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**TECHNOLOGY USE IN EVERYDAY ACTIVITIES
AMONG OLDER ADULTS WITH
MILD COGNITIVE IMPAIRMENT:
A STUDY OF CHANGES OVER TIME AND
VIEWS ON TECHNOLOGY AS SUPPORT**

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Technology use in everyday activities among older adults with mild cognitive impairment: A study of changes over time and views on technology as support

THESIS FOR DOCTORAL DEGREE (Ph.D.)

by

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ABSTRACT

The overall aim of this thesis was to provide new knowledge of everyday technology (ET) use and functioning over time, as perceived by persons with cognitive decline due to mild cognitive impairment (MCI). A secondary aim was to increase knowledge about their views on technology as part of and as potential support in everyday life.

The first three studies build on longitudinal instrument-based data from a cohort of 37 older adults with MCI at inclusion. The fourth study included six participants from the same cohort to a qualitative interview study. In **Study I** special focus was placed on changes in the perceived ability to use ET and involvement in activities. Patterns of different aspects of functioning in everyday life were explored over two years using a person-oriented approach. **Study II** used a mixed-linear-effect model to examine ET use over two years. Five predefined assumptions were tested regarding factors potentially influencing the amount of ET used. In **Study III** longitudinal involvement over four years in 15 everyday activities was investigated using differential item functioning. Furthermore, associations over time of perceived ability in ET use and overall perceived activity involvement was examined. **Study IV** used a grounded theory approach to explore how persons with MCI relate to technology as a part of and potential support in present and future everyday life.

The findings in **Study I** suggest an even distribution between a stable/ascending, a fluctuating, and a descending pattern of functioning the two first years after detection of MCI, with the highest conversion to dementia (58%) in the descending pattern. Perceived ability to use ET fluctuated or descended in 50% of the sample. **Study II** found a significant decrease in the overall amount of ET used over two years, but the number of users of specific ETs both decreased and increased. Less perceived ability in ET use, less activity involvement, declining cognitive state, and belonging to an older age group predicted use of less ET, while diagnostic state and length of education were non-significant factors. **Study III** showed that overall activity involvement decreased significantly over four years. Descending involvement was found in seven of fifteen activities. All leisure activities descended. The positive correlations between activity involvement and perceived ability in ET use became stronger over time. In **Study IV** the findings describe the participants' different ways of relating to existing and potential future technology in everyday occupations as a continuum of downsizing, retaining, and updating. In connection with the participants' actions and assumptions in relation to technology and doing, trade-offs between desired and adverse outcomes were made, challenging take-off runs were endured, and negotiations took place of the price worth paying.

In conclusion, the findings show that although overall activity involvement as well as the amount of ET used decreased significantly over time on a group level in this sample with MCI at inclusion, variations across activities, individuals and time-points were present. This means that the need for support in ET use is individual and likely to alter over time in persons with MCI. Therefore repeated evaluations of activity involvement and ability to use ET is suggested to facilitate timely interventions during cognitive decline due to MCI, not forgetting the area of leisure. Already-incorporated ETs may serve as a platform for support in daily life for this group.

LIST OF SCIENTIFIC PAPERS

- I. Hedman, A., Nygård, L., Almkvist, O., & Kottorp, A. (2013). Patterns of functioning in older adults with mild cognitive impairment: A two-year study focusing on everyday technology use. *Aging and Mental Health*, 17(6), 679-88.

(2015) Corrigendum. *Aging and Mental Health*, 19(6), 569-569.
- II. Hedman, A., Nygård, L., Almkvist, O. & Kottorp, A. (2015). Amount and type of everyday technology use over time in older adults with cognitive impairment. *Scandinavian Journal of Occupational Therapy*, 22(3), 196-206.
- III. Hedman, A., Nygård, L., Malinowsky, C., Almkvist, O., & Kottorp, A. (In press). Changing everyday activities and technology use in mild cognitive impairment. *British Journal of Occupational Therapy*.
- IV. Hedman, A., Lindqvist, E., & Nygård, L. How older adults with mild cognitive impairment relate to technology as part of and potential support in everyday life. In manuscript.

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LIST OF ABBREVIATIONS

AAL	ambient assisted living
AD	Alzheimer's disease
ADL	activities of daily living
AT	assistive technology
BADL	basic activities of daily living
BIC	Bayesian information criterion
DIF	differential item functioning
Dnr	diarienummer (English: reference number)
DSM	Diagnostic and Statistical Manual of Mental Disorders
ET	everyday technology
ETUQ	Everyday Technology Use Questionnaire
FAI	Frenchay Activities Index
GDS	Geriatric Depression Scale
IADL	instrumental activities of daily living
ICD	International Classification of Diseases
ICT	information and communication technology
IQR	interquartile range
MCI	mild cognitive impairment
MOHO	Model of Human Occupation
MMSE	Mini-Mental State Examination
MnSq	mean square
NS	not significant
PCM	partial credits model
ρ	Spearman's rank correlation coefficient (rho)
r	Pearson's correlation coefficient
SD	standard deviation
SE	standard error
SPSS	Statistical Package for Social Sciences

INTRODUCTION

PERSONAL INTRODUCTION

During my many years of clinical work as an occupational therapist in primary care, only once was a person with mild cognitive impairment (MCI) referred to me from a memory clinic. I remember being unsure of what everyday problems to expect, and how to address them. I was used to meeting persons with dementia, who oftentimes were referred to me for evaluation of safety risks in connection with applications of stove timers, or when they were in need of assistive technology for time orientation and memory support. However, the alternative solutions available for me to suggest were fairly limited. I paid little, if any, attention to the everyday technologies my clients had in their homes, such as telephones or television sets.

In the early 2000s this situation was starting to change. In addition to the fact that increasing numbers of assistive technologies for cognitive support were emerging, more and more clients were now users of cell phones with the possibility to insert reminders. Training clients in using that application became a new intervention strategy worth trying, and I started to realize that everyday technologies such as computers, cell phones, and remote controls could be both parts of the problem and parts of the solution. Additionally, the market of commercial technology products intended to facilitate everyday occupations grew. The boundaries between the clients' own everyday technology and assistive technology became less obvious. My interventions for persons with cognitive impairments due to for example dementia, Parkinson's disease, or stroke started to include providing information about easy-to-use remote controls and simple cell phones that were possible for older adults to purchase.

When working in a project aimed at informing family caregivers, health care professionals, and municipal employees about available technology support for older adults, my interest grew in the role of technology in the lives of people with cognitive impairments. I became curious about the conditions for persons with cognitive impairments to do everyday occupations in an increasingly technology-dense environment. This doctoral project made it possible for me to explore this issue. I hope that this research will contribute to increased awareness among clinicians meeting persons with MCI, for example at memory clinics and in primary care, of the challenges as well as the opportunities technology may entail in their everyday lives, and the importance technology may have for their possibility to engage in activities.

