine further stroke survivors' interest and preferences with regard to stroke rehabilitation research.

The Recruitment study

Participants

In the Recruitment study, participants were recruited by means of advertisement, presentations and a patient register during September 2017 to March 2018, see Table 4.

Table 4. Recruitment modes, information channels and distribution of surveys.

Mode	Information channel	Survey distribution
Advertisement	-National Stroke Association website, Facebook (Oct-Dec 2017) and member journal (Dec 2017) -Flyers posted on boards at three local occupational therapy/physiotherapy offices in the south of Sweden	Those interested answered by phone or e-mail they wanted to receive the survey (n=38)
Presentations	-Thesis author presented the study at local stroke organization member meetings (n=5) in the south of Sweden. -Senior researcher (SI) presented the study at senior organization meetings (n=5) in the south of Sweden.	Surveys distributed in people during the presentations (n=94)
Patient register	-Lund Stroke Register (people with onset Mar 2013-Feb 2014)*	Surveys posted by mail (n=200)

*Time point was set to decrease the risk of including participants in other studies within LSR.

Inclusion criteria were at least one stroke event from age ≥ 18 years, with no upper age limit. The participants had to live in Sweden and be able to respond to a self-administrated survey in Swedish (independently or supported by someone else).

Of the total sum of 332 surveys distributed, 128 (39%) were responded to and returned. The mean age was 71 years (34-102) and 41% were women. The advertisement mode had the highest response rate (90%), followed by presentations at meetings (37%) and the patient register (30%).

In addition to the 128 responses, 16 surveys were resent. Ten of those were blank with a note, or a family member phoned to explain the non-response, which was often due to illness. As the register recruitment was implemented in a later phase than the other modes, those participants were asked to resend the survey blank if they already had responded (n=6).

Data collection

Data were collected from a self-administered survey. The participants could choose between three different administration modes; 1) paper form, returned by post, 2) online, using an attached web-address, or 3) phone interview with the author of this thesis.

Study specific questions and instruments

The survey included two parts. The first was a study-specific questionnaire. Besides from demographic aspects, it comprised ten questions on interest and preferences in rehabilitation interventions (RI) overall and rehabilitation research (RR). The participants estimated their interest in participating in RI overall on a 0-10 scale (0=not at all interested; 10=very interested), while the other questions had a multiple-choice structure, with the possibility to mark more than one response option for more of the questions. In addition, the questionnaire included an open-ended question: What do you think is important for researchers to consider when

recruiting stroke survivors to rehabilitation research? Before the data collection, the questionnaire was tested in a pilot group of five stroke survivors and revised taken into account their comments.

The survey also included three established instruments. Two topics of the SIS 2.0 (Duncan et al., 1999) were included to assess the occurrence of physical and cognitive impairments experienced. Physical issues (i.e. strength) were assessed in four questions on a 5-point scale (1=No strength at all; 5=A lot of strength), while cognitive difficulties were assessed in eight questions on a 5-point scale (1=Extremely difficult; 5=Not difficult at all). In addition, GDS-20 were included, which comprise 20 questions on a dichotomous scale (yes/no), where >5 points indicate possible depression (Gottfries et al., 1997). Finally, the GSE (Koskinen-Hagman et al., 1999; Schwarzer & Jerusalem, 1995) was included (described in the Psychometric study above).

Data analysis

Descriptive statistics was used to analyze the quantitative data. The variable “interested in participating in RR” was dichotomized before the analysis to improve the interpretability of the results. This variable was then used to make comparisons between those interested/not-interested in relation to age, sex, time since stroke, SIS domains, GSE and GDS-20, using Mann-Whitney U or Chi-square tests. Missing values were imputed using documented rules for each questionnaire (Imai et al., 2014; Schwarzer, 2014; Duncan et al., 1999). Further, Chi-square or Kruskal-Wallis tests were used for comparison between response modes and administration modes. When applicable, pairwise Mann-Whitney U test with Bonferroni correction were utilized. Statistical significance was set at $p < 0.05$. The SPSS Statistics 22.0 software (IBM Corporation, Armonk, New York, USA) was used to analyse the data. The quantitative data was complemented with data from the open-ended. The qualitative data were read repeatedly and analyzed with thematic analysis according to Braun & Clarke (2006).

Ethical considerations

In this thesis, the World Medical Association Declarations of Helsinki for research on humans were followed (World Medical Association, 2013). Beauchamp & Childress (2013) point out some overall ethical principles that has been central in this thesis; non-maleficence (do not harm), autonomy (the right for the individual to make own choices), beneficence (acting with the best interest of the other in mind) and justice (fairness and equality among individuals) (Beauchamp & Childress, 2013). However, it is difficult to not at all discomfort the participants at any sense, not the least that participation in the studies can be time consuming and include travels. Still, we have estimated the benefits of the studies to exceed these potential inconveniences and has taken actions to maintain the ethical principles.

To meet different needs, make the participants feel safe and to let them have the same opportunities, the process of the data collection in the Long-term predictor study was flexible regarding place for the interview and the possibility to bring someone that knew the person well as assistant during the interviews. Informed consent was collected, but in case the participants were confused or had sensory dysphasia, consent were provided by caregivers if they judged that it matched the participants will. The decision to let someone else answer in the participants place might be an ethical concern. However, the proxies were persons that new the participants well and the procedure allowed inclusion of a group that many times are excluded in research.

In the Psychometric study and the Feasibility study, information of the studies were sent together with a form for written consent given the opportunity to in peace consider participation autonomously. The author also called all potential participants that resent their informed consent for further screening to give repeated information and to give the participants the opportunity to ask questions. The data collection for both these studies included several instruments and study specific questionnaires. To meet potential needs of a break, the participants were offered to split the interviews to two sessions instead of one. Since both of these studies also included trips to the hospital or university settings, the participants were compensated for their travels. High attention was paid to maximize the confidentiality of the participant's records when administer those compensations. Further, to make sure everybody travelled safe, the author also offered taxi services if preferred by the participants.

To protect the participant's integrity, the data collections took place in a secluded room in the local hospital or at facilities at the university. To facilitate continuity, the intervention group sessions in the Feasibility study took place at the same secluded room. In addition, to ensure security, the participants were in companion with one of the intervention leaders (experienced occupational therapist or physiotherapist) during the individual sessions.

People with cognitive impairments are often excluded from research, which might be seen as an ethical concern. In the Feasibility study, we paid special attention to people with such impairments. However, due to the nature of their impairments, this particular valuable group might be extra difficult to recruit to studies and related to the set time and opportunity to individual support during the group sessions; those with severe cognitive impairments were not included.

