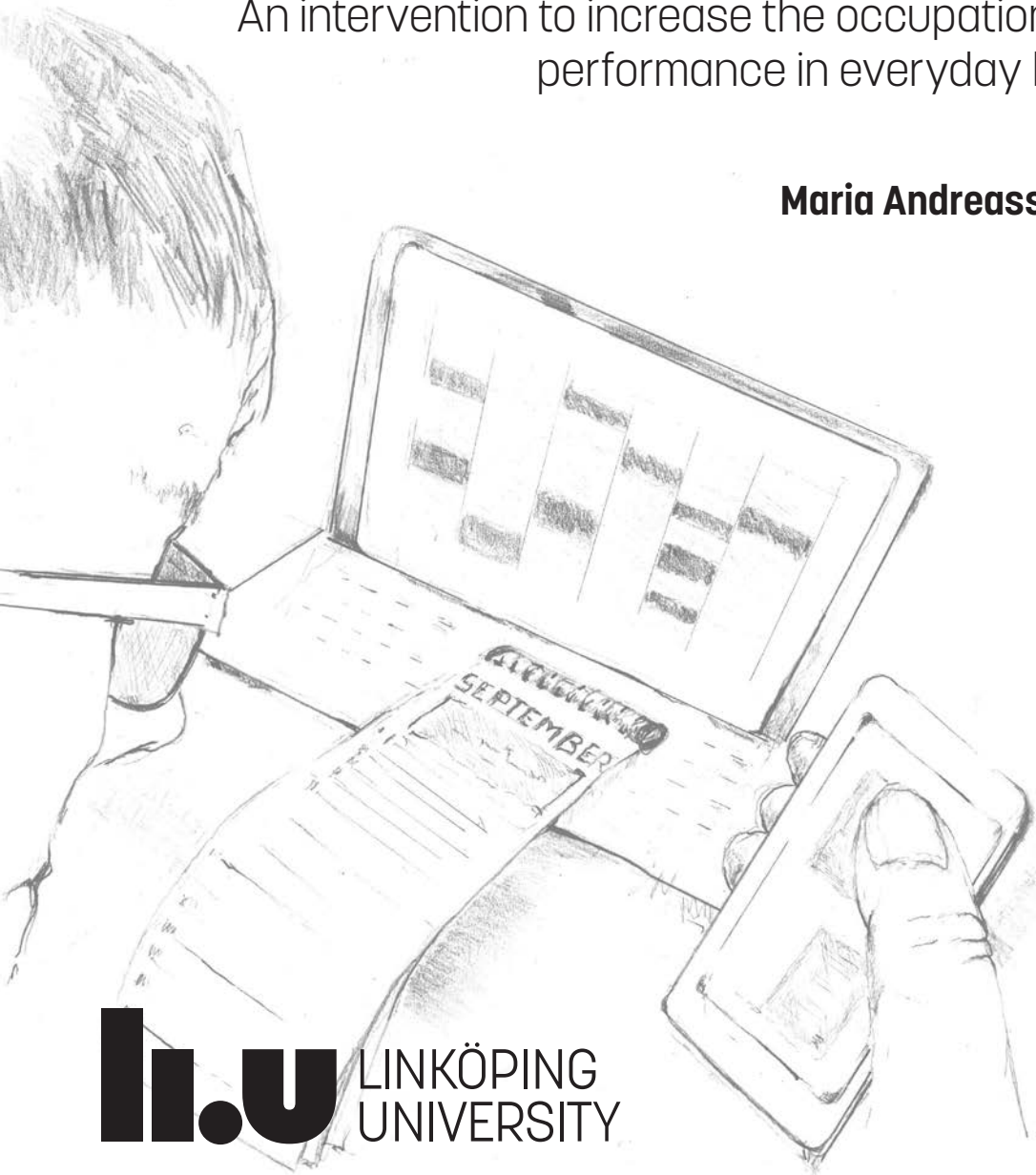


# Digital support for people with cognitive impairment:

An intervention to increase the occupational  
performance in everyday life

**Maria Andreassen**





Linköping University Medical Dissertations No.1785

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## An intervention to increase the occupational performance in everyday life

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Linköping 2021

Title: Digital support for people with cognitive impairment: An intervention to increase the occupational performance in everyday life



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Occupation is as necessary to life as food and drink,  
sick minds, sick bodies, and sick souls may be healed thru occupation

*Dunton 1919, p.10*



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# ABSTRACT

**Introduction:** Senior people with cognitive impairment may experience an inability to manage everyday life due to difficulties related to time management, and planning and structuring everyday life. These difficulties can affect people negatively, for example not remembering to carry out future planned activities. Interventions that compensate for lost cognitive ability often include using assistive technology for cognition (ATC).

By investigating the feasibility and potential effects of an intervention with the interactive digital calendar with active reminders, RemindMe, knowledge can be generated about aspects of learning to use and using digital support. Further, knowledge can also be generated about occupations in everyday life that people need to receive reminders for, both during the rehabilitation period and two years after the rehabilitation period. This knowledge can support building evidence-based interventions in rehabilitation for people with cognitive impairment using digital technology.

**Aim:** The overall aim of this thesis was to study an interactive digital calendar with mobile phone reminders (RemindMe) for people with cognitive impairment, as support to increase the occupational performance in everyday life.

**Methods:** This thesis includes four studies, using both qualitative and quantitative data collection methods.

Study I was a focus group interview, exploring twenty senior people aged between 66 and 85 and their experiences of learning to use and using RemindMe in everyday life. The seniors had used RemindMe for six weeks and had received weekly support calls from a research assistant during the study period. After six weeks, the participants took part in focus group interviews. Four focus group interviews were conducted, analysed with content analyses.

The use of RemindMe and feasibility aspects were also investigated in study II with a mixed-methods design. Eight patients with cognitive impairment, aged between 26–68, and seven occupational therapists participated. The occupational therapists were experienced in occupational therapy and were working at three different outpatient rehabilitation clinics in southeast Sweden. They had a median of 20 years of experience (range of 2–25 years). The patients received an introduction to using

RemindMe, as well as weekly support calls from occupational therapists or a research assistant for eight weeks. Quantitative data was collected using the Quebec User Evaluation of Satisfaction with Assistive Technology 2.0 (QUEST 2.0). The frequency of and the actual use of RemindMe was generated by RemindMe. Qualitative data was collected via face-to-face interviews with occupational therapists, via field notes from the weekly support conversations, and during the assessments with patients with cognitive impairment. Analyses were conducted using descriptive statistics and directive deductive content analyses.

Study III investigated the intervention with RemindMe, addressing plausible outcome measures by investigating changes in outcomes, impact on occupational performance, independence, health-related quality of life, and the psychosocial impact of support used for people with cognitive impairment. The design was a pilot randomized controlled trial with fifteen patients, with cognitive impairment, aged between 26–79, randomized to either an intervention group or a control group. The intervention group consisted of eight patients and the control group of seven patients. The outcome measures were assessed using the Canadian Occupational Performance Measure (COPM), the Functional Independence Measure (FIM), the EuroQol 5-Dimension Visual Analog Scale (EQ-5D-VAS), and the Psychosocial Impact of Assistive Devices Scale (PIADS). Study III was registered at ClinicalTrials.gov, identifier: NCT04470219.

Study IV explored seven patients, aged between 51–71, experiences of strategies and support used to establish a new everyday life and their experience of support for time management and planning and structuring everyday life due to cognitive impairment. The study was a qualitative, semi-structured, face-to-face interview. The interviews were analysed with inductive content analysis.

**Results:** The results of this thesis address learning to use and using assistive technology for cognition (ATC) in everyday life and outcomes from using RemindMe. The participants were accustomed to using calendars. However, there were differences in terms of whether they preferred to use “low tech” calendars (such as paper calendars), or “high tech” calendars (for example, digital calendars with reminders), or whether a combination of “low and high tech” was preferred (Studies I and IV). Other support strategies were also described, for example, the conscious use of objects as reminders in the home environment or everyday life routines (Study IV).

Participants were positive towards the use of digital technology, especially mobile phones/smartphones that they easily can carry with them (Studies I and IV). Participants also described the advantage of using

digital technology with active reminders and audio prompts, signalling, and telling them when to do something. This was described as the reminder “talks to me” (Study I).

The actual use of RemindMe showed that reminders were for example used for taking medication, do exercises, or meeting family or friends (Study II). Occupational therapists in Study II described that their patients benefited from using reminders and that patients have to be active in their everyday life and perceive a need for reminders. The outcomes from measurements of occupational performance (COPM) indicate that patients in the intervention group increased their occupational performance and their satisfaction with their performance compared with the control group. The intervention group also increased their independence (FIM) in the communication and social and intellectual abilities subscales (Study III).

**Conclusions:** The results indicate the importance of choosing a reminder that is suited to the patient’s needs, and this reminder can be either “low tech” or “high tech”. The important thing is that the reminder matches the patient’s needs. The result also indicates that for people with cognitive impairment to make full use of the reminder in everyday life, support with learning to use and using the device for a longer period is needed.

Participants (Studies II, III, and IV) described scheduling and receiving active reminders as important for achieving a feeling of comfort and security. Another technique was to find habits and routines or objects to support time management and planning and structuring everyday life.

Having a sense of comfort and security involved being in control of everyday life. It can be understood as people talking about being fully involved in their life situations, and in that sense as experiencing participation. However, this was not investigated in the present studies.

Two years after the rehabilitation period, digital or paper calendars were used to establish a new everyday life. Active reminders were trusted and resulted in a feeling of comfort and security as well as a sense of control and independence in everyday life.

**Keywords:** Active reminder; Assistive technology for cognition; Cognitive impairment; Digital support; Habits; Occupational Performance; Occupational therapy; Rehabilitation; Smartphone; Stroke; Time-management

# SVENSK SAMMANFATTNING

**Titel:** Digitalt stöd för personer med kognitiv funktionsnedsättning: en intervention för att öka aktivitetsutförande i vardagen.

**Bakgrund:** En neurologisk sjukdom eller skada kan medföra nedsatt kognitiv förmåga, som leder till svårighet med tidshantering, planering och strukturering av vardagliga aktiviteter. Den kognitiva funktionsnedsättningen kan innebära svårighet att komma ihåg att utföra planerade aktiviteter eller svårighet att planera och strukturera vardagen. Detta kan leda till att uppleva sig beroende av andra, vilket kan påverka den upplevda livskvaliteten.

Interventioner inom arbetsterapi har som syfte att möjliggöra att självständigt kunna utföra vardagliga aktiviteter. För att stödja en person med kognitiv funktionsnedsättning är det väsentligt att identifiera det som är viktig för den enskilde, i dennes livsmiljö. Samt att stödja de egna förmågorna, till exempel med kompenserade hjälpmedel, eller med strategier som stödjer utförande av vardagens aktiviteter.

Genom att undersöka den interaktiva digitala kalendern med aktiva mobiltelefonpåminnelser, RemindMe, och dess feasibility (genomförbarhet) för personer med kognitiv funktionsnedsättning och möjliga effekt kan kunskap genereras om, hur man lär sig att använda och att använda ett digitalt stöd i vardagen. Denna kunskap kan bidra till evidensbaserade interventioner, med digitalt stöd, vid rehabilitering för personer med kognitiv funktionsnedsättning. Denna avhandling är att undersöka om en digital kalender med aktiva påminnelser, kan stödja personer med kognitiv funktionsnedsättning, till ett mera självständigt utförande av aktiviteter i vardagen.

**Syfte:** Det övergripande syftet med denna avhandling var att studera en interaktiv digital kalender med påminnelsestöd, RemindMe, för personer med kognitiv funktionsnedsättning, som stöd för att öka aktivitetsutförande i vardagen.

**Metod:** Denna avhandling innehåller fyra delstudier med både kvalitativa och kvantitativa datainsamlingsmetoder.

Studie I bygger på fokusgruppsintervjuer som undersöker äldre personers erfarenheter av att lära sig att använda och använda RemindMe i vardagen. Deltagarna i studien var tjugo äldre personer, mellan 66 och 85 år. Deltagarna använde RemindMe i sex veckor och fick under studieperioden stödsamtal, via telefon, en gång i veckan av en forskningsassistent. Efter

sex veckor genomfördes fyra fokusgruppsintervjuer med deltagarna, intervjuerna analyserade med kvalitativ innehållsanalys.

I studie II användes en "mixed-method"-design där både kvalitativa och kvantitativa datainsamlingsmetoder användes för att undersöka användningen av RemindMe och feasibility (genomförbarhet) med interventionen. Åtta patienter med kognitiv funktionsnedsättning (mellan 26–68 år) och sju arbetsterapeuter deltog i studien. Arbetsterapeuterna arbetade på tre olika rehabiliteringskliniker inom primärvården i sydöstra Sverige. Arbetsterapeuterna hade mellan 2 och 25 års yrkeserfarenhet (median 20 år). Patienterna fick en individuell introduktion i att använda RemindMe, och använde sedan RemindMe i åtta veckor med stödsamtal en gång i veckan med arbetsterapeuten eller en forskningsassistent. Kvantitativ data insamlades med the Quebec User Evaluation of Satisfaction with Assistive Technology 2.0 (QUEST 2.0). Data om deltagarnas faktiska användning av RemindMe inhämtades via loggfunktioner i den digitala kalendern. Via loggfunktionen framgick de aktiviteter som RemindMe användes till och i vilken omfattning. Kvalitativa data insamlades via individuella intervjuer med arbetsterapeuterna på rehabiliteringsklinikerna, via fältanteckningar från veckosamtalen samt uppföljningstillfällen med patienterna. Analyser utfördes med deskriptiv statistik och kvalitativ deduktiv innehållsanalys.