POINT OF DEPARTURE

This thesis focuses on changes over time in technology use in everyday activities among older adults who have been diagnosed with MCI. It takes its point of departure in occupational therapy, a profession and academic discipline focusing on doing in everyday life. The starting point for this research was the debate on to what extent persons with MCI can be expected to perceive problems when performing everyday occupations. The diagnostic criteria commonly used in the beginning of the 2000s stated “essentially normal activities of daily living” (Petersen, 2004), which did not match clinical observations from occupational therapists and others. However, the tools used for evaluating functional ability were too imprecise to detect the subtle difficulties experienced in everyday occupations by persons with MCI (Nygård, 2003). Introducing everyday technology items in the assessments was suggested to better target the everyday functioning likely to be challenging for groups with early cognitive decline (Nygård & Starkhammar, 2007). Better knowledge of the ability to use everyday technology in persons with MCI is important both to increase awareness of the challenges they are likely to meet in everyday occupations, and also to identify areas where support is needed. The studies in this thesis address these issues from the perspective of the persons with MCI. Accordingly, the overall aim of this thesis was to provide new knowledge of everyday technology use and functioning over time, as perceived by persons with cognitive decline due to MCI. A secondary aim was to increase knowledge about their views on technology as part of and potential support in everyday life.

EVERYDAY OCCUPATIONS WHEN AGING

Theoretical framework

The profession and scholarship of occupational therapy rest on the view that humans have an active nature (Kielhofner, 2004). This nature is reflected in an innate need and drive to do things in order to discover, develop, and enjoy our competencies (Wilcock, 1993), to shape our identities and find purpose and meaning in life (Christiansen, 1999). By doing everyday occupations within the broad areas of activities of daily living, play, and productivity we maintain our selves and our lifestyles, recover and enjoy ourselves, and provide services or commodities to others in different ways throughout life (Kielhofner, 2004, 2008). Activities of daily living (ADL) are commonly divided into basic ADL (BADL), including self-care activities such as bathing, dressing, and eating, and instrumental ADL (IADL) referring to more complex activities within the home and community, such as community mobility, financial management, meal preparation and cleanup, and shopping (American Occupational Therapy Association, 2008). Based on

the core belief that occupations are central to human life and beneficial for health and well-being (Wilcock, 2006), the focus for occupational therapy is to address problems of participation in occupations (Kielhofner, 2004). Such problems are common in older adults who face the challenges of cognitive decline, but little is known about how their possibilities to participate in occupations develop over time in the technology-dense context of today.

Occupational therapists often add different meanings to the concepts of activity and occupation, but interchangeable use is also common. As Studies I, II, and III rely on questionnaire-based data of frequency of involvement in a set of predefined activities in daily life, the concept of everyday *activity* was used in connection to these studies. This is in line with the view that the concept of activity reflects and enables communication about “a culturally defined, general class of human actions” (Pierce, 2001, p.139). In Study IV the concept of *occupation* was chosen to emphasize the breadth and more subjective meaning of the everyday doings described in the qualitative findings (American Occupational Therapy Association, 2008). Even though the format of data gathering in Studies I-III did not capture subjective meanings, it can be assumed that many of the activities in these studies do carry such meanings for the participants. Therefore, I use the concepts of activity and occupation interchangeably when discussing the findings of the four studies in this thesis.

Understanding the interaction between person and environment

To facilitate understanding of how interactions over time between persons with MCI and their contexts may influence their everyday occupations and technology use, the theoretical framework of the *model of human occupation* (MOHO) was used in this thesis (Kielhofner, 2008). MOHO is a conceptual model intended to support occupational therapy practice and research by explaining human occupation. Additionally, MOHO describes doing at different levels, and recognizes that this doing is influenced by, and in turn influences, both the personal and environmental conditions. Personal aspects shaping why and how we do things are our values, interests, perceptions of competence, roles, habits, and performance capacities. When these interrelated aspects of the person and the physical and social environment interact, the outcome is occupational performance. MOHO recognizes that the context has great impact on what we do and how we do things, and everyday technologies such as electric household appliances and information and communication technologies (ICT) are part of this context. The environmental aspect of everyday technology may offer opportunities and support the doing of older adults with cognitive decline, but it may also entail demands and constraints. For example, the possibility to add reminders in a

cell phone might compensate for memory impairments and contribute to giving the user a sense of control. But on the other hand frequent reminders may be perceived as stressful, and a multi-layered interface of a cell phone, requiring several actions to be performed in a specific sequence, may make it too complicated to set the reminder alarm.

The explanation in MOHO of how a person's motivation, habits, and performance capacity interact with the social and physical environment to determine the environmental impact, build on the *competence-press model*, also known as the *general ecological model of aging* (Lawton & Nahemow, 1973). This model defines the ecology of aging as "a system of continual adaptations in which both the organism and the environment change over time" (p. 621). The competence of a person is a function of aspects such as cognitive, psychological, and physical abilities, while the environmental press is the contextual demands that may be problematic, stress-evoking, and of varying complexity and intensity. The competence-press model illustrates the zone of optimal match between competence and environmental press, where adaptive behavior and positive affect are the outcomes. In the above example, an easy-to-use cell phone demanding few actions in sequence to set a reminder alarm might offer an optimal match with the competence of the user with cognitive impairment, enabling him or her to use the cell phone as a means to structure the day, and thus feel secure and in control.

The *environmental docility hypothesis* within this framework assumes that a person with less competence is more vulnerable, in the sense that his or her adaptive behavior is more dependent on environmental factors than is the behavior of a person with more competence (Lawton & Nahemow, 1973; Lawton & Simon, 1968). That is, person-environmental fit problems are likely in persons with low competence (for example due to cognitive impairments) if a supportive environment (for example everyday technologies with intuitive design, or support from family members) is lacking. This hypothesis has been useful in the first three studies in this thesis as a basic assumption of how individual characteristics and environmental conditions may affect technology use and activity involvement in persons with cognitive decline due to MCI. Less perceived ability in technology use and withdrawal from activities may according to this framework indicate that more person-environmental fit problems are encountered. The same lines of thought are visible in MOHO's view on the environmental impact of occupational performance. The MOHO framework, with its greater emphasis on the importance of the motivation and habits of the person interacting with the environment, underlie the questionnaire used to assess everyday technology use in Studies I-III and guided Study IV.

Changes in everyday occupations

Healthy aging

Because the functional changes in MCI are very subtle and therefore difficult to differentiate from changes in healthy aging, this section gives an overview of how age-related changes in everyday activities is elaborated on in MOHO and three major theories within gerontology.

MOHO acknowledges that persons typically engage in different occupations across the life span. In later adulthood it is common that productivity and achievement become less important, while values concerning family, community, and leisure gain in significance. However, losses of capacity and roles that follow along with aging often constrain the activity choices of older adults, making involuntary alterations in habits and lifestyle necessary (Kielhofner, 2008). In MOHO the importance of having an engaging occupation in old age is highlighted, which among other things is characterized by intensity through longstanding and regular involvement. This has been shown, for example, in studies of the retirement process (Jonsson, Josephsson & Kielhofner, 2001).

Among gerontological scholars, the question of whether diminishing involvement in activities is a normal effect of old age or an undesirable and evitable outcome has been debated since the introduction of *disengagement theory* (Cumming & Henry, 1961). According to this theory, less involvement in activities and less social interactions reflect personal choice and positive adjustment to old age, which is reinforced by societal expectations. This view has been argued against by followers of the contemporary *activity theory* (Havighurst & Albrecht, 1953), who on the contrary stress the benefits of retaining one's middle-age lifestyle in old age. Activity theorists also recognize that older people generally engage less in activities, but argue that this is due mainly to society's withdrawal from the aging person. Instead society should strive to counteract disengagement, as a maintained lifestyle in old age is thought to be linked to well-being (Havighurst, 1961). *Continuity theory* offers yet another perspective by arguing that older adults seek continuity as they adapt to changes in later life (Atchley, 1989). Importantly, continuity is not thought of as lack of change, but rather as an internal and external coherence in how our ideas, dispositions, preferences, physical and social environments, role relationships, and activities are patterned.