The Recruitment study was a cross section survey. Potential participants called/e-mailed the author if they were interested in participate (recruitment through advertisement), received a survey (recruitment through presentations) or were sent a survey by post (recruitment through register) and approved to participate if they filled in and sent it back.

For all studies, the written information (and oral if applied) stated clearly that participation was voluntary and that the participants could withdraw at any time without any consequences. The participants were also encouraged to contact the responsible researchers if they had questions or thoughts they needed to raise.

The Regional Ethical Review Board in Lund approved all studies; Long-term predictor study (Dnr 2011/278), Psychometric and Feasibility studies (Dnr 2012/174) and Recruitment study (Dnr 2017/563).

Results

This section includes the main results of the four studies. Detailed results are provided in the respective paper (see Appendices).

Development of the first version of BUS TRIPS

Important factors for participation in social and leisure activities long-term after stroke

In the Long-term predictor study aiming to identify factors that predict participation in social and leisure activities 10 years after stroke, 20 of the 22 selected independent variables at the 16-month follow-up, were related to the dependent variable (FAI-CSC) at the 10-year follow-up. Thus, those variables qualified for inclusion in the multiple regression analysis of the four ICF components (body functions $n=8$, activities and participation $n=5$, personal factors $n=2$, environmental factors $n=5$). The main findings derived from the final multiple linear regression model where the significant independent variables from each of the ICF-category components were combined ($n=5$). Of those, four were statistically significant. Three had a positive effect on FAI-CSC: Driving a car ($B: 0.999, p=0.024$), Ability to walk a few hundred meters ($B: 1.698, p=0.001$) and Social anchorage (extent of social network) ($B: 1.235, p=0.004$), while higher age (≥ 75) had a negative effect ($B: -1.657, p<0.001$). The model had an explanatory power of 36.9%, see Table 5. No significant change was noticed in the coefficients of the final model when the potential confounders (stroke severity, stroke type, cardiac disease, recurrent stroke, and education level) were controlled for and the residuals in the final regression model were normally distributed ($p = 0.484$).

Table 5. Independent predictors of social and leisure activity frequency 10 years after stroke^a (N=145).

Predictors	B	95% CI	P
Driving a car	0.999	0.135; 1.863	0.024
Ability to walk a few hundred meters	1.698	0.738; 2.658	0.001
Extent of social network	1.235	0.396; 2.074	0.004
Age (≥ 75 years)	-1.657	-2.576; -0.738	<0.001

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

Identification of a possible instrument for use in the first version of BUS TRIPS

The GSE scale had been selected as a possible instrument to be used in forthcoming evaluations of the first version of the BUS TRIPS. Therefore, in the Psychometric study, the GSE was evaluated for its psychometric properties in a sample of stroke survivor's 6-10 months post stroke. The mean score of the GSE was 31.7 (SD 6.95), and the total scores spanned almost the whole scale range (13-40). Floor and ceiling effects were within the limits of 15-20% for total scores (0% and 8.8%, respectively), but not for each item separately. Skewness was estimated in total to -1.02 and for separate items between -1.55 to -0.33. The corrected item-total correlations were all above 0.3 except for one item (item 3), see Table 6.

Table 6. Means (SD) and corrected item total correlations (CI) for the ten GSE items, N=34.

No	Item	Mean (SD)	Corrected item-total correlation (95% CI)
1	I can always manage to solve difficult problems if I try hard enough	3.41 (0.86)	0.69 (0.46, 0.84)
2	If someone opposes me, I can find the means and ways to get what I want	3.41 (0.86)	0.55 (0.27, 0.75)
3	It is easy for me to stick to my aims and accomplish my goals	3.47 (0.71)	0.25 (-0.10, 0.54)
4	I am confident that I could deal efficiently with unexpected events	2.74 (1.02)	0.68 (0.45, 0.83)
5	Thanks to my resourcefulness, I know how to handle unforeseen situations	3.18 (1.00)	0.66 (0.42, 0.82)
6	I can remain calm when facing difficulties because I can rely on my coping abilities	3.15 (0.93)	0.52 (0.22, 0.73)
7	I can solve most problems if I invest the necessary effort	3.03 (1.00)	0.68 (0.45, 0.83)
8	When I am confronted with a problem, I can usually find several solutions	3.06 (0.85)	0.75 (0.56, 0.87)
9	If I am in trouble, I can usually think of a solution	2.94 (1.04)	0.80 (0.64, 0.90)
10	I can usually handle whatever comes my way	3.26 (0.86)	0.60 (0.32, 0.78)

Cronbach’s alpha was high (0.92) and the test-retest reliability was acceptable ($ICC_{2,1}=0.82$). The mean difference (\bar{d}) was -0.68 (n. s.) and the SEM was 2.97 (SEM%; 9.40), see Table 7.

Table 7. Reliability indices of the GSE, N=34

Index	Coefficient
Cronbach’s alpha (95% CI)	0.92 (0.86, 0.95)
ICC _{2,1} (95% CI) ^a	0.82 (0.67, 0.90)
Mean difference, \bar{d} (95% CI)	-0.68 (-2.23, 0.88)
SEM ^b	2.97
SEM% ^c	9.40

^aICC=Intra-class correlation coefficient (two-way random model, absolute agreement, single measure) ^bSEM=Standard error of measurement, defined as $SEM=SD_{baseline} \times \sqrt{(1-reliability)}$ ^cSEM%= (SEM/mean) $\times 100$

Feasibility testing of the first version of BUS TRIPS

Delivery and content of the first version of BUS TRIPS

The two main categories *Program delivery* and *Program content* formed the basis for analyzing the feasibility of the first version of the BUS TRIPS. The analysis resulted in four sub-categories, subordinate to the main categories shown in Table 8.

Table 8. Main and sub-categories of program feasibility.

Main category	Sub-category
Program delivery	-Appreciated group format despite too short sessions
	-Importance of skilled leaders and motivated participants
Program content	-Session material adequate but needs minor revision to fit target group
	-Homework is valuable but reflective group discussions must be supported

Appreciated group format despite too short sessions

The participants valued the group format, since it was a forum to meet and share experiences with others with the same difficulties as themselves. For example, one participant said, “*It is sociable and you can exchange thoughts and give each other tips*” (Kent). They were satisfied with the frequency of sessions, “*It is just what you can set aside time for*” (Carl), but they wanted the group sessions arranged closer to home. The participants did not mention dissatisfaction about the time allocation, but both leaders highlighted the importance of extending the sessions to cover all material that was planned for and to have time for breaks. In exchange, they suggested reducing the individual sessions to one instead of two. The occupational

therapy leader said, *“It is really difficult to make enough time. We probably need three hours for every session to make room for a break”*. According to the leaders, some of the sessions should change order to be more logical, for example, the communication session should be placed earlier in the program.