Studie III undersökte om interventionen med det digitala stödet RemindMe kunde visa förändring på aktivitetsutförande, självständighet, hälsorelaterad livskvalitet och hjälpmedlets psykosociala effekter samt om mätinstrumenten var lämpliga för äldre patienter med kognitiv funktionsnedsättning. Studiens design var en randomiserad kontrollerad pilotstudie med femton patienter med kognitiv funktionsnedsättning, i ålder mellan 26–79 år. Patienterna var randomiserade till antingen interventions- eller kontrollgrupp, interventionsgruppen bestod av åtta patienter och kontrollgruppen av sju patienter. Som utfallsmått användes the Canadian Occupational Performance Measure (COPM), the Functional Independence Measure (FIM), EuroQol 5-Dimension Visual Analog Scale (EQ-5D-VAS) samt the Psychosocial Impact of Assistive Devices Scale (PIADS). Studien finns registrerad via ClinicalTrials.gov, identifierare: NCT04470219.

Studie IV undersökte erfarenheter och upplevelser av stöd för tidshantering och planering och strukturerings av vardagen, samt strategier som användes för att skapa en ny vardag. Det var sju patienter med kognitiv funktionsnedsättning, i åldrarna 51–71 år som deltog. Datainsamlingen genomfördes via kvalitativa individuella, semistrukturerade intervjuer. Intervjuerna analyserades med kvalitativ induktiv innehållsanalys.

**Resultat:** Avhandlingens resultat beskriver hur man lär sig att använda och använder en interaktiv digital kalender, RemindMe samt den faktiska

användningen av den digital kalendern och andra stöd i vardagen. Deltagarna var vana vid att använda olika typer av kalendrar. De använde "låg-teknologiska" kalendrar (som papperskalendrar) eller "hög-teknologiska" kalendrar (till exempel digitala kalendrar med påminnelse funktion) eller en kombination av låg- och högteknologiska kalendrar (studie I-IV).

Andra stödjande strategier som beskrevs var att medvetet använda sig av föremål i hemmet som påminnelser eller att använda sig av rutiner i vardagen (studie IV). Deltagarna var positiva till användningen av digital teknik, särskilt mobiltelefoner eller smartphones, som är enkelt att bära med sig (studie I-IV). Deltagarna beskrev också fördelen med att använda ett digitalt stöd som signalerar när det är dags att göra något. Detta beskrevs som att kalendern "pratar med mig" (studie I). Den faktiska användningen av RemindMe visade att påminnelser främst användes för att ta mediciner, att träna eller för att träffa familj och vänner (studie II).

Arbetsterapeuterna i studie II beskrev att patienter med kognitiv funktionsnedsättning har nytta av att använda påminnelsestöd, men en förutsättning är att patienterna är aktiva i sin vardag och upplever ett behov av påminnelser, för att ha nytta av dem. Resultaten från mätningar av aktivitetsutförandet med COPM visade att patienterna i interventionsgruppen ökade skattningen av sitt aktivitetsutförande och sin tillfredsställelse med aktivitetsutförandet, i jämförelse med kontrollgruppen. Interventionsgruppen ökade också sin självständighet (FIM) i delskalorna för kommunikation och sociala och intellektuella förmågor (studie III).

**Slutsats:** Avhandlingens resultat visar på vikten av att välja ett påminnelsestöd som passar det individuella behovet och att påminnelsestödet kan vara antingen låg- eller högteknologiskt. Det viktiga är att påminnelsestödet matchar personens behov. Resultatet indikerar att för att få bäst nytta av ett påminnelsestöd i vardagen, så behövs stöd i att lära sig att använda det och stöd i användningen samt att stödet ges under en längre period. En annan strategi var att hitta vanor och rutiner eller objekt som stödjer tidshantering och planering och strukturering av vardagen. Deltagarna (studierna II-IV) beskrev att påminnelser med ljudsignaler kan ge en känsla av trygghet och säkerhet.

Att ha en känsla av trygghet i sin vardag kan förstås som att deltagarna uttrycker att de har kontroll på sin vardag, är involverade i sin livssituation och på så sätt upplever delaktighet. Detta undersöktes dock inte i de aktuella studierna. Två år efter rehabiliteringsperioden beskrev deltagarna att de använde aktiva påminnelse, digitala kalendrar och/eller papperskalendrar. De använde dem för att skapa sig en ny vardag med en känsla av trygghet och säkerhet, i vardagen.

## LIST OF PAPERS

This thesis is based on the following papers, which will be referred to in the text by their Roman numerals.

- I. Baric V, Andreassen M, Öhman A, Hemmingsson H. Using an interactive digital calendar with mobile phone reminders by senior people-a focus group study. *BMC Geriatr.* 2019;19:1-11.
- II. Andreassen M, Hemmingsson H, Boman IL, Danielsson H, Jaarsma T. Feasibility of an Intervention for Patients with Cognitive Impairment Using an Interactive Digital Calendar with Mobile Phone Reminders (RemindMe) to Improve the Performance of Activities in Everyday Life. *Int J Environ Res Publ Health.* 2020;17(7):2222.
- III. Andreassen M, Danielsson H, Hemmingsson H, Jaarsma T. An interactive digital calendar with mobile phone reminders (RemindMe) for people with cognitive impairment: a pilot randomized controlled trial. *Scandinavian Journal of Occupational Therapy,* 2021;1-12.
- IV. Andreassen M, Hemmingsson H, Danielsson H, Jaarsma T. Experiences of using support for time management for people with cognitive impairment: an interview study (manuscript)

## ABBREVIATIONS

ATC	Assistive Technology for Cognition
CMOP	The Canadian Model of Occupational Performance
CONSORT	Consolidated Standards of Reporting Trials
COPM	The Canadian Occupational Performance Measure
COREQ	Consolidated Criteria for Reporting Qualitative research
EQ-5D-VAS	EuroQol 5 Dimension Visual Analogue Scale
FIM	The Functional Independence Measure
ICF	The International Classification of Functioning, Disability, and Health
MRC	Medical Research Council
MS	Multiple Sclerosis
OT	Occupational therapist
PDA	Personal Data Assistants
PIADS	Psychosocial Impact of Assistive Devices Scale
PRO	The Swedish National Pensioners' Organization
QUEST	Quebec User Evaluation of Satisfaction with Assistive Technology
RCT	Randomised Controlled trial
SMS	Short Message Service
SPT	Subject Performed Task
TBI	Traumatic Brain Injury
TMT	Trail Making Test
WHO	The World Health Organization



# PREFACE

The Ph.D.journey is coming to its end, and it is time for reflection.

I have been an occupational therapist for over 30 years. Most of that time I have worked in the municipality, meeting elderly people living in special housing, and over the years it has entailed me to get insight into their everyday life. A frequent part of my everyday work has been to conduct assessments of occupational performance, mainly within self-care activities. These assessments often resulted in prescriptions of assistive technology to compensate for occupational restrictions within mobility, transportation, or personal hygiene. However, the assessments rarely led to prescriptions of assistive technology for cognition.

This Ph.D. project has allowed me to develop and deepen my knowledge within the field of cognition, assistive technology for cognition, and digital support. Especially concerning conditions for senior people with cognitive impairment, and the importance of support in everyday life. But also the importance of having robust habits and routines in everyday life. During the journey in this project, questions have been answered and new questions have been raised. Understanding of phenomenon and concepts has evolved, changed, but also become clearer over time. The result of the journey is put together in this thesis.

*Linköping, July 2021*

*Maria Andreassen*

# INTRODUCTION

Cognitive impairments due to neurological disease are most often invisible to others. However, for people who experience these challenges, they are present in most of the occupations performed in everyday life. Neurological injuries or diseases affect many people and yearly a large number of persons are newly diagnosed. Nevertheless, treatment is improving and more people survive from neurological disease or injury. This means that people will live with their impairments for many years. Today's digital technology developments are promising, and a lot of technology can compensate for impaired cognitive abilities, for example, technology including digital calendars or reminders. This technology may enhance the possibility for people with cognitive impairment to perform occupations in everyday life and become more independent. Research that is based on the real-life conditions of people with cognitive impairment is required. This thesis has a special focus on senior people with cognitive impairment due to neurological disease or injury and their everyday lives.

## Everyday life and occupational performance

In the process of completing this thesis understanding of theoretical frameworks has evolved. And as a theoretical framework to understand concepts related to everyday life the Canadian Model of Occupational Performance (CMOP) (Townsend & Polatajko, 2013) is used. Everyday life consists of the occupations and activities that people perform, such as self-care activities, going to work or enjoying leisure activities. From an occupational therapy perspective, the performance of everyday life occupations is crucial for people to experience health. Occupations that people chose to do derives from people's actual abilities, but also from their subjective experiences of what is important in their lives and the environment (Taylor, 2017; Townsend & Polatajko, 2013). However, what specifically affects the perception of health is an individual experience.

To explain the importance of everyday life occupations, the CMOP (Townsend & Polatajko, 2013) uses the core constructs of person, occupation and environment. Occupational performance is the result of the interaction between the person and the environment. For example for people with difficulties concentrating and focus, an environment with reduced stimuli offers better opportunities for occupational performance (Gillen, 2015). It is in the environment that people are offered various occupational opportunities, and people's performance components

(physical, affective or cognitive) have an impact on their occupational performance. In CMOP, there is a particular emphasis on the person's spirituality as the core that explains people's motivation, interests and occupational choices. Spirituality is people's drive, and in conjunction with their environment is what gives meaning to people's occupations (Townsend & Polatajko, 2013). The variety of occupations that occur in everyday life are divided into, self-care activities, productivity, and leisure (Townsend & Polatajko, 2013). People's habits and routines are also important, as they often simplify everyday life and ensure that effort is not needed in every activity performed during a day (Taylor, 2017).

Another aspect affecting people's perceptions of health is participation. Participation is explained by the International Classification of Functioning, Disability, and Health (ICF) as a person's engagement in a life situation and a prerequisite for health and well-being (WHO, 2001). However, the importance of participation is unique to each individual and depends on people's motivations, roles and habits (Taylor, 2017). Participation can also be affected by the environment, which can hinder or support participation. Participation can be facilitated by various forms of support in the environment (Taylor, 2017), for example, a positive social atmosphere, an adapted environment, or assistive technology. According to the World Health Organization (WHO) (WHO, 2020), assistive devices have the potential to improve people's functioning, independence, and well-being for senior people and people with disabilities, and therefore contribute to participation.

## Cognitive impairment

In 2019, about 27 000 people in Sweden suffered stroke (The National Board of Health and Welfare, 2019) and approximately 7000 suffered traumatic brain injury (TBI) (The National Board of Health and Welfare, 2019). Stroke usually affects senior people, and 74% of those who suffered stroke in Sweden in 2019 were aged 70 or older (The National Board of Health and Welfare, 2019). Impairments caused by stroke, traumatic brain injury or other neurological diseases affect the brain tissue, and depending on their location these impairments can be physical and/or cognitive (Gillen, 2015; Hedges, Farrer, Bigler, & Hopkins, 2019; Langhorne, Bernhardt, & Kwakkel, 2011; Stephens, Williamson, & Berryhill, 2015).

There is a huge variation in the consequences of cognitive impairments and how people are affected (Hedges et al., 2019), depending on factors as location, severity and age (Gillen, 2015). Therefore, it is advantageous to address cognitive impairments based on their type of impairment instead

of focusing on specific diagnoses (O'Neill & Gillespie, 2015). This thesis has focused on cognitive impairments related to difficulties in everyday life due to higher-level cognitive functions (WHO, 2001). Higher-level cognitive functions include abstraction, organization and planning, time management, cognitive flexibility, insight, judgment and problem-solving (Gillespie, Best, & O'Neill, 2012). Taking the initiative for, planning, and structuring everyday life occupations can also be referred to as executive functioning. Time management, or remembering to carry out future planned occupations, can also be referred to as prospective memory (Gillen, 2015; Hedges et al., 2019).

Having cognitive impairment and reduced executive functioning and time management can result in not being able to manage everyday life, having difficulties finding strategies that compensate for lost ability, a sense of being dependent on family and friends, or experiences of not having control of everyday life occupations (Langhorne et al., 2011; Stephens et al., 2015). These consequences of cognitive impairment can reduce participation and affect possibilities to handle and perform everyday life occupations relating to self-care, leisure or productivity, for example being unable to independently administer medication intake, attend an exercise class or manage work-related activities (Taylor, 2017; Townsend & Polatajko, 2013). People with impairments, due to stroke, traumatic brain injury, or other neurological diseases, expressed various aspects that affect the experience of participation (Hammel et al., 2008; Toglia, Askin, Gerber, Jaywant, & O'Dell, 2019). They pointed out the importance of everyday life with active and meaningful engagement, having access and opportunities to participate in society, feeling safe and secure, being able to make choices and being in control of their life situation (Hammel et al., 2008).

Mental fatigue can also be aligned with cognitive impairment. Mental fatigue is characterized by overwhelming tiredness affecting occupational performance in everyday life since people do not have enough concentration and endurance. Mental fatigue is often confused with cognitive impairment, and it can be difficult to distinguish between the two (Penner & Paul, 2017; Tremayne, Freeman, & Coppola, 2021).

## **Rehabilitation and occupational therapy**

People who have had an impairment due to a neurological disease or injury often need rehabilitation services to regain their abilities and to become active in everyday life (Gillen, 2015). The brain repairs itself to some extent, but full recovery is also dependent on rehabilitation interventions. Rehabilitation interventions start early on in hospital and after admission, it is advised that rehabilitation continues at outpatient clinics.

Rehabilitation interventions for people with cognitive impairment are complex since they include several components and training rarely affects only one cognitive component since several components interact. (Langhorne et al., 2011; Stephens et al., 2015).