In Studies I-III in this thesis, perceived longitudinal *activity involvement* in persons with MCI is investigated. This approach was chosen as changes in activity involvement – operationalized here mainly as frequency of engaging in complex everyday activities – was hypothesized to be a more sensitive marker of functional change in MCI than the

often-used constructs of independence/dependence (Albert, et al., 2011). That is, our underlying assumption was in line with the activity theory and continuity theory described above – a marked decrease in activity involvement would not in the first place be thought of as a positive adaptation to old age (as disengagement theorists may interpret it), but potentially indicative of withdrawal due to subtle difficulties in performing the activities, related to cognitive decline. This assumed relation of declining activity involvement to cognitive decline has been supported by cross-sectional comparisons between healthy older adults and older adults with cognitive impairments, where the groups with cognitive impairment showed less activity involvement (Nygård & Kottorp, 2014; Pettersson, Engardt & Wahlund, 2002). Thus, the view on activity involvement in healthy aging within activity theory and continuity theory guided the choice in Studies I-III of monitoring activities by frequency of involvement. These theories complemented the theoretical framework of MOHO, which more guided the understanding of how this involvement in activities and use of technology come about over time in the intersection of person and context.

OLDER ADULTS WITH COGNITIVE DECLINE

The participants in this thesis were diagnosed with MCI at inclusion. Based on the heterogeneity of diagnostic outcome over time in MCI (Winblad, et al., 2004), the expected scenario was that during the study time some of the participants would develop dementia of various types, some would remain diagnosed with stable MCI, and yet others would return to normal cognitive functioning. In this section the diagnoses of MCI and dementia are presented, followed by an overview of the consequences in everyday occupations when living with cognitive decline.

Mild cognitive impairment

MCI has during the past decade been the most widely used term to delineate a transitional, and sometimes reversible, state in between the cognitive decline seen in normal aging and the very early symptoms of dementia (Geda & Nedelska, 2012; Petersen, et al., 2014). In 2008, when recruitment started of MCI participants for this thesis project, MCI was generally diagnosed by use of the following criteria: (a) subjectively perceived cognitive decline, (b) objectively verified cognitive impairment compared to normal aging, (c) essentially preserved general cognitive function, (d) largely intact BADL/IADL, and finally (e) no dementia diagnosis warranted, all information from criteria (a)-(d) taken into account (Petersen, 2004; Winblad, et al., 2004). The criterion of intact IADL ability has been much debated since then. Later MCI criteria, elaborated by the National Institute on Aging and the Alzheimer's Association, specifically focused on identifying persons with MCI due to Alzheimer's

disease (AD) (Albert, et al., 2011). These criteria are similarly phrased as the above 2004 MCI criteria, but more explicitly recognize the accumulating evidence of functional impairments already in MCI, for example that persons who have developed MCI take more time, are less efficient, and make more errors than before when performing complex everyday activities (Albert, et al., 2011).

In the latest revision of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) a new term – *neurocognitive disorders* – is replacing what was in earlier editions referred to as “dementia, delirium, amnesia, and other cognitive disorders” (American Psychiatric Association, 2013b). This category is further divided into mild and major neurocognitive disorders. While *major neurocognitive disorder* comprises the earlier entity of dementia, *mild neurocognitive disorder* constitutes a new syndrome diagnosis which in many aspects corresponds to what has previously been known as MCI. However, both major and mild neurocognitive disorders lack the earlier association to older ages (Ganguli, 2013). Additionally, the DSM-5 definition of mild neurocognitive disorder requires more severe functional impairment than did the former MCI criteria (Breitner, 2015). The new diagnosis implies “a level of cognitive decline that requires compensatory strategies and accommodations to help maintain independence and perform activities of daily living” (American Psychiatric Association, 2013a). The upcoming revision of the International Classification of Diseases (ICD-11) is expected to follow this new terminology (Luciano, 2014). A recent epidemiological study, comparing MCI prevalence when applying both the 2004 MCI criteria and the new DSM-5 criteria for mild neurocognitive disorder, concluded that estimated prevalence of MCI halved in a sample of +55-year-olds when the new criteria were used (Lopez-Anton, et al., 2015). This has raised concerns regarding reduced sensitivity for early detection of MCI due to AD when applying the new DSM-5 criteria, i.e. risk of omitting true-positives (Breitner, 2015). However, from an occupational therapy perspective an important advantage of the new criteria is that the functional problems experienced in everyday activities by many persons with MCI/mild neurocognitive disorder are now likely to be more recognized and known. This is an important starting point for identifying suitable ways to support this group. But it also challenges the tools used for evaluation, both in relation to the functional domains addressed, and in relation to sensitivity to detect subtle problems.

Prevalence of MCI reported in the general population varies greatly, spanning from 3% to 42% (median 26.4%), depending on definition used and age span in the samples studied (Ward, Arrighi, Michels & Cedarbaum, 2012). In most studies prevalence estimates range from 16% to 20% (Roberts & Knopman, 2013). MCI and the new diagnostic entity of mild neurocognitive disorder refer to a heterogeneous syndrome

with multiple possible etiologies, e.g. progressive neurodegenerative disorders, vascular disorders, trauma, or psychiatric disorders (American Psychiatric Association, 2013b; Ganguli, 2013; Winblad, et al., 2004). This also entails heterogeneous prognosis in MCI which can be progressive, static, or reversible. Persons with MCI are at increased risk of developing dementia compared to the general population, but in the same way as for prevalence, different definitions and also settings produce varying estimates for conversion (Sachs-Ericsson & Blazer, 2015). A meta-analysis of progression from MCI to dementia reported annual conversion rates of approximately 10% at specialist settings and 5% in community settings (Mitchell, 2009). Reversion to normal cognitive function also occurs in MCI; on average 20% will improve over time (Roberts & Knopman, 2013). To date pharmacological treatment of MCI is lacking (Cooper, Li, Lyketsos & Livingston, 2013; Sachs-Ericsson & Blazer, 2015).

Dementia

Dementia is an umbrella term for clinical syndromes caused by neurodegeneration, with the shared characteristics of significant and progressive deterioration in cognitive domains such as memory, language, and executive functioning leading to impaired ability to perform ADL independently (American Psychiatric Association, 2000). The deterioration progresses from mild, to moderate and severe stages. AD is considered to account for 60% to 80% of all dementia cases (Sosa-Ortiz, Acosta-Castillo & Prince, 2012); other common underlying pathologies are vascular dementia, Lewy body, and frontotemporal dementia (Prince, et al., 2013).

The diagnostic distinction between MCI and dementia is largely based on the degree to which the cognitive impairment causes impaired ability to perform everyday activities. In MCI a person is still able to perform complex IADL independently or with minimal assistance despite mild problems (Albert, et al., 2011; Petersen, 2004) while a person who has progressed to dementia has impaired BADL/IADL ability due to the cognitive decline (American Psychiatric Association, 2000).