Importance of skilled leaders and motivated participants

The participants felt the leaders had the right skills and explained the program material in a way they understood. They appreciated the leaders’ skills and calmness, which made the participants feel secure during the individual sessions. *“She is very calm and very thoughtful, so even though it was the first time I traveled I did not feel stressed and worried. Instead I felt very calm because I felt secure with her”* (Elisabeth). The leaders expressed the importance of revising the recruitment process, as not all participants were motivated to travel by bus or expressed no problems when travelling by bus during the program, although all participants stated such interests prior to participation in the intervention. *“For some participants it was not obvious that they needed to practice travelling by bus. They experienced they could travel in other ways which worked well”* (physiotherapist leader).

Sessions material adequate but need minor revision to fit the target group

The participants ranked the program material as *good* to *very good* and stated that they had received information at a level they understood and at the right pace. Learning problem-solving skills was appreciated, though, the participants mentioned dividing larger activities into manageable tasks. Although the leaders experienced that most material worked well, *“It seemed like the participants assimilated the material, since they asked supplementary questions and shared personal experiences”* (physiotherapist leader), they stated that in the group the need for support in understanding some material was great. Further, some tasks, such as defining activity problems and goal setting, were difficult to implement in the group and should therefore have been done individually before program start up. The participants stated that some presentations were unnecessary, *“The lecture on the travel planner and cell phone did not give much, because I already knew it”* (Elisabeth). Instead, the participants lacked other aspects, such as whether they were allowed to bring an accompanying person on the bus for free, and practical use of mobility devices. Both the leaders and the participants expressed adaptation of the program material, such as printing in larger font size, as an improvement area.

Homework is valuable, but reflective group discussions must be supported

The homework tasks were appreciated, and seen as stimulating. *“It has been fun and instructive and I felt good doing it”* (Kent). Although introducing and monitoring of the homework was often successful, the leaders recommended that the presentations should also be in writing to avoid misunderstandings. Improvement to include all

participants in the homework discussions was stressed by both participants and leaders.

Possible improvements due to the first version of BUS TRIPS

In order to investigate a possible improved ability of outdoor mobility including travel by bus as well as general self-efficacy, stroke impact on participation and life satisfaction thanks to the first version of BUS TRIPS, narratives for each case (i.e., participant) were performed. Three of the participants (Elisabeth, Viola and Kent) travelled by bus during the program and two of them in particular (Elisabeth and Kent), had clear goals, identified concerns and how to handle them and managed the travel chain. Two participants (Carl and Lennart) did not travel during the program period. However, they made other progress related to outdoor mobility and the ability to travel by bus, such as seeing the benefits of travelling or were able to walk a distance independently (i.e., one link in the travel chain). Below follow examples of narratives describing two participants with different processes. For all narratives and detailed results on the instruments used (SIS, GSE and LiSat-11) before, after and at follow-up, see Appendix, Study III.

Kent

Kent lives with his wife in an apartment. He is a very slow walker and uses mobility devices indoors and outdoors. He does not have access to a car. He seldom travelled by bus prior to the stroke. Kent said access to transportation and the environment affected his participation in society. Subjectively, he reported faster tiredness, loss of concentration, and attention and memory deficits. He also reported some depressive symptoms. Kent was determined to travel by bus again, as pre-stroke when he had managed on his own: *“I will have that as a goal, to go out again and take the bus down town”* (Kent). According to the occupational therapist leader that traveled with him, Kent was concerned about his self-efficacy when travelling. His goal was to walk from home to the bus stop, to travel to the city center. Kent managed the practice trip himself, according to his plans. Afterwards, he formulated a new goal: to take the trip independently to get a haircut. Kent was satisfied with the support during the program, and expressed how it had meant a lot to him and made him feel more secure: *“It (the program) has given me incredibly much. I feel much stronger now”* (Kent). He expressed how the leader who had traveled with him (occupational therapist) was skilled, and had a personality that made him feel secure: *“She feels so knowledgeable and sends out an aura of security which I love and need”* (Kent). It was important for him to feel self-confident to travel again—an ability he now mastered: *“It’s about overcoming the fear that I don’t have to be afraid”* (Kent). The program had made him travel more by bus by himself and participate more in activities outside the home, according to the individual phone

survey. He felt he had adapted strategies during the program such as splitting up goals into targets, and learnt problem-solving skills. Kent perceived the stroke had affected his societal participation at all three data collections, especially during active leisure activities according to SIS. His general self-efficacy due to GSE was higher at discharge and follow-up than at baseline. He was very satisfied with life (according to LiSat-11, item 1) in general throughout, except for a small decrease after the program completion.

Carl

Carl lives with his wife in a single-family home. He walks slowly and uses a rollator in- and outdoors. He has access to a car but had been advised not to drive. Before the stroke, he travelled by bus about once a month. Carl identified that access to transport and the design of the environment affected his societal participation. Carl scored below normal cognition, but did not report any such impairments subjectively. He had no depressive symptoms. Although Carl stated that, he was interested in travelling by bus before the intervention started, during the program he seemed to change his mind and did not try to travel. He said: *“I don’t think I have a need for it”* (Carl). He expressed how it was difficult to change buses, and due to prior experiences he did not have confidence in the drivers. During the program, the occupational therapist leader noted that Carl needed repeated information about its purpose, and that due to lack of insight and motivation he should not have been admitted. Although Carl did not practice travelling by bus during the intervention, he expressed that the program had motivated him to try out new strategies and helped him to come closer to travelling by bus. For example, afterwards Carl expressed no fear of taking the bus: *“I don’t feel scared about it”* (Carl) and that his wife could help him with the bus card. He had also discovered advantages with travelling by bus: *“We only have 100 m to the bus stop and then the entire Skåne region within reach”* (Carl). Pre-program, Carl expressed how his stroke affected his participation in society, mostly activities together with others according to SIS. At discharge, this impact had increased, but decreased again at follow-up. His general self-efficacy increased from baseline to after program completion, but decreased below baseline at follow-up (according to GSE). Throughout, Carl felt quite satisfied with life in general at baseline, which increased to satisfied after the program and at the follow-up (according to LiSat-11, item1).