Rehabilitation interventions usually support the recovery of lost abilities in conjunction with interventions that compensate for lost abilities (Strobach & Karbach, 2020). When training a single ability such as prospective memory using a computer program, it can be difficult to generalize the individual ability into everyday life (Strobach & Karbach, 2020). Therefore, it is an advantage if the rehabilitation of cognitive impairments is incorporated into and based on people's everyday life occupations in their natural environment (Guidetti, Eriksson, von Koch, Johansson, & Tham, 2020; Swanton et al., 2020). This appears to be most effective in terms of improving cognitive abilities (Strobach & Karbach, 2020) together with coping strategies (Langhorne et al., 2011; Stephens et al., 2015). Interventions that compensate for lost cognitive ability often include using assistive technology for cognition (ATC) (Brandt, Jensen, Sørberg, Andersen, & Sund, 2020; Gillespie et al., 2012; O'Neill & Gillespie, 2015) or finding strategies to use from everyday life (Swanton et al., 2020). The Archives of Physical Medicine and Rehabilitation (ACRM) (Cicerone et al., 2019) emphasise that rehabilitation interventions for people with cognitive impairment derive from and support them in their everyday life.

## Assistive technology for cognition (ATC)

Assistive technology for cognition (ATC) refers to technologies that support cognitive abilities and thus enable people to become independent and participate in their everyday life, ATC can be “low tech” devices or “high tech” devices (O'Neill & Gillespie, 2015). Examples of “low tech” devices are paper, notebooks, or paper calendars, in this thesis, are “low tech” devices are also referred to as passive reminders following the definition by McDonald (2011). “High tech” devices, are for example digital calendars that often include reminders, in this thesis these devices are also referred to as active reminders following the definition by McDonald (2011). “High tech” devices often offer the user an alarm with sound and often a text message (Boman, Persson, & Bartfai, 2016; Brandt et al., 2020; Evald, 2018; Guidetti, Gustavsson, et al., 2020; McDonald et al., 2011; O'Neill & Gillespie, 2015) that alerts the user when it is time for an activity to occur. When advising and suggesting an assistive device, it is important to match the person's needs with the suggested technology via a thorough needs assessment (O'Neill & Gillespie, 2015; Scherer, 2019).

Several technical tools and systems have been developed to offer people with cognitive impairment different types of support, for example,

reminders via personal data assistants (PDAs), pagers, and other technical systems (Brandt et al., 2020; Lannin et al., 2014), as well as using a short message service (SMS) to send text messages to their mobile phones (Boman, Bartfai, Borell, Tham, & Hemmingsson, 2010; de Joode et al., 2012; Fors, Kamwesiga, Eriksson, von Koch, & Guidetti, 2019; Pijnenborg et al., 2010; Rathbone & Prescott, 2017). Mobile phones or smartphones have been found to have a better potential to support people with cognitive impairment in performing everyday life occupations (Brandt et al., 2020; Evald, 2018; Strobach & Karbach, 2020) compared to traditional compensatory strategies.

The disadvantages of certain technical solutions include requiring a specific technical device or a certain brand of mobile phone/smartphone or being linked to a specific personal computer (LoPresti, Simpson, Kirsch, Schreckenghost, & Hayashi, 2008). Off-the-shelf digital technology, such as a mobile phone or a smartphone, can be difficult for people with cognitive impairment to use due to their design being too complicated (Choudrie, Pheeraphuttrangkoon, & Davari, 2020). Another issue is that elderly people can have difficulties using technical devices due to small mobile phone buttons or problems operating a touch screen on a smartphone (O'Neill & Gillespie, 2015) or experience fear of using digital technology (Hill, Betts, & Gardner, 2015; Nimrod, 2018). Aspects that can increase support include encouraging active handling, for example, responding to a reminder and the possibility to save data history (Baric, Tegelström, Ekblad, & Hemmingsson, 2015). Therefore, there is a need for user-friendly calendars with active reminders to support everyday life occupations.

## **RemindMe and the core functions**

RemindMe was developed in 2012 as a user-friendly, cost-effective interactive digital calendar with mobile phone reminders for people with cognitive impairment. Initially, the focus was on supporting adolescents with neuropsychological impairments in everyday life occupations. During the development process, an interdisciplinary team of computer scientists and occupational therapy researchers at Linköping University used the technology available to most people, i.e., computers/tablets, mobile phones and digital calendars without links to specific technical devices or specific brands. The development work was conducted with three core functions in mind: easy and interactive scheduling, active reminders with audio prompts and active conformation, and interactive self-monitoring information (Baric et al., 2015). The emphasis was on designing RemindMe with a simple, clean design, and without unnecessary information or pop-up windows that can distract the user.

Usability testing was first conducted with people of various ages without disabilities. In the second step, usability was evaluated with young adults with cognitive impairments and the staff who support them in everyday life occupations (Baric et al., 2015). After the initial usability testing, adjustments were made so that RemindMe would have a user-friendly, simple layout and an easily administered web-based calendar. In RemindMe, it is the user who has access to the calendar and schedules activities. However, for users who need support, it is possible to invite and give a support person access to RemindMe and its components.

In RemindMe's web-based calendar activities such as making a daily phone call, attend a meeting with family or friends, going to the dentist, taking medication, or going to the gym are registered by the user. All planned activities are shown in purple on the calendar. A reminder for the registered activity can be programmed in a dialogue box. The user decides on the reminder text and when to receive it. RemindMe is not linked to any specific computer and works with all mobile phones/smartphones (Baric, Andreassen, Öhman, & Hemmingsson, 2019; Baric et al., 2015). Figure 1 shows the web-based calendar and the dialogue box.

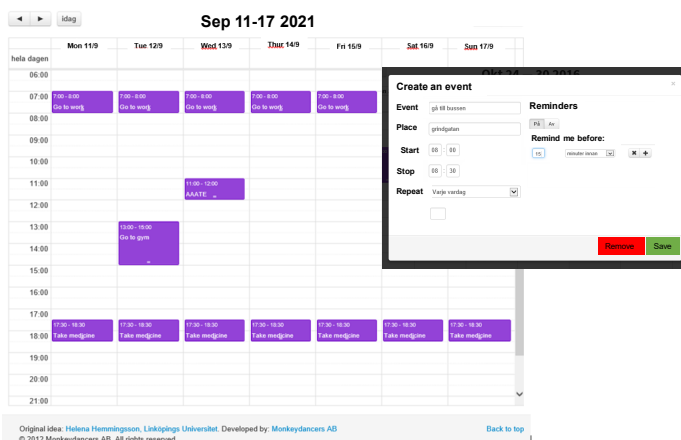


Figure 1: The web-based calendar in which activities are scheduled and a dialogue box in which reminders are set.

The reminder is sent by SMS to the user's mobile phone/smartphone. The SMS reminds the user what to do and when to do it. The user can confirm whether or not the activity will be performed by responding with an SMS saying "Yes" or "No" together with a four-digit code. The function of the four-digit code is to link the response SMS to the scheduled activity in the calendar (Baric et al., 2019; Baric et al., 2015).

The scheduled activities and the responses (yes or no) are logged in the interactive web-based calendar. In the calendar, "Yes" responses are shown

in green, “No” responses are shown in red and unanswered reminders are shown in grey. This allows for self-monitoring since the user can visualize whether or not an activity has been performed (Baric et al., 2019; Baric et al., 2015), see Figure 2.

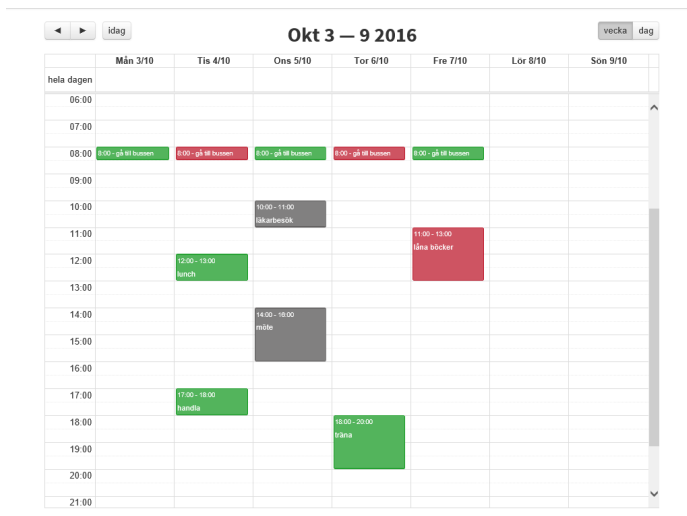


Figure 2: In the web-based calendar are the scheduled activities and the responses (yes or no) logged.

## Rationale

This thesis investigates digital support, for senior people with cognitive impairment using an interactive digital calendar, RemindMe, in everyday life occupations. People with cognitive impairment can experience being unable to manage everyday life, and this can affect people negatively in several ways. For example, it may result in a feeling of having lost control of everyday life and having become dependent on other people. Enhanced occupational performance can be one aspect that increases the perception of being independent and affects a person's perception of participation. By investigating the feasibility and potential effect for senior people with cognitive impairment of using RemindMe in everyday life, knowledge can be generated about aspects of learning to use and using digital support. Further, knowledge about everyday life occupations for which people with cognitive impairment need to receive reminders during both the rehabilitation period and two years following the rehabilitation period can be generated. This knowledge can help to build evidence-based occupational therapy interventions in rehabilitation for people with cognitive impairment using digital technology.



## Aims

The overall aim of this thesis was to study an interactive digital calendar with mobile phone reminders (RemindMe) for people with cognitive impairment, as support to increase the occupational performance in everyday life.

The aims of the included studies were:

- to explore senior peoples' experiences of learning and using RemindMe, an interactive digital calendar with mobile phone reminders (Study I).
- to investigate the feasibility of an intervention for patients with cognitive impairment using an interactive digital calendar with mobile phone reminders (RemindMe) as a support for the performance of activities in everyday life (Study II).
- to investigate the use of an intervention with an interactive digital calendar with mobile phone reminders (RemindMe) in relation to change in outcomes and impact on occupational performance, independence, health-related quality of life, and psychosocial impact of the support for people with cognitive impairment (Study III).
- to explore experiences of strategies and support used to establish a new everyday life by people with experience of support for time management and planning and structuring everyday life due to cognitive impairment (Study IV).

# METHOD

## Design

Four studies are included in this thesis, using both qualitative and quantitative study design, Table 1, gives an overview of the four studies included in this thesis.

Study I was a focus group interview study that explored community-dwelling seniors' experiences from learning to use and using RemindMe. They had used RemindMe for six weeks before participating in a focus group interview. Experiences from this study supported the development of an intervention with RemindMe which was appropriate for senior people with cognitive impairment.

Study II was a feasibility study with a mixed-methods design and with a focus on using RemindMe in everyday life from the perspective of patients with cognitive impairment and their occupational therapists.

Study III was a pilot randomized controlled trial (RCT) concerning outcomes of using RemindMe. The study investigated plausible outcome measures by investigating changes in outcomes and impact on occupational performance, independence, and health-related quality of life, as well as the psychosocial impact of the support for patients with cognitive impairment. Study III was registered at ClinicalTrials.gov, identifier: NCT04470219.

Study IV was a semi-structured interview study that explored the long-term experiences of digital support and other strategies to establish a new everyday life from patients with cognitive impairment.

Table 1. Overview of the four studies included in this thesis:

Studies	Design	Participants	Data collection methods	Analysis
I	Focus group interview study	20 community-dwelling seniors	Four focus group interviews	Inductive content analysis
II	Feasibility study	Eight patients with cognitive impairment Seven occupational therapists	Quantitative data from QUEST 2.0 <sup>1</sup> and frequency of and actual use of RemindMe. Qualitative data collected from face-to-face interviews with occupational therapists and field notes from assessments with patients with cognitive impairment.	Descriptive statistics Directed deductive content analyses
III	Pilot RCT study	15 patients with cognitive impairment	Patients' demographics were collected from medical records and a survey. Patients' cognitive ability was assessed with SPT <sup>2</sup> and TMT <sup>3</sup> . The outcome measure was assessed with; COPM <sup>4</sup> , FIM <sup>5</sup> , EQ-5D-VAS <sup>6</sup> , and PIADS <sup>7</sup>	Descriptive statistical analyses, nonparametric statistical analysis.
IV	Interview study	Seven patients with cognitive impairment	Semi-structured face-to-face interviews	Inductive content analysis

1QUEST 2.0: Quebec User Evaluation of Satisfaction with Assistive Technology 2.0; 2SPT: Subject performed task; 3TMT: Trail Making Test; 4COPM: The Canadian Occupational Performance Measure; 5FIM: The Functional Independence Measure; 6EQ-5D-VAS: EuroQol 5 Dimension Visual Analogue Scale; 7PIADS: Psychosocial Impact of Assistive Devices Scale.

## Sampling

For Study I participants were recruited from the Swedish National Pensioners' Organization (PRO). For Studies II-IV participants (patients and occupational therapists) were recruited from three outpatient rehabilitation clinics for neurological rehabilitation. Figure 3 displays the four studies and their samples.

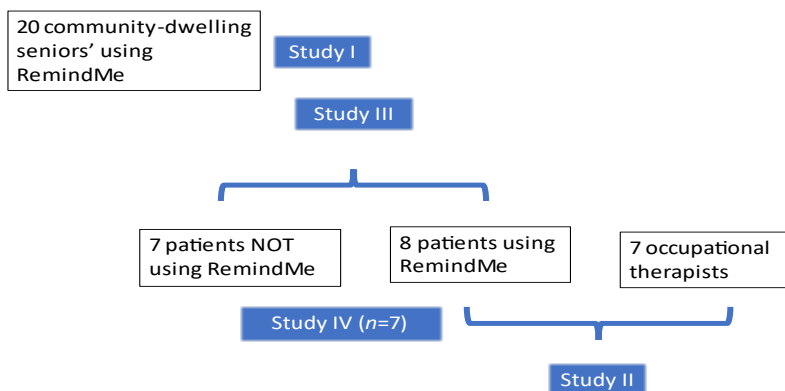


Figure 3. Illustration of the four studies and their sampling.