Most world regions report 5% to 7% prevalence of dementia in those aged 60 years or more (Prince, et al., 2013). In 2010, 35.6 million people around the world were estimated to be living with dementia, a number that is expected to double every 20 years (Prince, et al., 2013). However, many dementia cases are unidentified; as many as 28 million of those afflicted have not received a formal diagnosis (Alzheimer's Disease International, 2011). To date there is no cure for AD, but pharmacological treatment to slow the disease process is available, which may postpone or slow down decline in IADL ability (Wattmo, Wallin, Londos & Minthon, 2011) and prolong the time persons with AD continue to live in their own homes (Geldmacher, Provenzano, McRae, Mastey

& Ieni, 2003). This means increasing numbers of persons with cognitive decline who need to manage everyday life activities in the contexts of their own homes and in public space, activities that often involve use of everyday technologies.

As mentioned, this thesis included persons with MCI according to the 2004 MCI criteria (Petersen, 2004; Winblad, et al., 2004). At clinical follow-ups over the study time some participants converted to dementia as diagnosed by DSM-IV (American Psychiatric Association, 2000) or the similar ICD-10 criteria (World Health Organization, 2008). Lately DSM-5 has introduced the new terminology of mild and major neurocognitive disorders (American Psychiatric Association, 2013b). However, as mild neurocognitive disorder is a recently defined diagnosis, our understanding of it still rests mainly on research of MCI (Sachs-Ericsson & Blazer, 2015). Due to this, and as the concepts of MCI and dementia were dominant in research and clinical practice during the larger part of this doctoral project, I will predominantly maintain the use of these two terms in this thesis.

Everyday occupations in older adults with cognitive decline

Because impaired ability to perform everyday activities independently is part of the diagnostic criteria for dementia (American Psychiatric Association, 2000, 2013b), it is not surprising that impaired IADL have been identified as risk factors for progression to dementia in MCI. This has been demonstrated in samples in the community (Fauth, et al., 2013), in primary care (Luck, et al., 2012), as well as in memory clinics (Sikkes, et al., 2011). The advantages of early detection of cognitive decline, including access to treatment, information and support (Alzheimer's Disease International, 2011), make research aimed at identifying specific everyday activities likely to be affected early in MCI highly significant. From a medical perspective early detection is crucial for the possibility to initiate modifying drugs, while from an occupational therapy perspective early detection is important as it makes possible early interventions building on preserved abilities.

Over the past decade increasing numbers of studies have demonstrated subtly impaired IADL ability already in MCI. A review including 37 studies of IADL performance in MCI found that IADL deficits were documented in 35 of the studies (Jekel, et al., 2015). The authors conclude that it is difficult to discern specific IADL domains as typically impaired in MCI, but IADLs requiring higher cognitive functioning seem to be most affected. However, detection of the often subtle changes in IADL ability requires sensitive assessment methods (De Vriendt, et al., 2013; Gold, 2011; Kottorp & Nygård, 2011).

Managing finances and medication, as well as using telephone and transportation are everyday activities repeatedly being reported as impaired among persons with MCI in cross-sectional research (Barberger-Gateau, Fabrigoule, Rouch, Letenneur & Dartigues, 1999; Gold, 2011), and if impaired also predictive of dementia (Peres, et al., 2008). Additionally, cross-sectional research has indicated that older adults with cognitive decline involve less in everyday activities than healthy older adults already in the MCI stage (Nygård, Pantzar, Uppgård & Kottorp, 2012), especially in activities that are performed outside the home (Nygård & Kottorp, 2014). Others have reported less involvement in cognitive activities (sometimes also termed mental or intellectual activities) such as computer-based activities, craft activities, playing games, reading books, as well as less engagement in social activities such as travelling, in persons with MCI compared to the involvement of healthy older adults (Geda, et al., 2011). In many of the complex activities above, for example managing finances, using telephone and transportation, and computer-based activities, use of everyday technology is a prerequisite (Kottorp & Nygård, 2011).

The withdrawal from complex activities in MCI has been observed as generally being a slow process, often caused by a combination of life events, where discontinued activities sometimes are intended to be resumed again later at an anticipated improvement (De Vriendt, et al., 2012). At the same time worries about future loss of valued occupations are common in persons with MCI (Berg, Wallin, Nordlund & Johansson, 2013). Avoiding certain occupations, as well as preparing for them days ahead, have been described as self-initiated strategies to reduce MCI-related stress (Berg, et al., 2013). Other adaptation strategies used to enable continued valued occupations are performing them in an easier way, enlisting help from other persons, and using external aids such as memo notes (De Vriendt, et al., 2012). Persons with MCI have reported noticing their subtle functional changes when making occasional and unexpected minor errors, for example in sequencing a task, finding themselves doing activities in a slower manner, and having problems with multitasking (De Vriendt, et al., 2012), which have also been observed in performance-based assessment (Giovannetti, et al., 2008) and information from proxies (Jefferson, et al., 2008). Some studies have tried to identify specific activities where disability is first noticed during cognitive decline. A two-year study found items regarding finances, medication, and outings to be compromised first, followed by leisure and housework (Arrighi, Gélinas, McLaughlin, Buchanan & Gauthier, 2013). Later, as cognitive decline advances in dementia, difficulties in BADL also occur. This late functional decline also follows a hierarchical order, with problems in personal hygiene and dressing generally debuting before problems in eating and transferring (Arrighi, et al., 2013; Delva, et al., 2014).

Persons with MCI continue to live in their own homes, and this is also true for most persons with dementia. In high-income countries about 78% of the persons with dementia reside at home; in low- and middle-income countries the percentage is 94% (Wimo, Jönsson, Bond, Prince & Winblad, 2013). Thus, especially persons in the mild and moderate stages of a dementia disease continue to perform everyday occupations at home and in public space while facing a range of problematic situations (Brittain, Corner, Robinson & Bond, 2010; Brorsson, Öhman, Cutchin & Nygård, 2013; Brorsson, Öhman, Lundberg & Nygård, 2014). In Sweden, national guidelines highlight the importance of facilitating meaningful activities for persons with dementia, when feasible by support from assistive technology for cognitive support and ICT (National Board of Health and Welfare, 2010). However, these guidelines do not cover or describe recommended support to persons with MCI. Consensus regarding presence of functional decline in MCI has taken time to achieve within the research community, and detection of this decline is methodologically challenging. The lingering expectation of largely intact IADL in persons with MCI has likely contributed to health care personnel's low awareness of potentially unmet needs of support in their everyday occupations.

In conclusion, cognitively demanding everyday activities are most affected in MCI, although not as severely as in dementia, and many of these activities are likely to include use of everyday technologies such as computers and cell phones. To gain further knowledge of how functional decline evolves over time, detailed longitudinal descriptions of IADL function in persons with MCI have been called for (Sikkens, et al., 2011; Yeh, et al., 2011) but are still rare. For example, longitudinal studies of involvement in complex activities among persons with MCI including information of their technology use are yet lacking. The challenges and potentials of technology in the everyday life activities of persons with MCI or dementia will be addressed in the next section.

TECHNOLOGY USE IN EVERYDAY LIFE

Everyday technology

In this thesis the concept of *everyday technology* (ET) is used to delineate the range of technical objects and services that commonly exist in peoples' everyday lives, both in their homes and in the community. ET has earlier been defined as “technical objects (artifacts and systems) which are used or designed to be used on a daily base, or more seldom but habitually” (Hagberg, 2008; Larsson, 2009, p. 20). This definition is adopted here, with the addition of including the services accessed through the technical objects, for example internet banking or sending text messages. An artifact denotes a man-made object that has been produced for a certain purpose (Östlund, 2013). More specifically,

technical artifacts have been suggested to have one general function in common that distinguishes them from other artifacts (such as sculptures or toys) – the function to extend human capability (Lawson, 2008). In the definition of ET adopted here, technical artifacts are the objects themselves, for example a cell phone or a stove, while technical systems refer to the systems to which these artifacts sometimes are connected, such as the internet or the electricity network (Hagberg, 2008). Based on earlier research findings (Nygård & Starkhammar, 2003; Nygård & Starkhammar, 2007) and clinical experience, well-established mechanical artifacts (e.g. analogue cameras or egg timers) as well as newly developed electronic equipment (e.g. tablets or self-service check-out stations in stores) may present challenges to persons with cognitive impairment. In this thesis the concept of ET therefore spans a wide range of both familiar and more recently developed technical objects and services of varying complexity encountered in everyday life.