Recruitment and retention to the first version of BUS TRIPS

Retention to the intervention was high and the five participants completed the program (although one of the participants was unable to come to one session due to a holiday trip). Despite efforts to recruit participants to the intervention, only five people participated in the intervention.

A step back to the development element

The recruitment difficulties discovered in the Feasibility study prompted a move back to examine important factors when recruiting stroke survivors for RR.

Important factors when recruiting for rehabilitation research

Interest in participating in rehabilitation interventions and rehabilitation research

In the results from the Recruitment study, we found that interest in participating in RI overall was high, with a median of 7-8 (on a 0-10 scale) for different types of program. Further, the interest in participating in RR was high (82%) were more than 50% stated, “Definitely interested” and almost a third “Maybe interested”. Younger participants and those with a shorter time since stroke onset seemed to be more interested ($p=0.001$ and $p=0.047$, respectively). For details, see Table 9.

Program focus of interest regarding RR was mostly on regaining physical or cognitive functions (85%), followed by learning strategies to manage tasks and situations that can be difficult after stroke (59%). Finding new/alternative ways of performing daily activities (including provision of assistive devices/housing adaptations) were attractive for a good third (38%).

Table 9. Comparisons between those interested in RR and not ^a

Variable	Interested (n=102)	Not interested (n=23)	p-value
Gender, n (%)			
Women	44 (43)	7 (30)	0.263
Age, years			
Median	72 (34-91)	79 (63-102)	0.001**
Time since stroke^b			0.047*
0-6 month	3 (3)	-	
More than 6 months, but less than 1 year	3 (3)	1 (4)	
More than 1 year, but less than 5 years	64 (65)	21 (91)	
5 years or more	28 (29)	1 (4)	
SIS, strength^c			0.334
Median (min-max)	63 (0-100)	69 (25-100)	
SIS, cognition^c			0.708
Median (min-max)	88 (9-100)	89 (25-100)	
GSE^d			0.263
Median (min-max)	31 (10-40)	31 (12-40)	
GDS^e			0.915
Possible depression >5p, n (%)	60 (70)	12 (63)	

^aMissing, N=3. ^bDue to rounding of decimals, the total sum is lower than 100%. ^cSIS=Stroke Impact Scale (the higher proportion, the lower impact on strength/cognitive difficulties) ^dGSE=General Self-Efficacy Scale (=higher score indicates higher sense of general self-efficacy) ^eGDS=Geriatric Depression Scale

Reasons for being interested or not in rehabilitation research

Several reasons that would make the participants interested in participating in RR were reported. The most frequent were “Contribute to research and development” (69%), “Opportunity to try new rehabilitation programs” (48%) and “Meet others in the same situation” (46%), see Table 10. Reasons for *not* being interested were typically “No need for rehabilitation” (18%), “Difficulties in transporting oneself to and from rehabilitation setting” (11%), and “Insufficient energy to participate” (9%).

Table 10. Reasons that would make the participants interested in participating in RR, total sample, N=126^{a,b}

Item	%
Contribute to research and development	69
Opportunity to try new rehabilitation programs	48
Meet others in the same situation	46
Possibility of taking a break if I get tired	32
Get help to get to and from the setting, if the program is performed outside my home	22
Dissatisfaction with rehabilitation that I have received so far	19
Compensation for travel expenses and lost income	18
Investigators use an easy language	18
Possibility to bring a relative	16
Nothing, since I am not interested in participating in RR	11
Know the investigators from before	5

^aInternal missing, n=2. ^bIt was possible to choose several response options.

Information channels and administration modes

The frequencies of preferred information channels for participation in RR were postal mail (70%), personal meeting (36%), phone calls (34%), advertisement through Internet (21%), newspaper (3%) and TV/radio (3%). Qualitative results showed that RR should come closer in time after the onset of stroke, and the information should initially be directed to relatives, “*Long time since stroke limits the interest*”. Still, others underscored the importance of recruiting people in a chronic phase of stroke “*Recruit people with stroke onset a long time ago (20-30 years). Improvements occur even many years after the stroke.*”

In our study, most participants (90%) responded using the paper form, while less than a tenth responded online and less than 2% by phone. Differences due to administration mode used and gender, age or recruitment mode, did not show any significant differences.

Program form and focus

Regarding program form, the majority preferred group-based programs (in, for example, primary care, hospital or university facilities (67%)). This was also highlighted in the qualitative responses. Other program forms of interest were “Investigator makes home visits” (29%), “By phone” (19%), “Combining home

visits and phone calls” (13%), “Internet/video based, individually” (14%), “Internet/video based, in group” (3%).

Program focus of interest regarding RR was mostly on regaining physical or cognitive functions (85%), followed by learning strategies to manage tasks and situations that can be difficult after stroke (59%). Finding new/alternative ways of performing daily activities (including provision of assistive devices/housing adaptations) were attractive for a good third (38%).

In the open-ended question, “What do you think is important for researchers to consider when recruiting stroke survivors to rehabilitation research?” one theme was related to the importance of taking a broad spectrum of individual needs into account. This was related to for example different types and levels of impairments, but also regarding age and life circumstances. *“An important thing is to see the difference in age. What I, a woman not even 40 with small kids need compared to somebody newly retired or aged 80 needs when it comes to rehabilitation should differ in some respects. Not the least cognitively. ...Most people who get strokes are old and this causes trouble for us younger ones. This must be taken into consideration, so we can get help too”*. A piece of advice was to coordinate interventions with others with similar impairments but due to other diagnoses: *“Coordination can be done together with other neurological diseases, for example Parkinson’s”*. Individual needs were also related to the focus of rehabilitation interventions of interest such as *“everyday life”* and *“psychological stress”*. In addition, the participants highlighted incentives to participate in RR that is, an actual need for rehabilitation since not everyone has such needs. Another theme within the open-ended question was personal characteristics of potential participants. Those were genuine interest and motivation, but also confidence and ability to communicate: *“That they have an “ahead spirit” and want to improve their situation although the years have passed.”* and *“That they can and dare to formulate their thoughts”*. In the last theme, the participants stressed that the investigators’ approach and competence were essential, with statements like *“Kindness and patience”* and *“Do not hurry”*.