## Participants

In Study I, convenience sampling (Polit & Beck, 2016) was used to recruit participants. Inclusion criteria were being aged 65 or older, having access to a mobile phone/smartphone and a computer/tablet, and being interested in using RemindMe for six weeks and thereafter participating in a focus group interview. The participants were members of the Swedish National Pensioners' Organization (PRO) and were informed of the study via member meetings. Volunteers participated in the research projects investigating and developing digital technology for elderly people. Twenty community-dwelling seniors volunteered to participate in Study I. For characteristics of the sample, see Table 2.

Studies II and III had the same recruitment process. Patients with cognitive impairment were consecutively recruited (Polit & Beck, 2016) by occupational therapists at three different rehabilitation clinics in southeast Sweden. Inclusion criteria were having neurological disease or injury and experiencing a need for support with planning, organizing and remembering to do everyday life occupations (time management), having access to a computer/tablet and a mobile phone/smartphone, and having sufficient linguistic skills to participate in data collection. Patients were randomized to either a control group or an intervention group.

Study II included patients with cognitive impairment (from the intervention group in Study III) and occupational therapists at the rehabilitation clinics. Inclusion criteria for patients were having participated in the intervention group of the pilot RCT study (Study III). Eight patients with cognitive impairment who had used RemindMe participated in Study II. For patient characteristics, see Table 2. Seven occupational therapists also participated in Study II. The inclusion criterion for the occupational therapists was that they had recruited patients to the study. The seven occupational therapists worked at three different rehabilitation clinics in southeast Sweden for neurological rehabilitation of outpatients with cognitive impairment. Five of the occupational therapists had a bachelor's degree in occupational therapy and two had a bachelor's degree in occupational therapy with one year of postgraduate education. The occupational therapists were experienced and had a median of 20 years (range 2-25 years) of experience working in the profession.

Fifteen patients with cognitive impairment participated in Study III, and they were recruited from the three rehabilitation clinics in southeast

Sweden for neurological rehabilitation of outpatients with cognitive impairment. For patient characteristics, see Table 2. The patients were randomized to either the intervention group ( $n=8$ ) or the control group ( $n=7$ ).

Study IV used convenient sampling (Polit & Beck, 2016). Inclusion criteria were participation in Study III and the ability to express experiences in an interview. Seven patients from Study III, participated in Study IV, independent of group assignment. See Table 2 for characteristics of participants.

Table 2. Characteristics of participants in Studies I-IV. Frequencies are presented in median (M), range (Range) and numbers ( $n$ ) of the total sample (N).

Characteristic	Study I N = 20	Study II N = 8 **	Study III N = 15	Study IV N = 7
<b>Age</b> years: M(Range)	73(66-85)	58(26-68)	59(26-79)	61(51-71)
<b>Gender</b> $n(N)$				
Female	9(20)	2(8)	3(15)	2(7)
Male	11(20)	6(8)	12(15)	5(7)
<b>Education</b> $n(N)$				
Compulsory school	7(20)	1(8)	3(15)	0
Upper secondary school	5(20)	6(8)	10(15)	6(7)
University	8(20)	1(8)	2(15)	1(7)
<b>Domestic status</b> $n(N)$				
Single	4(20)	2(8)	4(15)	1(7)
Living with partner	11(20)	6(8)	11(15)	6(7)
Having a partner but living apart	3(20)	0	0	0
<b>Technology use</b> $n(N)$				
Daily/weekly computer use	11(20)	4(8)	9(15)	***
Daily/weekly mobile phone use	17(20)	8(8)	15(15)	7(7)
<b>Diagnosis</b> $n(N)$	*			
Stroke		4(8)	6(15)	4(7)
Traumatic brain injury		2(8)	4(15)	2(7)
Sepsis		1(8)	1(15)	0
Multiple sclerosis		1(8)	1(15)	1(7)
Parkinsons disease		0	2(15)	0
Aneurysm		0	1(15)	0
<b>Working condition</b> $n(N)$				
Retired	20(20)	3(8)	7(15)	4(7)
Sick leave	0	4(8)	6(15)	0
Working	0	1(8)	2(15)	3(7)

\* In Study I participants were recruited based on membership of PRO and diagnosis data were not collected.

\*\*Eight patients and seven occupational therapists participated in Study II. Occupational therapist characteristics are described in the text above.

\*\*\*Data regarding computer use was not collected in Study IV.

## Data collection methods

### Study I

#### ***Focus group interview***

The focus group interview in Study I followed an interview guide with questions to investigate community-dwelling seniors' experiences of challenges and benefits in connection with learning to use and using RemindMe. The interview guide included question areas to describe experiences of using RemindMe, experiences of the core functions, and experiences of receiving weekly support. The questions were asked by the moderator and the community-dwelling seniors were encouraged to discuss the questions with each other. Probing questions were asked by the moderator and the assistant moderator. Examples of probing questions include "Please tell me more about...", "Can you give an example..." and "You mentioned earlier..."

### Studies II and III

#### ***Quantitative data collection***

Quantitative data collection methods were used in Study II and Study III. Table 3 gives an overview of the measurements used. Outcome measurements were chosen to measure the change in outcomes for activity and participation variables and to assess the outcomes of using assistive technology. Outcome measurements are used in occupational therapy research and are perceived to be sufficiently sensitive to assess differences and reduce the risk of ceiling effects.

Table 3. Overview of data and measurements for Studies II and III.

	Baseline	2 months	4 months
<b>Background demographics:</b>			
Demographic data computer and mobile phone skills	X		
Cognitive ability (SPT <sup>1</sup> , TMT <sup>2</sup> )	X		
<b>Outcome measurements:</b>			
Use of RemindMe (intervention group)	Data generated by the system	Data generated by the system	Data generated by the system
Occupational performance (COPM <sup>3</sup> )	X	X	X
Independence (FIM <sup>4</sup> )	X	X	X
Health-related quality of life (EQ-5D-VAS <sup>5</sup> )	X	X	X
Psychosocial impact of an assistive device (PIADS <sup>6</sup> )		X	X
Satisfaction with assistive technology (QUEST 2.0 <sup>7</sup> )		X	X

<sup>1</sup>SPT: Subject performed task; <sup>2</sup>TMT: Trail Making Test; <sup>3</sup>COPM: The Canadian Occupational Performance Measure; <sup>4</sup>FIM: The Functional Independence Measure; <sup>5</sup>EQ-5D-VAS: EuroQol 5 Dimension Visual Analogue Scale; <sup>6</sup>PIADS: Psychosocial Impact of Assistive Devices Scale; <sup>7</sup>QUEST 2.0. Quebec User Evaluation of Satisfaction with Assistive Technology.

### Cognitive ability (Studies II and III)

Patients' cognitive abilities were measured using baseline assessment in Studies II and III to assess the difference between the intervention and control groups. The assessments used were the subject performed task (SPT) (Rönnlund, Nyberg, Bäckman, & Nilsson, 2003) and the Trail Making Test (TMT) (Tamez et al., 2011). SPT is a test of episodic long-term memory. In the test, the participant is shown 16 subjects which are attached to 16 different verbs. The participant is asked to remember as many subjects and verbs as possible. The participant then has two minutes to recall as many subjects and verbs as possible (Rönnlund et al., 2003). TMT tests executive functioning and contains parts A and B. The participants are timed while completing parts A and B, and the difference is calculated to give a TMT index that shows the time difference between the parts. A higher TMT index indicates more difficulties with cognitive ability (Tamez et al., 2011). Table 3 gives an overview of data collection for cognitive ability.

### Use of RemindMe (Study II)

Data about patients' use of and interaction with RemindMe were generated. RemindMe's web-based calendar showed which everyday life occupation the reminders were used for, how often these occupations occurred, and the response rate for the reminders.

### Occupational performance (Study III)

Occupational performance was measured using the Canadian Occupational Performance Measure (COPM) (Carswell et al., 2004). The patients identified everyday life occupations, that were perceived as important to perform, and that patients forgot to do or wanted to do. In the COPM, the patients assessed their perception of their performance of these activities, and their satisfaction with their performance on a ten-point scale, from one “=not able to do/not satisfied at all” to ten “= able to do it extremely well/extremely satisfied”. A two-point difference is found to be a clinically significant difference. The COPM is used in rehabilitation and has good sensitivity and good reliability (Carswell et al., 2004).

### Independence (Study III)

The Functional Independence Measure (FIM) (Pretz et al., 2016) was used to measure patients’ perceptions of independence. FIM measures the degree of independence on a seven-point scale, with a higher number indicating more independence. The measurement is divided into two subscales. Subscale a-m includes activities of personal care and mobility, and subscale n-r includes communication, social abilities and intellectual abilities. FIM is a commonly used outcome measurement with good psychometric characteristics (Pretz et al., 2016).

### Health-related quality of life (Study III)

Health-related quality of life was measured using the EQ-5D-VAS (EuroQol, G, 1990). Patients self-assess their perception of their health on a visual analogue scale (VAS) from zero to 100, zero indicates “the worst health you can imagine” and 100 indicates “the best health you can imagine”. The EQ-5D has good validity and reliability for people with stroke (Hunger, Sabariego, Stollenwerk, Cieza, & Leidl, 2012).

### Psychosocial impact of an assistive device (Study III)

The Psychosocial Impact of Assistive Devices Scale (PIADS) (Day, Jutai, & Campbell, 2002) was used to assess the psychosocial impact of support as perceived by the patients. In PIADS 26 aspects are assessed. These aspects are divided into three subscales: competence, adaptability, and self-esteem. The scores range from -3 (negative effect) to 3 (positive effect). Zero indicates no psychosocial effect of the support (Day et al., 2002). PIADS has shown good psychometric qualities (Day et al., 2002) and clinical relevance (Devitt, Chau, & Jutai, 2004).



## Satisfaction with assistive technology (Study II)

The Quebec User Evaluation of Satisfaction with Assistive Technology 2.0 (QUEST 2.0) (Demers, Weiss-Lambrou, & Ska, 2002) was used to assess patients' satisfaction with RemindMe. QUEST is divided into two parts. Part one measures patients' satisfaction with assistive technology and consists of eight questions. Part two measures satisfaction with service when assistive technology is delivered and consists of four questions. The questions are rated on a five-point scale from one "= not satisfied at all" to five "= very satisfied". QUEST has been found to have good reliability and validity (Demers et al., 2002).

## ***Qualitative data collection***

### Face-to-face interviews and field notes

In Study II, individual face-to-face interviews were conducted with the recruiting occupational therapists at the rehabilitation clinics. The interviews concerned the occupational therapists' experiences of various feasibility aspects of RemindMe and the intervention. The interviews were conducted by a researcher (MA) who was an experienced occupational therapist by profession. A structured interview guide with open questions was used. Examples of questions asked were "Describe your perception of RemindMe for patients with cognitive impairment" and "Describe your perception of the intervention". The questions were followed by probing questions, such as "Can you give an example..." and "Please tell me more about...". The occupational therapists were interviewed at the rehabilitation clinic and the interviews were tape-recorded and lasted 15-30 minutes (median 23 minutes).

Study II also consists of descriptive field notes taken by the research assistant (who was an occupational therapist by occupation) during weekly conversations and descriptive field notes taken by the researcher (MA) during the individual follow-up assessments two and four months after baseline assessment.

## **Study IV**

### ***Individual face-to-face interviews***

In Study IV, individual face-to-face interviews were conducted with patients from Study III. The interview followed an interview guide to explore the patients' experiences of using support for time management and for planning and structuring everyday life due to cognitive impairment. The interview guide included the following questions: "Describe difficulties in everyday life due to having difficulties remembering important activities

in everyday life”, “Describe experiences of using support to remember important activities in everyday life” and “Describe various forms of support that you use in your everyday life”. The interview questions were followed by probing questions such as “Please tell me more...” or “Please give an example...”.

The background demographics for Study I were collected using a questionnaire completed by the community-dwelling seniors before the interview started. In Studies II and III, background demographics were collected from medical records at the rehabilitation clinics during baseline assessment. During the baseline assessment in Studies II and III, the patients filled in a questionnaire about computer use, mobile phone use, and calendar skills and use. Table 3 gives an overview of data collection for demographic data. Before the interview in Study IV, additional background demographics for the patients were collected by the interviewer.

## Procedure

### Study I

All community-dwelling seniors who volunteered to participate were invited to an introduction course to learn about scheduling the digital calendar and reminders and practiced receiving and responding to reminders on their mobile phone/smartphone. They were also informed about the RemindMe feedback system and what information was stored and retrieved from there. The introduction courses were held at a local library or the university. All community-dwelling seniors received a written manual. When the study period began, a research assistant (who was an occupational therapist by occupation) had individual weekly phone calls with all community-dwelling seniors to support the use of RemindMe. After the study period of six weeks, the community-dwelling seniors were invited to focus group interviews. Four interviews were conducted at different convenient locations. The focus group interviews were tape-recorded and lasted 56–65 minutes (median 61 minutes).

### Studies II and III

Patients were recruited by seven occupational therapists at three different rehabilitation clinics. The patients received information about the study from their occupational therapists. Those patients who were interested in participating received written information and contact was made with the researcher (MA). The researcher (MA) provided verbal information about the study’s aim and procedure. Randomization (Study III) to the

intervention or control group was conducted at the rehabilitation centre by block-wise randomization. Block of four sealed envelopes was stored at each rehabilitation centre, two envelopes for the intervention group and two for the control group. Randomization was made by patients choosing one envelope. The researcher updated the blocks with envelopes so that the content of the blocks would not be known to the occupational therapists or the patients. The group assignment was not blinded.

Participants in both the intervention group and the control group received treatment as usual at the rehabilitation clinic. The usual treatment included interventions aiming to provide support with time management and with planning and structuring everyday life occupations. Examples of interventions included introducing weekly schedules, using “low tech” or “high tech” devices (O'Neill & Gillespie, 2015) or identifying compensatory strategies. The participants in the intervention group used RemindMe for two months. The participants in the control group were asked to use a specific calendar that they were accustomed to during the first two months, and this calendar would serve as a comparison with RemindMe. After the first two months, the participants in the intervention group could choose whether or not they wanted to continue using RemindMe.