When discussing the entirety of these technical objects and services, the concepts *technological landscape* and *technological room* will be used. The technological landscape is defined as the technical artifacts and systems people may use or encounter in their everyday doings at a given point in time (Hagberg, 2008), both within the home and in interactions with the community. Different parts of this landscape may come within reach of the individual to varying degrees under different circumstances. The part of this larger landscape that a person more permanently disposes, for example the technology in the home, represents the person's technological room.

ET is conceptualized in the MOHO as objects in the physical environment with which people interact. The properties of these objects, for example their complexity and familiarity, have a strong influence on how a person uses them and how the use is experienced (Kielhofner, 2008). Complex design, for example, makes ET more difficult to use (Patomella, Kottorp, Malinowsky & Nygård, 2011). More specifically, ETs requiring older adults to choose the correct button or command, identify services and functioning, and perform actions in logical sequence, are likely to be more challenging to use (Malinowsky, Nygård & Kottorp, 2011). In contemporary society, ET has become increasingly present in people's homes and in the community, thus influencing the conditions for performing many everyday occupations (Hagberg, 2008; Wahl & Mollenkopf, 2003). Consequently, access to and ability to use ET, and also ability to adapt to changes in the growing technological landscape have become important prerequisites for participation in occupations and in society (Czaja, et al., 2006; Mitzner, et al., 2010; Selwyn, 2006). This describes the situation for older adults in Sweden, where the research for this thesis has been conducted, and is similar in all parts of the industrialized world (Wahl & Mollenkopf, 2003).

Older adults as users of everyday technology

The participants in the studies in this thesis were 56-82 years old at inclusion, and are referred to as older adults. Especially the oldest participants – born in the 1920s – have during their lifetimes experienced a tremendous technological development in regard to ET. For all, the digitalization accelerating from the 1980s of many ETs common in the home environment, such as dishwashers, microwave ovens, and personal computers, took place during their adulthood (Wahl & Mollenkopf, 2003). Generally, older adults adopt technology innovations later than younger people do (Sackmann & Winkler, 2013; Selwyn, 2006), partly as the main expansion of peoples' technological rooms seems associated to the period of life when starting a family (Hagberg, 2008), and also due to birth cohort-related differences in pattern of technology adoption and use, such as which interface one is used to (Sackmann & Winkler, 2013). Despite the fact that older adults use a wide range of ETs (Mitzner, et al., 2010), they tend to possess and use less ET – both household technologies and ICT – than younger people do (Czaja, et al., 2006; Wahl & Mollenkopf, 2003). For example, older age predicts use of less ICT (Czaja, et al., 2006; Heart & Kalderon, 2011; Selwyn, Gorard, Furlong & Madden, 2003), even though the presence of ICT in older adults' lives is steadily increasing (Statistics Sweden, 2013). In 2014, 75% of Swedish persons aged 55-64 years used laptops, 67% used smartphones, and 44% used tablets to access internet at home. The corresponding percentages for those aged 65-74 were lower (65%, 43%, and 27% respectively), and for those aged 75-84 the percentages were approximately halved compared to those born a decade later (37% for laptops, 18% for smartphones and 13% for tablets) (Statistics Sweden, 2014). An “aging turn” has been described, when old age in itself makes people re-evaluate their views on appropriating new technology and even makes them discard certain ETs or avoid replacing broken ETs, as these are losing in importance (Hagberg, 2008; Larsson, 2009).

However, the stereotype picture of older people as generally resistant to technology is false. Instead, a multifaceted palette of attitudes to technology among older adults has been found (Mitzner, et al., 2010; Wahl & Mollenkopf, 2003), as well as a wide range of motives for use and non-use of both household technologies and ICT (Melenhorst, Rogers & Bouwhuis, 2006; Mitzner, et al., 2010; Wahl & Mollenkopf, 2003; Östlund, 2013). Older adults seem to be pragmatic in their choice of adopting new technology or not (Östlund, 2013) and perceived benefit of the technology has been shown as more decisive than the cost in terms of efforts and expenses, or the lack of skills (Melenhorst, et al., 2006; Mitzner, et al., 2010). Also, in line with continuity theory (Atchley, 1989), lifelong habits regarding attitudes to and experiences with technology have been found to predict ownership and use of both household appliances and ICT in older adults

(Wahl & Mollenkopf, 2003). Other factors that are associated with use and non-use of ET are education, income, and health status (Czaja, et al., 2006; Selwyn, 2006; Wahl & Mollenkopf, 2003).

The use of ET by older adults in general has been described above. Older adults with cognitive decline due to MCI can be assumed to share many of the discussed conditions regarding how their technological rooms have developed under the influence of age and aging, diverse attitudes towards technology, earlier habits and experience, socio-economic status, and health. They also share everyone's experience of living in a growing and increasingly complex technological landscape, but are likely more vulnerable to these changes (Lawton & Nahemow, 1973). For example, as e-health services such as online health guides and e-prescriptions (Jung & Loria, 2010) become more common, the widespread non-use of ICT in the oldest age group may risk excluding them from relevant health care services. This risk may be especially important to consider in older adults with cognitive impairments (Czaja, et al., 2013; Malinowsky, Nygård & Kottorp, 2013). Next I will introduce how cognitive impairment due to MCI or dementia affects use of ET in older adults. To date this knowledge base builds mainly on cross-sectional research, that is, very little is known of how ET use develops over time during cognitive decline.

Cognitive ability has been shown to affect how many types of ETs people use (Czaja, et al., 2006) and how efficient this use is (Slegers, Van Boxtel & Jolles, 2009).

Nonetheless, as for older adults in general (Mitzner, et al., 2010), a wide range of ETs exists in the homes and surroundings of persons with cognitive impairment due to MCI or dementia (Nygård, 2008b; Nygård, et al., 2012; Rosenberg, Kottorp, Winblad & Nygård, 2009). However, when comparing groups of older adults with and without cognitive impairments, less ET is perceived as relevant in those with MCI, and even less in those with dementia (Nygård, et al., 2012; Rosenberg, Kottorp, et al., 2009), suggesting a process of gradually moving into narrower technological landscapes. Furthermore, in earlier research, both perceived (Nygård, et al., 2012; Rosenberg, Kottorp, et al., 2009) and observed (Malinowsky, Almkvist, Kottorp & Nygård, 2010) ability to use ET is on a group level significantly lower in persons with MCI compared to that in controls, and even lower in persons with dementia. However, in all these studies overlaps in ET ability between groups have been found, i.e. some persons with high ability to use ET are also found in groups with dementia, and persons with low ability appear also in groups of healthy older adults. This pattern of less ability to use ET in groups with more cognitive impairments persists in studies including persons with cognitive impairments of other etiologies, such as acquired brain injuries (Fallahpour,

Kottorp, Nygård & Lund, 2014; Kassberg, Malinowsky, Jacobsson & Lund, 2013) and intellectual disabilities (Hällgren, Nygård & Kottorp, 2014).