Discussion

The overall aim of this thesis was to study prerequisites for activity and participation among stroke survivors. A first goal was to gain new knowledge of factors important for participation in society for people with stroke in a long-term perspective, thereby contributing to the evidence base warranted to nurture the development of a new intervention. A second goal was to further the development of complex interventions targeting participation among stroke survivors, and investigate feasibility aspects of the first version of a new self-management intervention to support outdoor mobility including travelling by bus, targeting stroke survivors with cognitive impairments. To support the process, the MRC guidelines (Craig et al., 2008, Craig et al, 2006) for complex interventions were used. Consequently, the use of the guidelines also clarified the role of the four papers comprising the thesis. This thesis contributes with new knowledge about prerequisites for activity and participation after stroke. We identified predictors of importance for participation in social and leisure activities 10 years after stroke and gives an example of a self-management rehabilitation intervention that has the potential to support outdoor mobility ability and readiness to travel by bus, although there is still much to study before the intervention can move on to larger scale evaluations. Not the least regarding recruitment strategies and instruments used for evaluation of the intervention. The findings are discussed below.

The importance of outdoor mobility ability for activity and participation in a long-term perspective

The Long-Term predictor study showed that four aspects (Ability to walk a few hundred meters, Driving a car, Social anchorage and Age) seemed to be of particular importance for long-term frequency of social and leisure activities. Two of those (Ability to walk a few hundred meters and Driving a car) represent outdoor mobility activities. A potential reason for these results might be that outdoor mobility activities are overrepresented in the FAI-CSC. Still, the two of them have been reported as important in relation to activity and participation as well as reintegration into society after stroke in previous research (Singam et al., 2015, Combs et al., 2013; Liddle et al., 2009; Marottoli et al., 2000). Therefore, our results indicate that

difficulties in relation to outdoor mobility have not been compensated for over time. Reflecting those results in relation to international and national goals for sustainable health and participation for everyone (United Nations, 2015; Kommissionen för jämlik hälsa, 2017; prop. 2002/03:35; WHO, 2015), community accessibility is important to address to reach those goals. Our results can be useful to create prerequisites for outdoor mobility on a structural level to avoid inactivity among stroke survivors. However, also other efforts need to be made to support stroke survivors to increase their outdoor mobility ability. For example, based on our results offering driving assessments as well as information on the process of resuming driving is important (White et al., 2012). However, alternative transportation is also important, such as public transportation, which was the focus of this thesis.

Supporting outdoor mobility ability

Lessons learned regarding content and delivery of the first version of BUS TRIPS

The participants that attended to the first version of the BUS TRIPS intervention expressed the value of the group format. This confirms earlier research into which benefits of social support in such programs have been shown (Clark et al., in press; Lexell et al., 2013; Lorig & Holman, 2003). Based on the results from the Recruitment study, if invited to participate in a rehabilitation study, the highest proportion preferred group-based interventions. In addition, the importance of a broad social network for long-term social and leisure activity was shown as a significant predictor by the results of the Long-term predictor study. Having supportive social networks has been related to recovery, participation and reintegration into society after stroke (Elloker & Rhoda, 2018; Woodman et al., 2014; Knapp & Hewison, 1998; Colantonio et al., 1993), while difficulties in maintaining and gaining new social relationships have been described (Woodman et al., 2014). Therefore, it might not be a surprising result that the group-based approach was valued. The group-based form of BUS TRIPS in combination with individual sessions that let the participants practice in a real world context seems to be a successful concept, as the participants expressed the importance of the opportunity to travel together with skilled leaders. The importance of such practice has also been reported elsewhere (Ståhl & Lexell, 2018; Patterson et al., 2016). In addition, having such tailored elements within the intervention is positive since not all participants has the same needs (Trappenburg et al., 2013).

The leaders in the Feasibility study highlighted the importance of motivated participants. Especially one of the participants (Carl) had low motivation and the intervention in its current form might not have matched his needs. One can argue that his inclusion was a fail, but also a strength, since it gave important information that can be used to develop the intervention and its frames. Detecting such weak links at an early point is an important argument for investing in small-scale feasibility and pilot studies (Craig et al., 2008, Craig et al, 2006). This knowledge can be used to shape the program and individualize it even further due to different motivation levels, or to tighten up the inclusion criteria by not letting people with low motivation participate. The leaders emphasized the need to extend the time for the group sessions and that the intervention should start with an individual session for individual support to form goals. This session could also be used to evaluate the participant's motivation level and readiness to change (Prochaska & DiClemente, 2005) in order to distinguish those who have come furthest. Although, peer support within group SM interventions is related to increased motivation (Clark et al., in press), the results from the Recruitment study showed that the constellation of rehabilitation intervention groups is important. Putting people together who have needs and prerequisites that are too different from each other did not seem to be preferable. This has also been documented in the literature, showing that it is important to have peers in the group that share similar concerns and abilities as one self (Clark et al., in press). From the result of the Recruitment study researches were advised to coordinate rehabilitation interventions with different diagnoses. This result is in line with one of the key principles of the Chronic Disease Self-Management Program (CDSMP) (Jonker et al., 2009) (a well-established SM program for people with different types of chronic conditions), that is, people with different chronic diseases share comparable self-management difficulties and disease-related challenges (Jonker et al., 2009). Although there are examples of qualitative results showing benefits from keeping SM groups to specific diagnosis (Clark et al., in press), we can learn from the principles of the CDSMP and the results from the Recruitment study. SM interventions focusing on improving outdoor mobility and participation such as BUS TRIPS might be suitable for mixed diagnosis groups. Not the least since transportations difficulties regarding access to public transportation has been documented also for people with other neurological diagnosis (Ponzio et al., 2015; Hariz & Forsgren, 2011). Mixing groups with different chronic diseases might also has the potential to circumvent recruitment challenges for such programs, which will be discussed later in this thesis.

Other aspects raised by the participants and leaders regarding the content of the intervention were that the program material was on an understandable level. This is a positive result, since others have stressed the importance of using simple language (Hadidi et al., 2012) and this was also addressed by the participants in the Recruitment study. The positive opinions about the homework, where the

participants felt good and were encouraged to practice new skills in their everyday environment, confirms the SM principles (Lorig & Holman, 2003) and speaks to the overall feasibility of the first version of the BUS TRIPS intervention.