Assessments were performed at baseline and two and four months after baseline assessment. It was performed at the most convenient location for the patient: the rehabilitation clinic, the patients' home or the university. Each assessment (for outcome measurements, see Table 3) followed a predetermined schedule and took about 45-60 minutes with a short break after 25 minutes. All assessments were performed by the same researcher (MA) to ensure uniformity. Before data collection began the researcher (MA) underwent training in conducting the assessment and performed two pilot assessments. The pilot assessments are not included in the results.

Patients allocated to the intervention group received an individual introduction in using RemindMe. An account was created, and patients were shown how to schedule the web-based calendar and the reminders. Patients were assigned a support person either an occupational therapist at the rehabilitation clinic or a research assistant (who was an occupational therapist by occupation). Patients were also informed that if they wanted, a significant other could have access to RemindMe. Patients also received a written manual. For patients that by using RemindMe had found appropriate support in everyday life, could continue using RemindMe for one year after completing the study without any charge and thus having the opportunity to find another reminding system meanwhile.

The researcher (MA) and the research assistant made field notes during the assessments and during the weekly conversations, to collect qualitative data about patients' perceptions of the intervention and RemindMe.

## Study IV

Participants from Study III that met the inclusion criteria for Study IV were eligible for the interview and were contacted by telephone. Seven of the patients were contacted, and all agreed to participate. This was independent of the group allocation in Study III. The intention was to contact another four participants, but due to the Covid-19 pandemic, it was not deemed appropriate to contact these participants. Interviews were conducted at the most convenient locations for the patients: at the participants' homes, the university, or their workplace. The interviews were tape-recorded and lasted 40-64 minutes (median 48 minutes).

## Intervention

The intervention (Studies II and III) was based on the experiences from Study I. Initially the occupational therapist at the rehabilitation clinics received training in using RemindMe. The intervention consisted of: 1. an individual introduction, 2. individual weekly support conversations and 3. follow up assessments - see Figure 4. The intervention was perceived to fit with the infrastructure at the rehabilitation clinics.

The intervention with RemindMe (described on pages 14-16) was designed to support people with cognitive impairment in time management and in planning and structuring occupations in everyday life. (Figure 4) Before the intervention began, the occupational therapists working at the three outpatient rehabilitation clinics received training in using RemindMe. They also received a written manual on how to use the core functions of RemindMe. The occupational therapists had contact with the researcher (MA), who was an occupational therapist by profession, throughout the study. The researcher answered questions and was a support in the use of RemindMe.



Figure 4. The intervention with RemindMe consisted of three parts.

- 1) In the first part of the intervention, the patients allocated to the intervention group were introduced to RemindMe by the researcher (MA). A user profile was created, and patients were given access to the calendar. Patients invited a support person who

was also given access to the calendar. These support persons were occupational therapists at the rehabilitation clinic or a research assistant (who was an occupational therapist by occupation). Patients were provided with a written manual and were trained by the researcher in using the calendar and responding the reminder SMS. During the introduction, patients scheduled the calendar with everyday life occupations that they perceived a need to be reminded about. The choice of everyday life occupations derived from patients' experiences and from occupations identified during the COPM assessment with the occupational therapists at the rehabilitation clinic. The patients decided which text should be shown in the reminder and scheduled the time at which the reminder should be received (see Figure 4).

- 2) The second part of the intervention was the actual use of the calendar for eight weeks, with weekly support from the support person. During the weekly support conversations, the patients were asked about the reminders from the previous week and the need for reminders over the coming week. Conversations were held concerning appropriate everyday life occupations to be reminded about and when to receive the reminders. After eight weeks the weekly conversations stopped, and the patients decided whether or not they wanted to continue to use RemindMe (see Figure 4).
- 3) The third part of the intervention consisted of individual follow-up assessments, two and four months after the baseline assessment, conducted by the researcher. During these assessments, conversations were held about the future use of RemindMe or some other form of reminder support (see Figure 4).

## Analyses

### Study I

Analyses of the transcribed focus group interviews were conducted following Graneheim and Lundman (2004). The interviews were transcribed verbatim and were read several times and combined with listening to the tape recordings. Meaning units of text with similar content were identified. These meaning units were abstracted and condensed to give condensed meaning units, describing the content close to the respondents' wording. Similarities and differences were discussed within

the research group. In Study I, there was a particular focus on the discussion between the participants (Krueger, 2014). The condensed text material was then categorized into codes and labelled close to the respondents' own words. These codes were abstracted and combined into subcodes based on descriptions of challenges, benefits and the process of learning to use RemindMe. Subcodes with similar content were combined into categories. The categories were discussed by the research group. From the categories, the latent content of the interviews was identified and resulted in four themes. These themes describe the latent content in the interviews (Graneheim & Lundman, 2004).

## **Study II**

In Study II a mixed-method design with quantitative and qualitative data collection was used and feasibility aspects were analysed with support from the aspect descriptions (acceptability, demand, implementation, practicality, and integration) proposed by Bowen et al. (2009). Quantitative data about participants' demographics, data generated by RemindMe about the actual use of RemindMe and data from the QUEST assessment (Demers et al., 2002) were analysed with descriptive statistics (frequencies, median and range) (Field, 2018). The qualitative data derived from field notes taken during the follow-up assessments after two and four months and interviews with occupational therapists were analysed with directed deductive content analyses (Hsieh & Shannon, 2005). The feasibility areas of acceptability, demand, implementation, practicality, and integration described by Bowen et al. (2009) were used as predefined categories. A protocol of field notes was compiled, and the interviews were transcribed verbatim. Analyses were conducted by highlighting content describing the predefined categories. In the next phase of the analyses, the feasibility aspects of the feasibility areas (Bowen et al., 2009) were analysed and combined into subcategories.

## **Study III**

The data from Study III were analysed with descriptive statistical analysis (background characteristics, use of digital technology, calendars at baseline and cognitive ability). Data with continuous variables were presented with median and range, and data with categorical variables were described in numbers. Nonparametric statistics were used since the data was on an ordinal level. The Mann-Whitney U test (Field, 2018) was used to analyse differences between the intervention and control groups (using COPM). The Wilcoxon signed-rank test (Field, 2018) was used on analyses of differences between the baseline and four-month assessments within the intervention group and the control group (using FIM, EQ-5D-VAS and PIADS).

The results were interpreted in relation to the significance (alpha level of 0.05 used). The analyses were performed following the intention-to-treat approach (Moher et al., 2012). IBM Statistical Package for the Social Sciences version 25 (SPSS, Chicago, Illinois) was used in all statistical analyses.

## Study IV

Interviews were transcribed verbatim and were analysed with inductive content analyses (Graneheim, Lindgren, & Lundman, 2017; Graneheim & Lundman, 2004). In Study IV, the manifest content is analysed. The interviews were read several times to get a sense of the content. The content was discussed and domains meeting the study's aim were identified in each interview.

From these domains, meaning units were identified. Meaning units are text with similar content (Graneheim et al., 2017; Graneheim & Lundman, 2004). Identified meaning units were condensed into shorter condensed meaning units, with wording close to the participants' words. The condensed meaning units were then labelled with codes. The codes were read and discussed against the meaning units during the analysis process. The established codes were then sorted into subcategories based on similarities and differences in participants' descriptions of experiences of using support for time management and planning and structuring everyday life, difficulties in everyday life, experiences of using support for time management, and support used. From the subcategories, categories were formed.

## Ethical aspects

Study I was designed and carried out following the ethical guidelines of the Swedish Research Council (Hermerén, 2011) and the ethical standards of the Declaration of Helsinki (World Medical Association, 2013). Studies II, III and IV received ethical approval from the Regional Ethical Review Board in Linköping, study protocol 2016-417-31, 2017/316-32, 2018/263-32.

For all the included studies, the participants received written information about the aim of the study, the study procedure and the planned presentation of the results before agreeing to participate. All participants were informed that participation was voluntary, and that participants could withdraw at any time without giving any reason. In all studies, the data has been treated confidentially, participants' names have not been used and participants' conditions have been treated so no participant can be identified.

When Study I was conducted, there was no legal requirement to obtain approval from an ethical board when conducting a research study with participants who had volunteered to participate and where no personal data relating to health or biometrics were collected. The study followed the Declaration of Helsinki (World Medical Association, 2013), ensuring that participants were informed about and had understood the study's aim, that participation was voluntary and that the results would be reported confidentially. Only research personnel had access to the audiotaped and transcribed interviews. The participants in Study I received written information of the study and they had the opportunity to ask the researchers questions about the study before giving their informed consent verbally. This verbal consent was recorded before the focus group interview started. Participants who had found RemindMe to met their need for reminders were allowed to continue using RemindMe for free for up to one year after completing the study.

In Studies II, III and IV, the participants received written and verbal information about the study before giving their written consent. This took place before participating in the study. The participants were informed that participation was voluntary and that they could withdraw at any time without giving a reason.

In Studies II and III, the participants received verbal information from the researcher to ensure they understood the information. The participants were informed that the researcher and support persons had access to RemindMe for as long as the participants agreed to this. Study procedures were planned to reduce the burden on the participants. This was achieved by collecting demographic data from medical records to reduce inquiring about data that had already been collected by treating occupational therapists. The chosen measurements and assessment procedure were planned in order not to exhaust participants with difficult and demanding assessments. Assessments were conducted at the most convenient location for the participants. Participants in the intervention group who had found that RemindMe met their need for reminders were allowed to continue using RemindMe for free for up to one year after completing the study.



# RESULTS

The result will address learning and using ATC in everyday life and outcomes from using RemindMe.

## Learning and using ATC in everyday life

### **Use of “low and high tech”**

The community-dwelling seniors (Study I) and the patients (Study IV) described their use of calendars in everyday life. The type of calendar they preferred to use depended on habits and the activity to be performed, whether the everyday life occupations were performed at home or in society, and whether or not the activities were coordinated with family members. For patients living with a partner, home calendars were used in combination with their partner (Study IV). Most of the community-dwelling seniors (Study I) used a home calendar, often located in the kitchen, and did not use digital calendars to a great extent. Patients (Study IV), however, used digital calendars or a combination of both more often. An example of combining “low- and high tech” was using the voice recorder in the smartphone to record a reminder, set an alarm at a time being at home, and then transfer the appointment to the calendar in the kitchen (Study IV). Patients (Study IV) who preferred paper calendars found them easier for getting an overview (of both what had been performed and what was to be performed) and browsing. For participants who worked used one calendar at work and another was used at home. The least preferred reminder was memos on paper because paper notes were often difficult to find when needed (Study IV).

Patients (Study IV) described how objects in the home environment often served as reminders. For example, objects in the kitchen were described. For one patient, it was the coffee machine and the pill organizer placed next to the coffee machine that served as reminding objects. For another patient, it was a pair of scissors and their position in the kitchen that worked as a trigger for taking the medication. Patients (Study IV) established and consciously used routines to support the performance of everyday life occupations. These routines were usually added to other well-established habits, and were especially mentioned when describing how to remember to take medication. Described routines included always looking at the wall calendar in the morning while preparing breakfast, or taking medication when eating breakfast. This was a way to ensure that

medication would be taken. It was described how evening medication was often forgotten due to the lack of established habits (Study IV). The variation of support needed for people with cognitive impairment is illustrated in Figure 5.

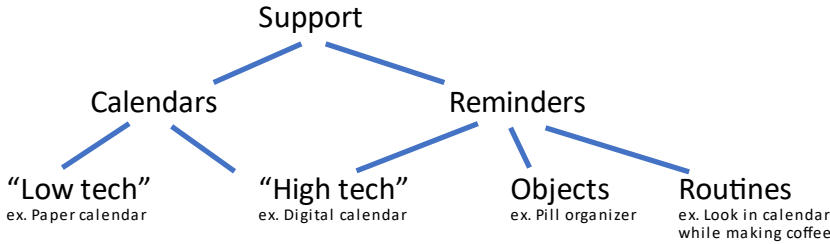


Figure 5. Variation of support needed for people with cognitive impairment.

The community-dwelling seniors (Study I) were not experienced at using mobile phones/smartphones as mobile devices; instead, they mostly used their phones to make calls in the home environment (Study I). By contrast, patients with cognitive impairment (Study II) were younger and accustomed to using mobile phones/smartphones. For the community-dwelling seniors, creating habits and adjusting routines for using mobile phones/smartphones (for example, changing charging habits or using their phones outside the home) was a challenge (Study I). Patients with cognitive impairment did not have the same difficulties with habits related to mobile phone/smartphone use, and expressed that an advantage of having a digital calendar on their smartphone was that they could easily take their calendar with them (Studies II and IV). However, participants described challenges using the mobile phone/smartphone due to tiny buttons, a small display, or difficulties using touch screens (Studies I and II). From the occupational therapists' perspectives, digital calendars were viewed as appropriate since many people have a calendar on their smartphone and always bring it with them (Study II). Therefore, it was important to support learning to use and using digital calendars for those who were not accustomed to doing so.

### **RemindMe and feasibility aspects**

Learning to use a new technical device is related to previous technical knowledge and experience. The community-dwelling seniors appreciated the introduction course and perceived it as instructive. They found it easy to learn to use RemindMe, but challenging to integrate into everyday life (Study I). The additional weekly telephone support from the research assistant was perceived as positive and was appreciated since it gave them individual support (Studies I and II).

The occupational therapists at the rehabilitation clinics (Study II) perceived that RemindMe was successfully implemented via the weekly support conversations. These conversations gave the patients with cognitive impairment continuous support for using reminders in everyday life. This meant that the intervention derived from the patients' needs and thus had a positive impact on their everyday lives. The occupational therapists experienced that the intervention made patients aware of the support they needed and resulted in an interest in finding support on their own terms (Study II). However, one prerequisite for patients with cognitive impairment – according to the occupational therapist – was that the patient must perceive a need for a reminder and be active in everyday life and thus have activities to schedule (Study II).