Generally, domestic ET, such as coffee maker, stove, electric kettle, and microwave oven, are perceived and observed to be easier to use by older adults with and without cognitive impairments, while complex ICT items, like cell phones or computers, are more difficult (Malinowsky, Kottorp & Nygård, 2013; Patomella, et al., 2011). Thus, it is likely that ET may facilitate some occupations in everyday life for persons with MCI, such as preparing meals, dishwashing, and doing housework, while complicating others, for example communicating or searching for information. Interestingly, the above ICT items more likely to be difficult to manage are often needed when managing finances, using a telephone, doing computer activities, and social activities, which as mentioned have been identified as affected early in MCI (Geda, et al., 2011; Gold, 2011). On the other hand, these and other ICT items offer several opportunities that have the potential to compensate for cognitive impairments (de Joode, van Heugten, Verhey & van Boxtel, 2010; Linden, Lexell & Larsson Lund, 2011), and may thus be both parts of the problem and parts of the solution.

Although some ETs are likely to imply challenges for persons with MCI or dementia, it is also important to acknowledge that ETs may be perceived as highly motivating to continue using or to learn how to use for persons with cognitive impairment, despite difficulties. ETs often carry symbolic meanings (Kielhofner, 2008), and striving to use certain ETs, such as an up-to-date smartphone, can serve as a means to preserve one's self-image (Nygård, 2008b). Embodying the technology (Nygård, 2008b) by frequent use and support from others (Nygård, 2008b; Rosenberg & Nygård, 2014) have been shown to make it possible for persons with MCI or early dementia to continue using existing or learning to use unfamiliar ET when a strong need is experienced (Kielhofner, 2008; Nygård, 2008b; Rosenberg & Nygård, 2014).

The empirical knowledge base of the relationship between ability in ET use and everyday occupations in older adults with MCI or dementia is still very limited, and rests on a few qualitative and cross-sectional studies. In a mixed sample of older adults with AD, MCI, and controls, a significant positive association of $r=0.56$ was found between perceived ability to use ET and activity involvement (Nygård, et al., 2012). Another study has found stronger associations between perceived ability to use ET and activity involvement in groups with MCI or dementia compared to those in controls (Nygård & Kottorp, 2014). This suggests that difficulties in ET use may increasingly challenge a person's possibility to remain active as cognitive decline progresses. However, another study has found, on the contrary, stronger associations between perceived ET ability and observed IADL performance in MCI, compared to those in

mild AD (Ryd, Nygård, Malinowsky, Öhman & Kottorp, 2015). Longitudinal research is needed to investigate this relationship further.

Assistive technology and AAL technology

In addition to the potential ET may have to facilitate everyday occupations for older adults with cognitive impairment, support aimed at compensating for reduced cognitive abilities and enabling continued participation in occupations can also be provided by *assistive technology* (AT). As Study IV in this thesis concerns both existing ET and potential future technology, this section gives an introduction to AT for cognitive support and so-called *ambient assisted living* (AAL) *technology*.

The boundaries between ET and AT are blurred. For example, a smartphone or a computer can be considered ET in one situation, while regarded as AT in another, depending on whether its purpose is to meet a need related to a disability (Lindqvist, 2012). AT is defined in Sweden as products or systems aimed at (a) compensating for deteriorated or lost function or ability, (b) improving or preserving, or (c) preventing future loss of function or ability in persons with disabilities (Swedish Agency for Participation, 2014). By its design, and by the applications used in a smartphone, its potential to meet such objectives may vary radically. In Sweden, the main difference between ET and AT is how they are acquired; people have to purchase ETs themselves, while many ATs are funded by tax revenues and prescribed by health care professionals according to specific regulations (National Board of Health and Welfare, 2013).

A new type of assistive technology, still largely in a prototype state, is AAL technology. The concept denotes assisted living technologies based on ambient intelligence, i.e. digital environments that are sensitive, adaptive, and responsive to human needs (Rashidi & Mihailidis, 2013). AAL technologies are aimed at providing older or otherwise vulnerable persons with a safe environment and improved quality of life, and furthermore at reducing costs for health and social care (Cardinaux, Bhowmik, Abhayaratne & Hawley, 2011). In light of the growing populations of aging post-1945 baby boomers in Europe and other parts of the developed world, much hope is directed at future possibilities for aging well at home using support from AAL technology despite issues like cognitive impairments (European Commission, 2012).

AAL systems gather data from the given context and the user by either embedded sensors in the environment, e.g. magnetic switches or cameras, or mobile and wearable sensors, which can be integrated in items like smartphones or even in clothing by use of smart fabrics (Rashidi & Mihailidis, 2013). This exemplifies how ET, AT, and AAL become increasingly intertwined, as existing technologies are connected to new systems

(Greenhalgh, et al., 2013; Procter, et al., 2014). To date real world usage beyond research prototypes and pilot studies is still fairly limited for most AAL systems (Memon, Wagner, Pedersen, Beevi & Hansen, 2014). However, there are hopes that computer vision-based AAL solutions will be able to detect deviances in complex activities such as cooking and housework, and automatically support activity performance by well-timed prompts useful for persons with cognitive impairments (Cardinaux, et al., 2011). Automatic scheduling and flexible reminders of daily activities, and navigation assistance tools for persons with early dementia are also promising initiatives (Rashidi & Mihailidis, 2013). It is important to gain more knowledge of how persons with MCI relate to AAL technologies like these, and also to existing ETs, as potential support in daily life.

RATIONALE OF THE THESIS

Based on the state of our present knowledge as presented in the introduction, the research described in this thesis intended to address the following knowledge gaps. Firstly, most studies concerning functional ability in older adults with MCI have so far been cross-sectional, even though an emerging knowledge base exists of how IADL are affected over time in cognitive decline due to MCI. It is still uncertain which areas of IADL are likely to be compromised first. Moreover, empirical cross-sectional findings have established that ET use is affected by cognitive impairment. However, longitudinal studies of functional ability in persons with MCI, including their use of ET are lacking, and very few studies have investigated how ET use and everyday occupations are related in the everyday lives of persons with MCI. To our knowledge none have been longitudinal. Therefore, knowledge is needed of how persons with MCI perceive the consequences of cognitive decline over time, regarding involvement in activities and use of technology. More knowledge is also needed concerning how they view technology as an actual or potential support in everyday life. Taken together, this knowledge is important, as it may guide health care professionals, especially occupational therapists, in timely identification of key areas where support may be needed for clients with MCI.

RESEARCH AIMS

OVERALL AIM

This thesis aims to provide new knowledge of ET use and everyday functioning over time, as perceived by persons with cognitive decline due to MCI. A secondary aim is to increase knowledge about their views on technology as part of and potential support in everyday life.