The potential to improve outdoor mobility ability

Turning to possible improvements of outdoor mobility and travel by bus among the five participants in the Feasibility study, the progress of ability varied. Elisabeth and Kent were highly motivated to travel. They were able to formulate doable goals, managed to travel by bus, and completed the whole travel chain with support from the leader who accompanied them. Although they subjectively reported cognitive impairments, according to MoCa (Nasreddine et al., 2005), they were within the range of normal cognition. This might explain why they managed better compared to the others in the group. This result might indicate that the intervention in its current form is most suitable for people that only have mild cognitive impairments. However, our intention was to focus on stroke survivors with cognitive impairments, and although not all participants travelled by bus during the intervention, all made progress in their outdoor mobility ability and readiness to travel by bus. This progress is important steps in moving towards the ability to travel since it is not always the actual tasks directly related to the bus as such that are perceived as challenging, but rather other links in the travel chain. Considering the stages of Prochaska and DiClemente's (2005) change model, our results show that all participants had developed their readiness to change.

Reflections on how to evaluate future versions of BUS TRIPS

We used a wide range of both qualitative and quantitative data in the Feasibility study. The qualitative data and data from the study specific phone survey indicated some improvements in participation and self-efficacy and such complement to established instruments might be useful in forthcoming evaluations of BUS TRIPS. However, none of the established instruments (SIS, GSE and LiSat-11, item 1) (Duncan et al., 1999; Schwarzer & Jerusalem, 1995; Koskinen-Hagman et al., 1999; Fugl-Meyer et al., 2002) did show any trends of the same progress. With a small study such as the Feasibility study, statistical conclusions cannot be drawn and it is a difficult task to evaluate a SM intervention (Boger et al., 2013; Trappenburg et al., 2013). Nevertheless, a discussion is needed to reflect on the suitability of the used instruments, not the least for future evaluations of BUS TRIPS.

SIS

Four of the participants scored lower on the SIS (Duncan et al., 1999) after the program completion, although one suggestion is that they subsequently became aware of their limited ability in outdoor mobility. The participation domain of the SIS has shown good psychometric properties (Ekstrand et al., 2018a). SIS is also one of the most used instruments for measuring participation after stroke and has shown to be linked to several domains of activity and participation in the ICF (Tse et al., 2013). Using the SIS would make it possible to compare results with other studies and the instrument should still be considered in forthcoming evaluations of future versions of BUS TRIPS.

GSE

Turning to the GSE (Schwarzer & Jerusalem, 1995; Koskinen-Hagman et al., 1999), this instrument showed overall good psychometric properties among mobile stroke survivors 6-10 months post stroke, as reported in the Psychometric study. However, some of the results need comment before discussing the use of GSE in future versions of BUS TRIPS. For example, the Internal consistency was high and comparable with such values in other populations (Scholz et al., 2002; Luszczynska et al., 2005; Nilsson et al., 2015). However, according to some authors (Streiner & Norman, 2008; De Vet et al., 2014) a value exceeding 0.9 might point to redundancy among the items in the scale. This would in turn indicate that not all items should necessarily be included in the GSE scale. This is important to keep in mind, although our value was just slightly above 0.9. Further, the test-retest value ($ICC_{2,1}$) was acceptable and in line with a sample including people with Parkinson's disease (Nilsson et al., 2015). An important aspect to reflect on for forthcoming interventions using the GSE as an outcome measure though, is that in order to show a meaningful change after the intervention, the score should increase by at least 2.97 points to exceed the measurement error at the group level.

Further, one item (item 3) did not exceed the desirable level of 0.3 in respect of corrected item total correlation. The same item has also shown a low level in other samples (Scholz et al., 2002). A suggestion is that this item has a higher abstract level than the others have and might therefore be particularly challenging to answer for people affected by a stroke. However, it would not be appropriate to exclude this item based only on the results from this study. Instead, there is a need of further research to establish such a statement. The high ceiling effects at item level are disadvantageous since they do not give room for improvements. In addition, the slightly negatively skewed score distribution has not been observed at this level in other studies (Scholz et al., 2002; Nilsson et al., 2015). In summary, the results indicate some limitations regarding the studied psychometric properties of the GSE among stroke survivors and further evaluations should be performed. However, the

overall results indicate that the scale had acceptable psychometric properties and was therefore used in the feasibility testing of the first version of BUS TRIPS.

Turning back to the use of GSE during the feasibility testing, the results did not show a positive trend compared to the scores before, two weeks after program completion and at three-month follow-up. In addition, Bandura (1997) argues that self-efficacy is related to specific tasks and is not a general phenomenon. Therefore, there is a need to consider if the GSE is the most suitable instrument for forthcoming evaluations of the intervention. An instrument that specifically catches outdoor mobility and participation SE could probably be more responsive to change. Jones et al. (2009) for example showed significant positive outcomes using a specific SE instrument, while the GSE did not show such improvements post intervention. At the time when the first version of BUS TRIPS was developed, we did not know of such an instrument and there has been a lack of instruments that can measure SE in relation to participation after stroke. However, since it is a challenge per se to find suitable instruments for use of evaluations in RR (Lejeune & Stoquart, 2015), not least with potential to capture effects following SM interventions (Boger et al., 2013) development of such instruments has gained more attention. One such is named Participation Strategies Self-Efficacy Scale (PS-SES) and has been used in participation focused SM interventions among stroke survivors (Lee et al., 2017; Wolf et al., 2016). It has shown good psychometric properties (Lee et al., 2018). The instrument covers a range of aspects with several subscales, community management among others, which would be of relevance for the evaluation of forthcoming versions of BUS TRIPS. However, currently the PS-SES has only shown short-term improvements after a SM intervention (Wolf et al., 2016).

LiSat-11

The third instrument used in the first version of BUS TRIPS was the first item in LiSat-11. Using the first item only (satisfaction with life as a whole) is common in research (Ekstrand et al., 2016; Bergström et al., 2015; Bergström et al., 2017) and new research has shown good psychometric properties for the LiSat-11 for use among people with chronic stroke (Ekstrand et al., 2018b). Life satisfaction is an important aspect to consider in rehabilitation since activity limitations and restrictions in social participation are common (Skolarus et al., 2014; Jansen et al., 2012), which in turn are aspects linked to reduced life satisfaction (Bergström et al., 2017; Hartman-Maeir et al., 2007). LiSat-11 should therefore still be considered for forthcoming evaluations.

Besides the instruments used in the first version of BUS TRIPS, an additional instrument targeting environmental aspects should be considered for inclusion in future versions of BUS TRIPS. This is further discussed in the strengths and limitations section later in this thesis.