Patients who were accustomed to using smartphones pointed out that navigating and scheduling RemindMe was difficult because it was designed to be scheduled from a computer and was therefore difficult to schedule from a smartphone (Study II). This was also acknowledged by the occupational therapists as a negative aspect, and it was seen to be appropriate for RemindMe to be redesigned as a smartphone app (Study II). Other difficulties described by the patients with cognitive impairment included adjusting the calendar for daylight saving time and scheduling with limited internet access (Study II).

The feasibility aspect of demand reflecting patients' interest or intention to use is reported through RemindMe logs displaying the actual use of reminders in everyday life occupations by patients with cognitive impairments (Study II). Reminders were used for occupations within self-care, leisure, and productivity. The most common self-care activities for which reminders were scheduled were taking medication, doing exercise, and going to rehabilitation clinics or other healthcare services. The leisure activities for which reminders were most often used were those carried out with others outside the home. There was a variation in scheduling depending on whether the occupation was performed regularly, or occasionally. For occupations performed regularly most patients needed reminders for taking medication. For occupations performed occasionally most patients needed reminders for attending health care services. For the occasional occupations, several patients also needed a reminder in preparation for the occupation. Table 4 displays the everyday life occupations for which patients scheduled reminders in RemindMe.

Table 4. Occupations in everyday life for which patients with cognitive impairment scheduled reminders (Study II).

	<b>Occupations performed regularly</b>	<b>Occupations preparing for occasional occupations</b>	<b>Occupations performed occasionally</b>
<b>Self-care</b>	Taking medication, having lunch Carrying out an exercise programme Making a daily phone call to a family member	Remembering to book an appointment with the authorities Reserving mobility services	Visiting the rehabilitation clinic, visiting a physician/dentist, attending medical assessments Meetings with authorities Leaving the car at a garage for repairs
<b>Leisure</b>	Watercolor painting Watching a specific TV-show Attending church	Booking an exercise class	Meeting family and friends Going on a weekend vacation, or attending a concert Attending a photography course Visiting a gym or going golfing
<b>Productivity</b>			Work-related activities

Regular scheduling was used for self-care occupations that were performed daily (taking medication), every weekday (watching specific a TV show), or on a specific day of the week (attending church). Several patients with cognitive impairment replied to the reminder SMS. A median of 56% of the reminders was answered (range 0%–91%). This response rate was the same throughout the four months. After the study period, seven out of eight patients continued to use RemindMe at the median rate for 28 weeks (range 8–52 weeks). The response rate for the reminder SMS was lower during this period, with a median of 13% of reminders being answered (range 0%–66%) (Study II).

The feasibility aspects of acceptability including satisfaction and perceived appropriateness with RemindMe are reported in the assessment of patients with cognitive impairments by assessing their satisfaction with RemindMe and the service when introducing RemindMe, using QUEST 2.0 (Demers et al., 2002) (Study II). The assessment shows that the participants were satisfied with RemindMe and the service. However, there was a wide range of answers. After four months, the patients with cognitive impairment assessed their satisfaction with RemindMe and service at a median score of 4.50 (range 2.09–5.00). See Table 5.

Table 5: Results from the assessment with QUEST (Demers et al., 2002) to assess patient satisfaction with RemindMe as a product and satisfaction with the service, and the sum score of how satisfied patients were with RemindMe and the service. The scores range from one to five, with higher scores have higher satisfaction.

	Two months		Four months	
	Median	Range	Median	Range
Satisfaction with RemindMe	4.44	2.14–5.00	4.48	1.75–5.00
Satisfaction with the service	5.00	4.00–5.00	4.58	3.00–5.00
Total score, satisfaction with RemindMe, and the service	4.40	2.70–5.00	4.50	2.09–5.00

The feasibility aspects of implementation and integration concerning factors affecting ease or difficulties with implementation were reported by occupational therapists at the rehabilitation clinics (Study II). Components that were perceived to fit with the clinics' infrastructure were the weekly support conversations and having access to the calendar. It was reported that the weekly conversations enabled the occupational therapist to evaluate the received reminders and schedule new reminders while talking to the patient on the phone.

The intervention procedure could be a structure to use when introducing digital support of any kind. The occupational therapists expressed that a close relationship with the patient and knowledge of the patient's needs, habits and routines (for example, knowing which everyday life occupations to schedule reminders for and when reminders should be sent) were crucial for successful implementation of the intervention. (Study II).

RemindMe was also perceived as an appropriate tool for scheduling rehabilitation activities, for example striking a balance between activity and rest for patients who experience mental fatigue. At the same time, it was pointed out that interventions with reminders often reveal new problems and therefore become time-consuming. For example, patients could arise new problems related to the activities scheduled in the calendar. It was also expressed that it was difficult to keep up to date with digital technology because of rapid technological developments. Therefore, using strategies to implement digital technology that can be applied to any digital technology was perceived to be necessary (Study II).

### **Everyday life experiences of ATC use**

Active reminders were important for most of the patients (Study IV). This was a way to become independent and get a feeling of comfort and security in everyday life. The possibility to receive reminders from a digital calendar was described as positive. By using self-scheduled active reminders, participants felt confident that important tasks such as, taking medication

would be done. The patients (Study IV) described that they had learned how many reminders they needed. They recalled that at the beginning of the study period, some of those using RemindMe had scheduled too many reminders. When too many reminders were scheduled, they became annoying. Active reminders scheduled by others, for example, healthcare clinic or dentists visits were appreciated. These active reminders support remembering and visiting pre-booked appointments. As these reminders were often sent via SMS they could also be saved on the smartphone (Study IV).

The community-dwelling seniors (Study I) perceived that receiving reminders with an audio prompt initiated the performance of activities in everyday life. They especially pointed out the advantage of reminders that came at a predefined time, had an audio prompt, and that the reminder told them what to do. The calendar was described as it “talks to me”. Receiving reminders and responding to them enhanced independence and gave a sense of control, and more everyday life occupations were performed. This supported the formation of new routines and reduced the burden on their significant others to some extent, as they did not need to remind them to take their medication (Study I). Despite using reminders, the patients (Study IV) described how problems occurred when they were disturbed when doing something. Disturbances included receiving telephone calls or reminders arriving at the wrong time. To reduce the risk of not performing important tasks, they needed to be done at once and this was used as a routine (Study IV).

Community-dwelling seniors' descriptions of using digital reminders were related to symbolic value (Study I). Digital reminders could signal being part of modern society and its technological developments. Digital calendars such as RemindMe could also be a sign of aging and dependency, signalling decreased memory and reduced ability to remember activities. Some of the community-dwelling seniors' expressed the perceived advantages of the new digital technology, which could enable them to have contact with their family and friends, and to plan and schedule future events (Study I). The community-dwelling seniors (Study I) who experienced reduced memory were positive about using RemindMe. While some of the community-dwelling seniors (Study I) were hesitant about using RemindMe because they did not perceive any added value in using a reminder. They described how they did not need to use reminders, and were not interest in doing so. These participants were not comfortable with using technology instead of their minds and cognition (Study I). Patients (Study IV) described the early stages of the rehabilitation period as a stressful time, and experienced that the cognitive impairment made them forget about important and unimportant things, therefore making everyday

life difficult to manage. Situations with a lot of stimuli were pointed out as being especially difficult to handle (Study IV).

The process of establishing a new everyday life was described as finding ways to master and accept the new situation and to account for mental fatigue. This mental fatigue resulted in a feeling of exhaustion and difficulties in performing occupations in everyday life in the same way as before (Study IV) described a need to challenge themselves to master everyday life occupations that were perceived to be difficult to perform. The patients described how the occupational repertoire of everyday life had changed, with social activities decreasing and other occupations being performed in a less stressful manner. This made it possible for them to focus and concentrate (Study IV).

## Outcomes from using RemindMe

### **Occupational performance (COPM)**

Patients with cognitive impairment self-assessed their occupational performance (Study III). Both the patients in the intervention group and the control group increased their perceptions of their occupational performance from baseline (intervention group Median = 5.13 and control group Median = 2.67) to two months after the baseline assessment (intervention group Median = 6.75, and control group Median = 7.00). At four months after the baseline assessment, the patients in the intervention group persisted in their perception (Median = 8.04) of occupational performance, while this perception decreased for those in the control group (Median = 5.00).

The Mann-Whitney test showed that there was no significant difference between the intervention and control groups at baseline or after two months. However, after four months patients in the intervention group rated their occupational performance significantly higher than those in the control group ( $p = 0.006$ ). See Figure 6.

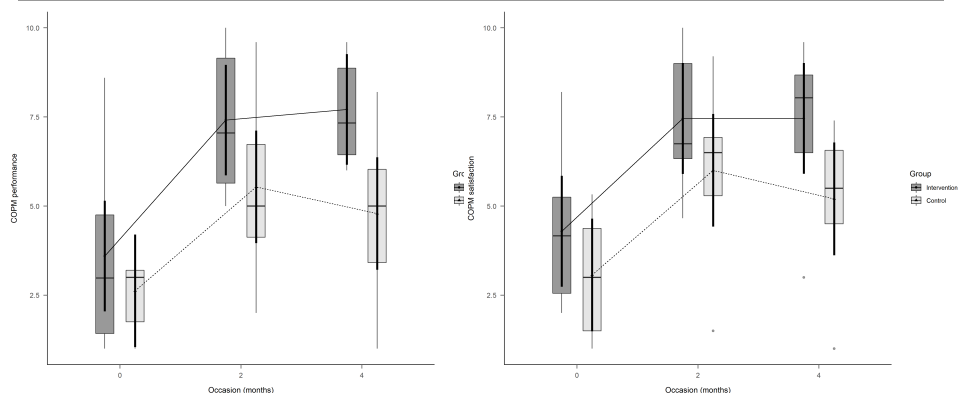


Figure 6. Self-assessed perception of occupational performance and satisfaction with occupational performance using the Canadian Occupational Performance Measure (COPM) at each time point, (intervention group  $n = 8$ , and control group  $n = 7$ ). A score of one indicates “not able to do”/“not satisfied at all” and a score of ten indicates “able to do it extremely well”/“extremely satisfied”.

Patients with cognitive impairment also self-assessed their satisfaction with occupational performance (Study III). Both patients in the intervention group and the control group increased their perception of their satisfaction with occupational performance from baseline (intervention group Median = 4.00 and control group Median = 2.67) to two months after baseline assessment (intervention group Median = 7.50, and control group Median = 6.17). At four months after the baseline assessment, patients in the intervention group persisted in their perception (Median = 7.75) of occupational performance, while this perception decreased for those in the control group (Median = 3.33).

The Mann-Whitney test showed that there was no significant difference between patients in the intervention and control groups at baseline or after two months. However, after four months there was a significant difference, with patients in the intervention group rating their occupational performance significantly higher than those in the control group, ( $p = 0.006$ ). See Figure 6.

### Independence (FIM)

Both groups of patients with cognitive impairment (Study III) rated high scores in the subscale of personal care (item a-m) which indicates that participants in both groups were independent in these activities. The Mann-Whitney test showed no significant differences between the groups at any time point. Nor did the Wilcoxon signed-rank test indicate that there was any significant difference. See Figure 7.



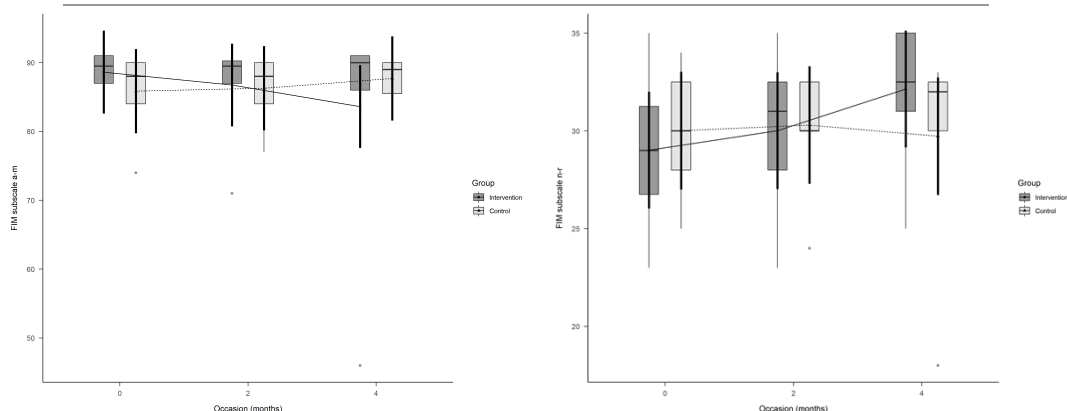


Figure 7. Self-assessed independence with the Functional Independence Measure (FIM) (intervention group  $n = 8$ , and control group  $n = 7$ ). Personal care and mobility subscales, at each time point. A higher score indicates more independence, with a maximum score of 91. Communication (understanding and expression) and social and intellectual abilities (social interaction, problem-solving, memory) subscales, at each time point. A higher score indicates more independence, with a maximum score of 35.

In the communication and social- and intellectual abilities subscale (item n-r) (Study III), several participants in both groups assessed that they needed support from another person. However, the Mann-Whitney test showed no significant differences between the groups at any time point. A Wilcoxon signed-rank test indicated that there was a significant difference between baseline assessment and assessment after four months in the intervention group, ( $p = 0.017$ ). There was no significant difference in the control group between baseline assessment and assessment after four months, ( $p = 0.684$ ). See Figure 7.