Specific aims for the studies

To explore patterns of different aspects of functioning in everyday life over two years in older adults with MCI, with special focus placed on changes in the perceived ability in ET use and involvement in activities. (Study I)

To examine ET use over time in older adults with MCI by empirically testing five predefined assumptions regarding factors potentially influencing the amount of ET used. (Study II)

To deepen the knowledge about longitudinal involvement in a range of everyday activities in older adults with cognitive decline, and to provide new knowledge about the associations over time of perceived ability in ET use and perceived activity involvement in this population. (Study III)

To explore how persons with current or recent experience of living with MCI relate to technology as a part of and potential support in present and future everyday life. (Study IV)

METHODS

STUDY DESIGNS

This thesis includes four studies building on data from the same cohort of older adults with MCI at inclusion. In Studies I, II, and III longitudinal instrument-based data were collected to develop knowledge of ET use and everyday functioning over time in this population. To explore how persons with MCI relate to technology as a part of and potential support in everyday life, qualitative interviews were used in the fourth study. In Table 1 an overview of the studies is presented.

Table 1. Overview of the focus, design, and research methods in the four studies.

	Study I	Study II	Study III	Study IV
Focus	Exploring patterns of functioning over time	Identifying factors affecting technology use over time	Investigating changes in involvement in everyday activities in relation to ET use	Exploring ways of relating to technology in daily life
Design	Prospective two-year study, quantitative		Prospective four-year study, quantitative	Qualitative grounded theory study
Data collection	Questionnaires used in semi-structured interviews on four occasions over two years		Questionnaires used in semi-structured interviews on five occasions over four years	In-depth interviews on two occasions
Instruments	ETUQ ¹ , FAI ² , MMSE ³		ETUQ ¹ , FAI ² , MMSE ³ , GDS ⁴	
Primary data analysis	Person-oriented analysis of case plots	Mixed-linear-effect model	Differential item functioning; Pearson's correlation	Constructivist grounded theory approach

¹ Everyday Technology Use Questionnaire, ² Frenchay Activities Index, ³ Mini-Mental State Examination,

⁴ Geriatric Depression Scale

PARTICIPANTS

The longitudinal studies (Studies I-III) included older adults newly diagnosed with MCI. Sampling for the qualitative study (Study IV) took place within this sample followed prospectively, four or five years after the initial inclusion. The sampling frame for Study IV was those participants who at year two had still been diagnosed with MCI, i.e. neither had progressed to dementia nor reverted to normal. In the following, criteria for selection and sampling procedures in the longitudinal and qualitative studies, respectively, are presented. A description of the participants at inclusion to Studies I-III and Study IV is found in Table 2.

Sampling Studies I-III

Participants in the longitudinal data collection were recruited consecutively between April 2008 and May 2009 at an outpatient memory clinic in Stockholm, Sweden. All 152 persons diagnosed with MCI by the specialized team at the memory clinic (including physician, neuropsychologist, speech therapist, and nurse) during this period of time were assessed for eligibility based on four inclusion criteria. First, criteria for MCI according to Petersen (Petersen, 2004) and Winblad and colleagues (Winblad, et al., 2004) should be met. These include subjectively perceived and objectively verified cognitive decline beyond what could be expected in normal aging, but not to the extent of fulfilling criteria for dementia. Furthermore, the MCI criteria include intact BADL ability and only minimally impaired IADLs. Second, age should be 55 years or older. Third, the person should be a user of some ET, and fourth, should be able to take part in data collection in Swedish. Exclusion criteria were the presence of other medical conditions in addition to MCI that also might result in cognitive impairment (e.g. Parkinson's disease or stroke), and severe vision or hearing problems impossible to compensate for with appropriate aids.

Seventy-one potential participants (47% of the 152 diagnosed with MCI at the clinic during this time period) did not meet these criteria for selection and were therefore not invited. In addition, 28 persons (18%) were not invited due to other reasons such as being in an overly stressful situation due to the diagnosis given, having ongoing alcohol abuse, or living too far away from the clinic for data collection to be convenient. Fifty-three persons meeting the criteria for selection were given information about the study by staff at the memory clinic. Among them 37 persons (24% of the sampling frame) showed interest in participation and came to constitute the sample in the longitudinal data collection (Table 2). This sample size was judged sufficient according to a calculation of power to detect group differences on the main outcome measure (ETUQ) in an earlier cross-sectional study where the same MCI sample was compared to groups

with dementia and controls (Nygård, et al., 2012). The participants were contacted by one of the data collectors to agree on a suitable time and place for inclusion and baseline assessment.

Table 2. Characteristics of the participants at inclusion.

	Studies I-III	Study IV
Participants	Older adults newly diagnosed with MCI, $n=37^1$	Older adults with MCI, or recent experience of living with MCI ² , $n=6$
Gender, n (%)		
Female	18 (49)	2 (33)
Male	19 (51)	4 (67)
Age, years		
Median (IQR)	67 (11)	76 (15)
Min-max	56-82	61-86
Living condition, n (%)		
Cohabiting	28 (76)	4 (67)
Living alone	9 (24)	2 (33)
In gainful work past 6 months, n (%)		
None	28 (76)	5 (83)
<10 h/week	2 (5)	0 (0)
10-30 h/week	0 (0)	1 (17)
>30 h/week	7 (19)	0 (0)
Education, years		
Median (IQR)	12 (5.5)	14.5 (4)
Min-max	6-20	11-19
MMSE		
Median (IQR)	28 (2)	28 (3)
Min-max	19-30	24-29

¹ In Study I $n=32$, as only those with data from at least three follow ups were analyzed. ² MCI, $n=4$; AD for six months, $n=1$; no known cognitive impairment for 3½ years, $n=1$.

Sampling Study IV

Sampling for Study IV took place between June 2013 and April 2014. Inclusion of participants, data collection, and analysis took place in parallel, as recommended in grounded theory (Charmaz, 2006). This means that emerging findings and gaps detected in early data continuously guided data collection and inclusion until sufficiently rich data to fulfill the aim was obtained. The number of participants was not decided in advance, however it was somewhat restricted by the number of eligible participants in the sample followed longitudinally. Similar criteria for selection as in Studies I-III were applied (see above) with one distinction; persons in the sample who after the two-year follow up had progressed to dementia, or reverted to cognitively normal, were also eligible for inclusion. This decision was based on the assumption that these persons would still be able to provide valuable reflections of everyday life with cognitive decline, based on the fact that the transitions from MCI to dementia are gradual and not sharply defined. Additionally, by including the person who had reverted to normal, more variability in the sample was achieved, as that person was still in gainful work. Altogether six older adults, aged 61 to 86 years, were contacted by telephone, given information about the purpose and practical arrangements of the study, and invited to participate (Table 2). All consented, and time and place for the first interview were agreed upon.

ETHICAL CONSIDERATIONS

When inviting persons with cognitive limitations as participants in research it is particularly important to pay attention to the consent process. This is true, as the capacity to give informed consent has shown to be reduced already in MCI (Okonkwo, et al., 2007), with attenuated pace of decline in this capacity after conversion to dementia (Okonkwo, et al., 2008). To ensure that potential participants are able to *understand* what the research situation implies, *appreciate* the consequences of participating in the research, give rational *reasons* for participating, and finally also *express their choice*, recommendations have been suggested for the consent process involving persons with cognitive impairment. These recommendations include using simple language, reducing information load, repeating information (Okonkwo, et al., 2007), and viewing the process of obtaining consent as continuing over the whole research period (Nygård, 2006). These approaches were adopted in this doctoral project.