Recruitment difficulties despite meeting stroke survivors preferences

It was a difficult task to recruit participants to the intervention, which left us with a small sample. Recruitment challenges in stroke research are not unusual. Many researcher do not reach their predetermined sample size (Sully et al., 2013) and a large number of potential participants may need to be invited. Logan et al (2014) invited more than 11 000 potential participants to reach the goal of about 500 participants in their intervention supporting outdoor mobility among stroke survivors. A possible explanation for our struggle with recruitment might be that the national stroke register that we recruited from did not, at the time of our recruitment, include information on cognitive impairments, outdoor mobility or societal participation. Instead, we had to start from a broader spectrum of stroke survivors, which for natural reasons meant a higher proportion of loss during the process. Another reason for the struggle with recruitment in our case might have to do with the nature of consequences of stroke that make the target group particularly vulnerable (Boxall et al., 2016). Health issues (Polese et al., 2017; Boxall et al., 2016), high age (Boxall et al., 2016) and inability to give informed consent (Boxall et al., 2016; Berge et al., 2016) have earlier been documented as aspects related to recruitment challenges to stroke research.

As a consequence of the recruitment difficulties in the Feasibility study, we used our experience to form new questions regarding stroke survivor' interests and preferences regarding participation in RR. These questions were stressed in the Recruitment study, where we turned directly to stroke survivors. The Recruitment study was small related to recruitment challenges, which is common for survey studies (Ekholm et al., 2009). In addition, the sample was not representative due to low level of cognitive impairments (Kapoor et al., 2017; Delavaran et al., 2017; Jokinen et al., 2015; Mellon et al., 2015) and higher level of depressive symptoms (Hacket & Pickles, 2014) than the general stroke population. Therefore, the results need to be interpreted with care. Still, the results showed that the first version of BUS TRIPS was in line with many of the preferences of the stroke survivors. For example, the participants were invited through postal mail, the intervention was formed as a group-based program where the participants had the possibility to meet others in the same situation as themselves and at the same time, it was individualized through the individual session and the opportunity to receive individual support when formulating goals. An interesting finding in the Recruitment study was that a common reason for being interested in participating in RR was the opportunity to get help with transportation to and from the rehabilitation setting. Previous research has identified lack of transportation as one aspect that challenge participant recruitment to research among stroke survivors (Polese et al., 2017; Berge et al., 2016; Boxall et al., 2016; Scianni et al., 2012). Although conclusions cannot be drawn as to why many of the participants in the Recruitment study preferred travel

support, a possible explanation is that they find transportation to be a challenge. This result would suggest that the first version of BUS TRIPS targets an important area and therefore should attract many stroke survivors. However, it can also be seen as a barrier to even attending to such an intervention.

Further, the participants in the Recruitment study highlighted the importance of skilled intervention leaders, supported by previous research (Boxall et al., 2016; Berge et al., 2016). Although potential participants for the first version of BUS TRIPS did not know of the leaders' skills during the recruitment process, those who actually attended the intervention saw them as highly competent. This may be one reason for the high attendance.

The overall results of the Recruitment study did show that there is a high level of interest among stroke survivors in participation in RR and as discussed above, many of the preferences addressed by the stroke survivors themselves were included in the recruitment process, the form and focus of the first version of the BUS TRIPS. Nevertheless, we struggled with recruitment. This paradox indicates a need for further investigation of how stroke survivors reflect regarding whether or not they want to participate in stroke RR.

Strengths and limitations

As discussed in the individual papers and to some extent already in the discussion section, there are a number of strengths and limitations in the four thesis papers. Some aspects reflecting the thesis overall and some specific aspects are discussed below.

The order of the studies

The order of the papers in this thesis is not optimal. For example, although the results from the Recruitment study showed that the first version of BUS TRIPS largely was in line with stroke survivors' preferences, having the knowledge from the Recruitment study before starting the recruitment process of the intervention would have been helpful. The knowledge could have helped us to refine inclusion criteria's and consider alternative recruitments strategies. However, this confirms how development of a complex interventions is not a linear process (Craig et al., 2008, Craig et al., 2006).

The use of the MRC guidelines

Using the MRC guidelines to support the process for developing and feasibility testing the first version of BUS TRIPS should be seen as a strength. The guidelines have reminded us of important questions of methodological nature, which increase the possibility to create robust interventions (Craig et al., 2008, Craig et al., 2006). For example, it is common that researchers refrain from provide smaller scale studies before larger evaluations (Eldrige et al., 2004). However, this is an important step in identifying weak links at an early point (McDonald et al., 2006), which was the case for our intervention regarding for example recruitment challenges, used instruments and refinement of the content and delivery. Therefore, starting with a small-scale feasibility study as we did for this thesis should be seen as a strength. We have also used both qualitative and quantitative methods (Craig et al., 2006) which have given us the opportunity to answer our research questions with rich descriptions and from different perspectives. As emphasized in the guidelines (Craig et al., 2006), user involvement have also been prominent. During the development of the first version of BUS TRIPS, the intervention was presented to stroke survivors for comments and in the Recruitment study, we turned directly to the users which should also be seen as a strength.

However, although the use of the MRC guidelines (Craig et al., 2008, Craig et al., 2006) overall is positive, there are also aspects which may be criticized. The intention of the guidelines is to support researchers to make proper decisions of methodological and practical type. However, the guidelines are not entirely clear to some points. An example is that the guidelines do not express an exact definition of a feasibility or pilot study (Craig et al., 2008, Craig et al., 2006). This can be seen as flexible, but also a concern. Researchers use the terms equivalent or see them as different things (Whitehead et al., 2014). The different interpretations might be due to the fact that none definition have gained full acceptance in the science community. However, this gives room for interpretation that can involve misunderstandings and decrease the possibility to compare results as ours with other studies.

Another observation related to this, is that it is not always easy to judge where in the process one is. As an example, we had to discuss back and forth about the Recruitment study. Was this study part of the development or the feasibility element? Since we did not focused on recruitment aspects for the BUS TRIPS explicitly, we argue that this study was included in the development element rather than the feasibility/pilot element. This did not affect our results, but as discussed above, such leeway can be seen as a limitation of stringency of the guidelines which makes it possible for researcher to interpret those in different ways, while it again makes the them more flexible.

The context of the studies

The context of the four thesis papers limits the possibility to generalize our results. Context related aspects are discussed from three different perspectives.