### Health-related quality of life (EQ-5D-VAS)

Patients with cognitive impairment (Study III) self-assessed their health-related quality of life. Patients in the intervention group had almost the same assessment throughout the study period while patients in the control group, who started with a lower baseline score, increased their perception between baseline and two months, and their perception persisted until four months. The Mann-Whitney test showed no significant differences between the groups at any time point. A Wilcoxon signed-rank test did not show any significant differences at any time point. See Figure 8.

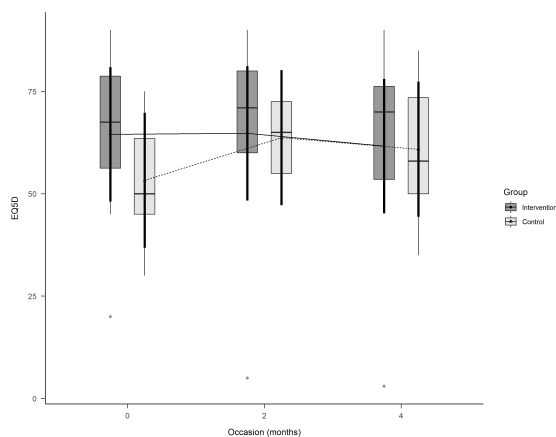


Figure 8. Self-assessed health-related quality of life with the EQ-5D-VAS at each time point (intervention group  $n = 8$ , and control group  $n = 7$ ). A score of zero indicates “the worst health you can imagine” and a score of one hundred indicates “the best health you can imagine”.

### Psychosocial impact of support used (PIADS)

Patients with cognitive impairment (Study III) self-assessed their perception of the psychosocial impact of support used. In the assessments of adaptability, competence, and self-esteem the Mann-Whitney test showed no significant differences between the groups at any time point.

In the adaptability subscale differences between patients in the intervention group and the control group (Study III) could be seen. The assessment shows that patients in the intervention group increased their adaptability, while those in the control group assessed a decrease in their perception. However, the difference was not statistically significant. In the competence and self-esteem subscales, no significant differences were found. See Figure 9.

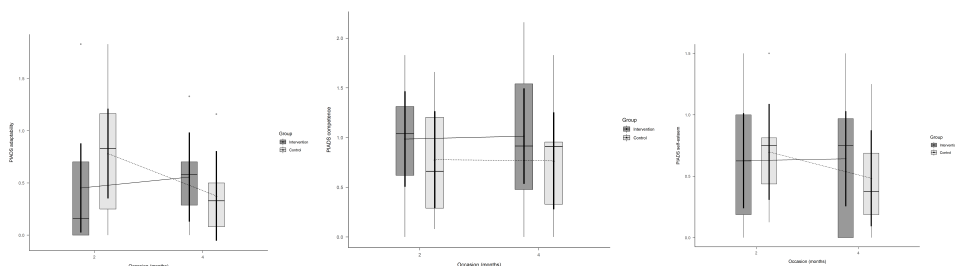


Figure 9. Self-assessed perceived psychosocial impact of the support used, according to the Psychosocial Impact of Assistive Devices Scale (PIADS) at each time point (intervention group  $n = 8$ , and control group  $n = 7$ ). The aspects are divided into three subscales: adaptability, competence, and self-esteem. The scores range from -3 (negative effect) to 3 (positive effect) and 0 indicates no effect.

# DISCUSSION

## Discussion of the results

The overall aim of this thesis was to study an interactive digital calendar with mobile phone reminders (RemindMe) for people with cognitive impairment, as support to increase occupational performance in everyday life. The findings of the use of “low and high tech” and support for occupational performance in everyday life are discussed. RemindMe is an example of a “high tech” device with active reminders and audio prompts and the support for learning to use and using RemindMe is discussed and the fact that besides active reminders were also strategies used to support everyday life. The used outcome measurements are discussed and the occupational therapists’ experiences of the intervention.

### Use of “low and high tech”

The “low tech” devices for time management and for planning and organizing occupations in everyday life, used by the participants in this thesis were paper calendars (Studies I, II and, IV). It seemed like home calendars in the kitchen were preferred for various reasons. One reason was that they are easy to browse and give a good overview, another reason was that they are easy to use when sharing a calendar with a family member (Studies I and IV). However, preferences for calendars varied, and it was also described that “high tech” devices, such as digital calendars were used and preferred since they are easy for users to take with them (Studies II and IV). Digital calendars integrated into a smartphone have several advantages (Brandt et al., 2020). Some participants had found a way to combine the use of “low and high tech” calendars. This demonstrates the need to be person-centered and to adjust possible ways of using assistive technology to patients’ preferences and to encourage people to find their preferred way of using support for time management and for planning and organizing occupations in everyday life.

It is well known that seniors can experience a digital divide and difficulties with using digital technology (Nimrod, 2018; Olsson, Samuelsson, & Viscovi, 2019). However, many seniors are positive towards and interested in using digital technology (Choudrie et al., 2020; Hill et al., 2015). The community-dwelling seniors participating in Study I experienced difficulties with handling mobile phones/smartphones and adjusting their habits and routines for using mobile phones/smartphones. This shows the importance of digital technology having a user-friendly

design, and of providing support for learning to use and using digital technology (Choudrie et al., 2020; Hill et al., 2015). The perceptions of using a digital calendar with reminders were both positive and negative, and we learned from the study involving community-dwelling seniors (Study I) that there are diverse opinions about using digital technology for reminders. This could be perceived as being part of modern society or a sign of dependency and aging (Study I). It is important for health care professionals to acknowledge these varying opinions, and for researchers and developers of digital technology to consider them when developing assistive technology with reminders.

For people with cognitive impairment, it can be difficult to learn how to use new technology (Brandt et al., 2020). Even when a technology device has been used, difficulties can arise when software is updated. A system update or a new interface might result in difficulties finding functions that were often used before (Choudrie et al., 2020; Savage & Svoboda, 2013). With cognitive impairment, generalization is often difficult. This means that assistive technology must be able to adjust to the specific user. Even though there are many possibilities, these are not worth anything if the user cannot use them. Therefore, there is a need for user-friendly technology. The assistive technology must be matched to the user (Ravenek & Alvarez, 2019; Scherer, 2019; Scherer & Glueckauf, 2005) and not the other way around.

Patients with cognitive impairment (Study IV) described that they had regained a feeling of comfort and security and a sense of control and independence in everyday life, about two and a half years after the baseline assessment. However, the process of mastering and accepting the new situation as part of everyday life when performing important occupations had been challenging. Assistive technology both “high tech” and “low tech” (O'Neill & Gillespie, 2015) was used as a means of support. To master and accept the new situation, and account for the experienced mental fatigue was to challenge themselves and perform activities perceived as difficult to perform.

### **Active reminders with audio prompts**

Digital technology often offers active reminders with audio prompts (Brandt et al., 2020). For most of the participants in the studies included in this thesis, active reminders were important since an active reminder with audio prompts alerts the user when it is time to do something. Using active reminders was a way to become independent and obtain a feeling of comfort and security in everyday life (Studies I and IV). Besides having an active reminder with audio prompts that alerts when it is time to do something, the advantages pointed out by participants included the

possibility to schedule into the future and to choose the reminder text This was described as it “talks to me” (Study I).

RemindMe was developed as a user-friendly digital reminder with easy, interactive scheduling, including active reminders with audio prompts and active confirmation for people with cognitive impairment (Baric et al., 2015). The results of actual use showed that most participants used RemindMe for everyday life occupations within self-care that occurred daily. Taking medication was especially mentioned. An important aspect of RemindMe was the possibility to confirm whether or not an activity was performed, for example when the medication had been taken. RemindMe was also used to schedule everyday life occupations that occur occasionally.

### **Support with learning to use and using RemindMe**

In the intervention with RemindMe, an effort was put in to support for learning to use and using RemindMe. For the community-dwelling seniors (Study I), learning was conducted in groups. Experiences from these learning sessions were used when planning the introduction for people with cognitive impairment (Studies II and III). For people with cognitive impairment, it is an advantage when learning focuses on real-life experiences and situations that are experienced as difficult (Toglia et al., 2019). Patients with cognitive impairment (Studies II and III) therefore received individual learning support. These different strategies seemed relevant when monitoring the populations’ diverse needs. Community-dwelling seniors found it beneficial to learn in a group, while patients with cognitive impairment benefited from individual support tailored to their needs and their experience of using digital technology.

Individual telephone support seemed to make things easier for the participants (Studies I, II, and III), but for different reasons. For the community-dwelling seniors, this support was largely related to habits connected to mobile phone/smartphone use. These participants were not accustomed to using these devices outside the home (Study I). The patients with cognitive impairment needed support when choosing which occupations in everyday life to set reminders for, and when to set the reminders. They also needed support to evaluate the remainder of the week that had passed (Study II).

### **Strategies used to support everyday life**

Participants also described strategies used to support time management and planning and structuring everyday life. Several patients described the kitchen as an environment that is often used in everyday life (Studies I and IV). It is an environment shared with other family members, and it is a place related to everyday life habits. Besides using calendars, the use of

objects is also an important reminder tool. The participants gave examples of objects in the home environment (Study IV) which were often described together with routines and habits. This is an issue to highlight in occupational therapy practice. People's occupational performance derives from the person in their environment (Taylor, 2017; Townsend & Polatajko, 2013). There is little point in identifying assistive technology or compensatory strategies if they do not fit with the person or the environment. This implies client-centered care with a thorough assessment and goals based on the patient's views and perceived needs (Guidetti, Eriksson, et al., 2020). Another strategy was to do important things at once, because, the intended activity was easily forgotten in the event of a disruption. Receiving appointment notifications by SMS with details of the date and time, for example from healthcare providers, was appreciated since the reminder message was stored on the smartphone and was thus easy to find when needed (Study IV). However, the downside is that these reminder SMS seldom is possible to reply to.

### **Outcome measurements**

The process of developing complex interventions includes deciding on and examining outcome measures. These outcome measures need to determine those aspects relevant to assess, and be sensitive enough to capture differences, and be reliable and well-validated (Craig et al., 2019). The recommendation from CONSORT of pilot testing an RCT is to assess plausible assessment but not effect (Moher et al., 2012). For an intervention aiming to affect aspects of activity and participation, the measurements must assess these aspects (Scherer & Glueckauf, 2005; Taylor, 2017).

To assess whether the intervention with RemindMe had an impact on participants' occupational performance, the COPM (Carswell et al., 2004) was used. The results showed that both the intervention group and the control group enhanced their perception of occupational performance and their satisfaction with performance (Study III). This indicates that COPM is sensitive enough to measure change for people with cognitive impairment using support for time management and to plan and structure everyday life (Carswell et al., 2004). An interesting difference between the groups was that the perception from two months remained in the intervention group but not in the control group. A larger study is needed to confirm and further explore these differences. One possible explanation is that the intervention group used RemindMe and thereby received support with performing everyday life occupations. Another explanation might be the weekly individual support conversations and the support in learning to use and using RemindMe. However, this also needs to be investigated further.

To investigate and assess whether the intervention supported independence FIM (Pretz et al., 2016) was used. In this study, the items concerning personal care and mobility did not show any effects, because participants were already independent in these activities (Study III). It can be questioned whether these aspects of the assessment are relevant to use with a study population such as included in Study III. However, the items concerning communication and social and intellectual abilities, showed that several participants in both groups needed support from another person (Study III), and for these activities, FIM can be considered relevant to use.

It is advisable to use outcome measures to assess the effect of assistive technology effect on health and wellbeing (Scherer & Glueckauf, 2005). Health-related quality of life was therefore measured using EQ 5D-VAS (Study III). This gives an insight into the participants' views of health at the specific time and situation of the assessment. EQ-5D also includes items that overlap with items in FIM (Pretz et al., 2016). In this thesis, the results from FIM have been reported since FIM was perceived as more sensitive than EQ-5D-5L. However, if research aims to assess cost-effectiveness the EQ-5D-5L is a relevant assessment to use since it can be used to express quality-adjusted life years.

Although no significant differences were identified in the assessment of psychosocial impact using PIADS (Day et al., 2002). An interesting difference was shown in the adaptability subscale. The intervention group perceived that their adaptability increased, whereas the opposite was true for the control group. This might indicate that the intervention group perceived more ability of adaptability (Study III). This is an interesting aspect when investigating plausible measurements for an intervention that aims to help people with cognitive impairment to adapt to a new situation in life.

### **Occupational therapists and the intervention**

It was described by occupational therapists (Study II) that before suggesting and introducing reminders to people with cognitive impairment it is an advantage if patients have insight into their time management and planning and structuring difficulties, otherwise it is hard to support them. They also mentioned that people who might benefit from reminders need to have everyday occupations to be reminded of.

The occupational therapists experienced benefits with RemindMe in their planning of rehabilitation treatment, for example when scheduling rehabilitation activities in the patient's calendar (Study II). One example described patients suffering from mental fatigue and needing to learn and experience how a good balance between activity and rest is vital for

everyday life to function well. For patients experiencing mental fatigue, it is often important to learn how to strike a balance between activity and rest (Penner & Paul, 2017). When adjusting lifestyle, it is important to evaluate the sense of tiredness in relation to what has been performed. RemindMe and the opportunities for feedback can then be used by patients in self-reflection and when evaluating treatment with the occupational therapist.

The occupational therapists also acknowledged the importance of adjusting the calendar according to the patients' needs (Study II). Participants described having too many reminders scheduled became annoying (Study IV). This is an example of when recurring and regular support is important so the patient will not lose patience and stop using assistive technology too early. The occupational therapists mentioned the importance of knowing their patients and base rehabilitation interventions on patients' needs, which is also supported by research (Guidetti, Eriksson, et al., 2020; Toglia et al., 2019).

Being able to carry out evaluations of treatment planning and scheduled occupations by telephone calls can enable alternative or complement to appointments at the rehabilitation clinic (Gustavsson, Ytterberg, & Guidetti, 2020), and thus be time effective. However, at the same time, a telephone call might reveal new problems related to the scheduled reminders and therefore become time-consuming (Study II).