Geographic:

A limitation due to the context in all four studies was that the vast majority of the participants were from the south of Sweden. This restricts the possibility to draw conclusions at an international or even national level. However, the advertisement mode in the Recruitment study to some extent included participants from other parts of Sweden. This can reflect the differences regarding rehabilitation access across the country (The Swedish Stroke Register, 2018), something that is also present internationally (Hall et al., 2016).

The first version of BUS TRIPS was not only carried out in the south of Sweden, none of the participants lived in a rural area, but rather urban or sub-rural. This is important to be aware of since people in rural areas might have other prerequisites and needs in relation to outdoor mobility and public transportation, as reported for other samples (Gallagher et al, 2011; Iwarsson & Ståhl, 1999). In addition, the first version of BUS TRIPS was carried out during springtime in the south of Sweden, which might have affected our results. Not the least since snow and ice on the ground have shown to be a barrier for outdoor mobility in older people (Wennberg et al., 2009) and stroke survivors with mild cognitive impairment have stated that they avoid travelling by bus when roads are slippery (Ståhl & Lexell, 2018). In the Feasibility study, we used the CHIEF instrument (Lund & Lexell, 2009; Whiteneck et al., 2004) at baseline to describe environmental barriers for participation in activities of importance for the participants. However, due to what has been discussed above, this instrument could also be useful in forthcoming evaluations of the intervention. Therefore, an evaluation of psychometric properties of CHIEF in a stroke sample is ongoing within our research team (Carlsson et al., forthcoming).

Location and leaders:

Another context related aspect is that the first version of BUS TRIPS was carried out in a university setting and it was led by a researcher (although she also is an experienced OT) and a clinical PT. This might have affected the outcomes of our study and future evaluations should be performed in primary care and led by rehabilitation staff in those settings as intended.

Time

In the Long-Term predictor study, the many years between the 16-month and ten-year follow-up limit the generalizability of the results to other stroke samples with onset in the present time, due to the development of society regarding for example,

health care and rehabilitation. In addition, separating the consequences of stroke from normal ageing or life-changing personal events such as loss of a spouse is difficult which speaks for caution when interpreting the results. With this in mind, the predictors found in the study should be read as areas that need further investigation. For the Psychometric study the time between the two test occasions was three weeks (± 2 weeks). Two weeks has been recommended for such evaluations (Mokkink et al., 2018) and the extended time might have increased the risk of a possible change among the participants in respect of GSE.

Successful recruitment was also represented

As discussed before, challenges with participant recruitment formed a central part of this thesis, which left us with small samples that limits the possibility of generalizing the results to a larger stroke population. However, in the Long-term predictor study the researchers succeeded in reaching a large representative sample. The low rate of dropouts throughout speaks for the overall validity of the sample, which is a strength. The extensive efforts to reach potential participants and have the same researcher, who was well known for the participants, at follow-ups, were probably reasons for reaching a comprehensive population-based sample with no dropouts from the 16-month to the 10 year follow-up. In addition, an explanation for the successful recruitment might be that the researcher directly caught the participants at an early point after onset, while it might be more difficult to identify participants when time has passed and when most stroke survivors have completed their rehabilitation. Identifying potential participants is essential though and further research is needed to evaluate alternative recruitments modes to be able to reach acceptable sample sizes also for studies in a chronic phase of stroke.

Extracting items from FAI

As the instruments used in the Feasibility study has been discussed in an earlier section, the FAI used in the Long-Term predictor study also deserves a comment. Earlier research showed good psychometric properties for FAI (Piercy et al., 2000; Wade et al., 1985), although it does not meet all such criteria (Tse et al., 2013). However, in our study only a sub-domain of FAI was used. Extracting the items that actually measure social and leisure activities as we intended to evaluate increases the study's validity. Although we lean on the evidence from Norlander et al. (2016), extracting the three items is not routine and needs further evaluation to be established. Another important facet to consider is that these items only cover a few aspects of social and leisure activities, which is an implication for further research

to consider. In addition, FAI only measures frequency of activities, while future research should consider including other aspects, such as the value of the activities.

Conclusions and implications for further research

The overall conclusions of this thesis is that there are several important aspects regarding long-term frequency of social and leisure activities to consider after stroke. Stroke survivors, who are able to walk a few hundred meters, drive a car, who had a broad social network and were younger than 75 are more often engaged in social and leisure activities ten years after stroke. In order to support stroke survivors to be more active and participate in society in the long-term, a first version of the new SM intervention BUS TRIPS was developed. The intervention has potential to support the ability of outdoor mobility and readiness to travel by bus among stroke survivors with cognitive impairments. However, further revision of the program and additional considerations regarding suitable instruments for evaluation are needed. While recruitment difficulties appeared as a noteworthy challenge, the SM approach as well as the content and format of this first version of BUS TRIPS matched the preferences of stroke survivors. This is promising for future evaluations and subsequent implementation of the intervention.

Outdoor mobility (in terms of, the ability to walk a few hundred meters, drive a car), social resources and age, seems to be important factors for long-term frequency of social and leisure activities after a stroke. These four factors should be considered in research and clinic rehabilitation interventions aimed at improving participation among stroke survivors.

The GSE achieve acceptable psychometric properties among mobile stroke survivors, although additional evaluations is needed. However, if this is the most suitable instrument for evaluation of forthcoming versions of the BUS TRIPS remains to be considered. When it comes to using SIS and LiSat-11-, those instruments should still be considered as useful for evaluation of forthcoming versions of BUS TRIPS. An instrument catching environments aspects should also be added. Although none of the established instrument could catch improvement on individual level, more of the participants expressed such improvements after the first version of BUS TRIPS. Qualitative outcomes and study specific questions should therefore be used as a compliment to established instruments in evaluations of future versions of the intervention.

The first version of BUS TRIPS is feasible regarding program content and delivery but needs minor revision to meet the needs of the target group. This first version has also the potential to contribute to outdoor mobility and a readiness to travel by bus for people with stroke and cognitive impairments. Before moving forward to a larger scale pilot study, additional development and feasibility aspects needs to be studied. These include recruitment strategies and reconsiderations of instruments to be used for evaluation.

Although the Recruitment study included only a small sample and further research is needed to confirm the results, the broad range of preferences (regarding form, focus and contact modes) can guide researchers while recruiting and planning for new rehabilitation studies. More of the preferences were included in the first version of the BUS TRIPS intervention, but still it was difficult to recruit participants. The imbalance between a high interest among stroke survivors in participating in rehabilitation studies and recruitment challenges to such studies indicate a need for further investigation of how stroke survivors reflect regarding whether or not they want to participate in stroke RR.

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