In clinical rehabilitation practice for patients with cognitive impairment, occupational therapists help patients to gain awareness of their specific needs and match the patients with appropriate assistive technology (Scherer, 2019). Occupational therapists described their challenges of staying up to date with digital technology (Study II) and expressed a need to use strategies to implement digital technology that can be applied for any digital technology. This suggests the need for education, network, or workshops among occupational therapists in order to support the knowledge of available digital support. In order to support patients with cognitive impairment to increase their occupational performance in everyday life.

## Methodological considerations

In the methodological considerations, the design and methods for data collection are discussed. Discussion is also conducted of sampling recruitment, measurements, and the thesis generalizability and trustworthiness.



## **Design and methods for data collection**

The studies included in this thesis aim to support senior people with cognitive impairment in learning to use and using RemindMe in real-life situations. Both qualitative and quantitative data collections methods were used, as recommended by The Medical Research Council (MRC) when developing complex interventions (Craig et al., 2019). Different data collection methods and designs are recommended because this gives a wider perspective of the researched area (Polit & Beck, 2016) and the included studies in this thesis have contributed to investigating the feasibility and piloting issues. One perspective missing from the conducted studies is the perspectives from significant others. Their experiences could have given a broader perspective of everyday life for people with cognitive impairment.

The focus group interviews in Study I allowed the participants to gain new insights during the interviews and these were important for the results. The feasibility study (Study II) investigated the actual use of RemindMe and perceptions from the patients with cognitive impairment and their occupational therapists. A compliment to the feasibility study could have been to make a survey or interviews with occupational therapists treating outpatients (with cognitive impairment), about the occupational therapist's familiarity with "low and high tech" devices. The pilot study (Study III) had a focus on finding plausible outcomes measures appropriate to use in research including patients with cognitive impairment. This allows finding outcome measurements sufficiently sensitive to assess differences in a study. The interview study (Study IV) explored the perceptions of people with cognitive impairment to support the occupational performance of everyday life.

## **Sampling recruitment**

In study I, participants was recruited from the Swedish National Pensioners' Organization (PRO) by asking for volunteers. This procedure was chosen to recruit people within the appropriate age group and not recruit on basis of diagnosis. This was viewed as appropriate since the aim was to investigate RemindMe and the procedure to support learning to use and using RemindMe for elderly people. A request for volunteers might appeal to the most initiated and knowledgeable people and thus might not capture perceptions in general among the population.

One ethical aspect was not to disturb vulnerable patients, and consecutive recruitment of participants was therefore chosen along with data collection integrated with assessments already been conducted in clinical practice. Recruitment to the pilot RCT (Study III) was challenging and took more than two years. Initially, contact was made with the clinics, and it was assumed that each clinic would have a sufficient amount of

patients in the senior age group to enroll. However, when the study began, one clinic could not participate due to organizational issues and one clinic postponed participation for one year. Another four clinics were contacted but were unable to participate in the study. None of the four studies had large dropouts, and the enrolled participants recruited in the studies (I–IV) did not withdraw. Only one participant (Study III) declined further participation after baseline assessment.

The design of the studies (Studies II and III) was planned to ensure that patients would not be exposed to additional disturbance, and data collection was planned to use the same assessments carried out in clinical practice. The design intended to reduce the burden on the patients and use the assessments that the occupational therapists used in daily practice. A consequence when incorporating data collection in daily practice, was that this involved extra work for the occupational therapists. They had to keep the inclusion and exclusion criteria in mind, ask and inform patients, and contact the researcher when a patient was interested in participating. The recruiting occupational therapists asked for closer cooperation with the researcher after about six months, and this was granted. The procedure was then that the occupational therapists asked patients whether they were interested, and the researcher was contacted. The researcher informed patients and assisted with randomization. The weekly conversations were conducted by a research assistant instead of the occupational therapists. A recommendation for future research is that the researcher makes weekly contact with the occupational therapists and jointly identifying newly enrolled patients at the rehabilitation clinic. The researcher ascertains that patients, meeting inclusion criteria will become informed by the occupational therapist. The occupational therapists ask patients whether they would be interested in participating.

The inclusion criteria were based on restriction in activity and participation and were not diagnosis-specific. This was a choice since the aim of the intervention was to contribute to evidence-based interventions in patients' everyday life and to work in everyday practice in rehabilitation clinics. Therefore, the inclusion criteria were having a neurological injury/disease. This affected inclusion of patients both with impairments with prognosis to recover and progressive prognosis. This reflects the real-life setting at the rehabilitation clinic, and both groups of patients need interventions using compensating techniques and finding new strategies in everyday life. However, for generalizability, it would be advisable to diverse and focus on participants with a prognosis to recover or patients with progressive prognosis. In the early stages, it might be the same intervention procedure, but for long-term follow-up, different approaches can be appropriate.

More males than females participated in studies II and III. The reason for this is not known. This may reflect men being more interested in technology development than women. However, this has not been found in other studies investing technology use among senior people (Choudrie et al., 2020).

Four participants were not contacted for the interview in study IV. Due to the Covid-19 pandemic, the research group did not perceive it was appropriate to contact the participants. In March 2020, society was in shock, and the study procedure was not prepared for conducting digital interviews at that time.

### **Data collection**

The quantitative data collection measurements for Studies II and III were carefully chosen to be instruments validated for the population and sensitive enough to assess the possible effects of the intervention. The researcher received training in conducting the measurements used and the same researcher conducted the assessments. This was chosen to ensure intrarater reliability (Polit & Beck, 2016). Plausible outcome measures are assessing what was intended to measure and are sensitive to capture differences (Polit & Beck, 2016). Outcome measures were assessments of the level of activity and participation according to ICF (WHO, 2001). The chosen measurements align with the intervention design. For example, an outcome measure of cognitive capability would have been a measurement of body function, but the intervention was not designed to affect these functions. Plausible outcome measures were found in data from occupational performance and independence (Study III).

The qualitative data collection used interview guides aiming to explore participants' experiences in everyday life and constructed for these studies (I, II, IV). The interview guides included questions to explore people's experiences of learning to use and using assistive technology and strategies in everyday life. This was considered appropriate to ensure experiences related to learning to use and using RemindMe would be captured. During the assessments and weekly conversations, descriptive field notes were taken. For this, there was no predefined protocol. This could have been constructed to uniform the collection of field notes.

### **Generalizability**

The results from Studies II and III are hard to generalize since the population is small. The results should be validated with other studies. However, CONSORT (Moher et al., 2012) recommends that feasibility and pilot studies are conducted with small sample sizes. This approach reduces the burden for participants. Another aspect is that the aim of Study III was

not to assess the effect but to investigate measurements plausible for studies.

Randomization in the pilot study was not blinded since neither the patients nor the treating occupational therapists could be blinded. However, the researcher conducting the assessments could have been blinded, but this had made it difficult for the researcher to support the randomization procedure. Another possibility would have been to randomize the participating clinics, with each clinic conducting either the intervention or treatment as usual. However, this could have made it difficult to ensure that enough participants were recruited to both the intervention group and the control groups.

Data collection could have been added with questionnaires and thus reached a larger population which enable the result to become generalizable. The questionnaire could have collected data on patients with cognitive impairment and if they use ATC and if so “low or high tech”. Further data could have been collected on occupations in everyday life perceived as difficult to perform.

### **Trustworthiness**

Qualitative data in Studies I and IV were analysed with content analysis. This was seen to be an appropriate analysis method due to the aims and procedures of the studies. Analyses were conducted following Graneheim and Lundman’s qualitative content analysis approach, (Graneheim et al., 2017; Graneheim & Lundman, 2004), the approach is well known and often used in medical research. Trustworthiness in Study I was ensured by involving the whole research group in the process of analysing with a back-and-forth movement in the analyses. Quotations were used to increase credibility and participants’ demographics were presented to enable the transferability of the results (Patton, 2015; Polit & Beck, 2016).

In Study II trustworthiness of the coding of qualitative data was encounter by rereading the field notes, transcribed interviews, and the predetermined feasibility areas several times and discussed in the research group. Feasibility aspects were analysed with support from Bowen et al. (2009) and this gave good support in reporting feasibility aspects.

In Study IV reporting was conducted in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (Tong, Sainsbury, & Craig, 2007). Using COREQ ensures trustworthiness by reporting aspects in a study that can affect trustworthiness. A credibility aspect in Study IV is that the interviewer was familiar with the participants from the pilot RCT study (Study III). Transparency was obtained by displaying participants’ quotations to supplement and enrich the understanding of the results (Patton, 2015). The

interviewer was an occupational therapist experienced in clinical reasoning and in the occupational restrictions that can occur in everyday life. This was used when conducting the interviews.

## Clinical implications

Findings in this thesis are related to support in learning to use and using digital support and findings can be used in clinical practice. Support can be provided by an individual introduction based on the patient's perceived need, weekly support conversations for eight weeks by phone calls, and individual follow-up after two and four months. The support provided by phone calls makes the patient receive a shorter contact but more often. This could serve as a complement to rehabilitation service and reduce strain for patients being able to receive rehabilitation support without traveling to the rehabilitation clinic.

Digital support has the potential to support people with cognitive impairment. When initiating digital support the introduction is crucial so the patient knows how to handle the digital technology and it is beneficial to receive training in the use for a longer period. With a longer period, in learning to use and using ATC, patients can find reminders that suit them the best, either "low tech" or "high tech" or a combination of both.

RemindMe's shared digital calendar could be a tool in clinical practice. With the shared digital calendar occupational therapists are offered a tool to both schedule patients' planned treatment and a tool to use when evaluating treatment. The occupational therapist can prepare for the evaluation by analysing the feedback in the calendar. For example, whether there is a pattern if activities were performed or not performed or when activities were performed or not performed. The calendar also displays what type of activities were performed or not performed.

It is a challenge to stay updated with rapid digital development. This implies the need for occupational therapists to receive and give support in the knowledge of available digital support. This could be conducted by establishing networks or workshops but also by tailored education for occupational therapists.

## Future research

The studies in the thesis indicate that the intervention with RemindMe is feasible to support people with cognitive impairment in everyday life. By receiving and responding to reminders participants increased occupational performance and independence. This has to be further studied with a larger population. The results indicate that COPM and FIM are plausible outcome measurements when investigating the effect of interactive reminders, here RemindMe.

There is a need for research designs that can be used to evaluate novel digital technology in new patient groups in a timely and efficient manner. An RCT might not be the optimal design for such kinds of interventions. Therefore, other experimental designs could be appropriate to use, as suggested by MRC, or non-experimental alternatives to conduct studies and keep up with the digital development.

Future studies could address the optimal way of how to adapt interventions to the preferences of the patients. Some patients in this thesis preferred paper calendars, others wanted digital, with or without reminders. How can health care professionals optimally adapt their interventions to patient preferences?

PIADS proved to be an appropriate instrument to use when conducting studies of psychosocial impact from digital support. Participants described that besides reminders other aspects such as habits, routines, and objects were important. Using PIADS in a larger population could explore important aspects of the impact of digital support in everyday life.

The process to establish a new everyday life could be further studied in longitudinal studies, following patients for a longer time. The assessment with PIADS showed that the intervention group perceived their adaptability to increase and for the control group it was the opposite. Aspects of adapting to a new situation in life would be an interesting aspect to investigate.

One perspective missing from the conducted studies is the perspectives from significant others. Their experiences can give a broader perspective of everyday life for people with cognitive impairment. Several participants in the included studies used reminders to independently administer medication intake. It was mentioned that this reduced burden for significant others. It could be interesting to combine studies for people with cognitive impairment with studies with significant others and explore their views of everyday life.

## CONCLUDING REMARKS

The overall aim of this thesis was to study an interactive digital calendar with mobile phone reminders (RemindMe) for people with cognitive impairment, as support to increase the occupational performance in everyday life.

This was studied by investigating methods to help senior people when learning to use and using RemindMe. Further, the result from use of RemindMe and feasibility aspects from patients with cognitive impairment and occupational therapists display outcome measures. The results also describe patients' perceptions about the use of assistive technology for cognition (ATC) in everyday life. Figure 10 shows aspects identified in this thesis to achieve a positive outcome.

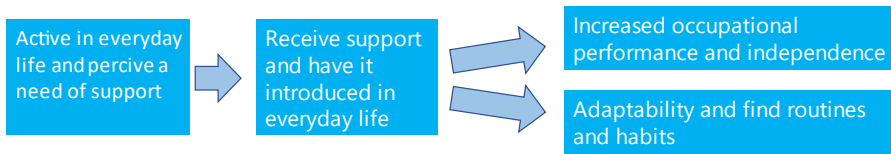


Figure 10. The figure shows aspects for achieving a positive outcome.

Occupational therapists described how patients with cognitive impairment who receive reminders have to be active in their everyday lives and perceive a need for reminders.

The next step is to choose a reminder that is tailored to the patient's needs. This reminder can be "low tech" or "high tech". The important thing is that the reminder should match the patient's needs. To make full use of the reminder in everyday life, the patient needs support with learning to use and using the device over a longer period.

The studies in this thesis indicate that occupational performance increased and persisted when using RemindMe and that patients perceived themselves to be more independent. However, this needs to be investigated further since the present thesis has a small sample size. However, the data collection measurements for occupational performance and independence can be seen as plausible.

The participants (Studies II-IV) described scheduling and receiving active reminders as a cornerstone for achieving a feeling of comfort and security. Another technique was to identify habits and routines or objects



to support time management and planning and structuring everyday life. Having a sense of comfort and security involved feeling in control of everyday life. This can be referred to as a sense of autonomy. It can also be understood as people talking about being fully involved in their life situations and thus experiencing participation. However, this was not investigated in the present studies.

Two years after the rehabilitation period digital or paper calendars were used to establish a new everyday life. Active reminders were trusted and resulted in a feeling of comfort and security as well as a sense of control and independence in everyday life.

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