Before written informed consent was obtained from the participants they received verbal and concise written information about the purpose of the study, and about what participation in the research would entail. As the data collector in the longitudinal studies who first approached potential participants at the memory clinic also was an

employee at the clinic, extra caution was made to stress that the decision about participating or not would in no way affect future contacts with the memory clinic. It was also stressed that after inclusion, participation could be stopped at any time. Moreover, the above information was repeated verbally in the preparations for each data collection session and the participants were again asked to give verbal informed consent. In this procedure the data collector was responsive to possible indications that the person wanted to withdraw or take a time-out from participating. After year three, one participant was excluded for such ethical reasons. The participant had considerable difficulties answering the questions on her own, and the data collector considered it uncertain that the person still had the ability to give informed consent for continued participation.

When a need for contact with health care professionals was identified during the interviews, assistance to establish such contact was offered. Examples of needs identified were consultation regarding memory aids, assistance in applying for housing adaptation grant concerning stove timer, and help to resume participation in day-care for persons with dementia after relocation to a new neighborhood.

Ethical approval for the studies was obtained from the Regional Ethical Committee in Stockholm, Dnr 2008/304-31/2 (Studies I-II), Dnr 2010/7878-32, and Dnr 2013/617-32 (Studies III-IV).

DATA COLLECTION

Studies I-III in this thesis build on longitudinal questionnaire-based interview data, collected prospectively over two (Studies I and II) or four years (Study III). Data for Study IV were collected through in-depth individual interviews. This section presents the procedures and instruments used. An overview of the data collected is found in Figure 1.

Data collection Studies I-III

Procedures

Data for Studies I-III were collected between 2008 and 2013 by four research assistants and the author, all occupational therapists with clinical experience from work with persons with cognitive impairments. Before initiating data collection, all attended a one-day training course on the administration and scoring of the assessment tools to be used. To further promote inter-rater reliability, any uncertainties regarding scoring arising during the interviews were discussed afterwards in the research team until consensus

was reached. The semi-structured face-to-face interviews were most often conducted in the participants' homes. However, based on the choice of the participants about 20% of the interviews took place in a clinical setting instead. In total the interviews lasted between one hour and a half and four hours, most often about two hours. The longest interviews were prolonged as participants engaged data collectors in conversations and offered coffee breaks.

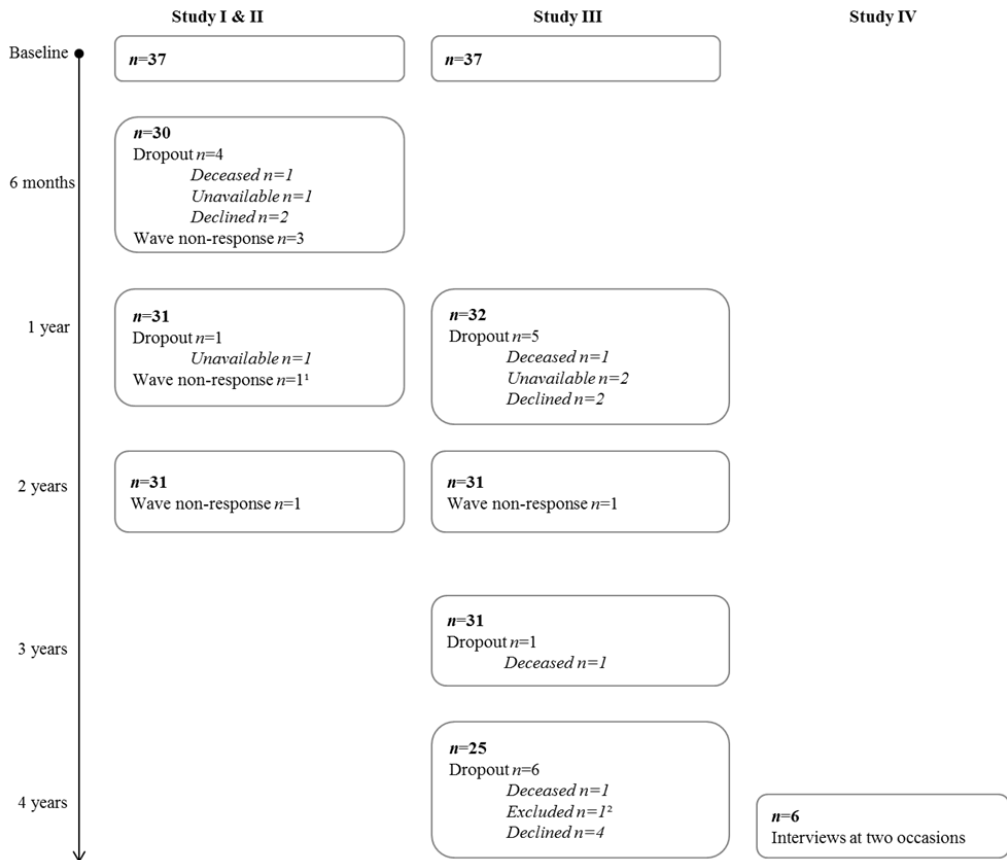


Figure 1. Overview of the time points of data collection in the four studies, and of data available and missing.

Notes: ¹ This person provided data in between 6 months and 1 year; in Studies I and II this data was assigned to the 6-month follow-up, in Study III to follow-up at 1 year. ² Due to ethical reasons.

Part of the questionnaire-based data collection for Studies I-III implied remembering and reasoning about perceived difficulties in the use of 92 different ET items. Based on earlier experiences in the research group, showing that inclusion of a significant other as a memory support can facilitate the interview situation (Rosenberg, Kottorp, et al., 2009), this was allowed for the participants who so wished. However, as the participants' subjective perception of using ET was in focus, the scoring was based on the answers of the participants.

Information regarding diagnostic status was collected from the medical files at the memory clinic ahead of each wave of data collection during the first two years, thereafter at the end of the longitudinal data collection for those who at that point gave written informed consent to this. As mentioned, the 2004 MCI criteria (Petersen, 2004; Winblad, et al., 2004) were used at the memory clinic for diagnosing MCI, and dementia diagnosis was based on ICD-10 (World Health Organization, 2008) or DSM IV criteria (American Psychiatric Association, 2000).

Instruments

The main instruments in Studies I-III were the *Everyday Technology Use Questionnaire (ETUQ)* and the *Frenchay Activities Index (FAI)*, presented in detail below. The *Mini-Mental State Examination (MMSE)* and the *Geriatric Depression Scale (GDS)* were mainly used as background variables, and are therefore presented more briefly. The instruments were used in the following predetermined order, thought to facilitate the interview: (1) ETUQ, (2) FAI, (3) GDS, and finally (4) MMSE.

To access detailed information about ET use among the participants the *Everyday Technology Use Questionnaire (ETUQ)* was used (Nygård, 2008a; Rosenberg, Nygård & Kottorp, 2009). The version of the ETUQ used in this thesis includes 92 technological artifacts and services that are common in the homes and surroundings of older adults in Sweden. The items are divided into eight activity areas, such as household activities (e.g. microwave oven, iron), personal care (e.g. electric toothbrush, hair dryer), and accessibility (e.g. elevator, flushing public toilets). In addition to the 92 ordinary items in ETUQ, extra items may be included if an ET relevant to the respondent appears to be missing in the questionnaire. This was taken into account in Studies I and II, where additional items identified as relevant by five participants or more were included. Ten extra ET items were thus added in the analyses of Studies I and II. During the ETUQ interviews each participant reported whether the ET items were perceived as relevant or not, whether the items were used or not, and, if used, at what level of difficulty. A relevant ET was defined as one existing in the person's life, which was used, or at some

point had been used, or was intended to be used. The scoring was done by the data collectors using the six-step-scale presented in Table 3.

This procedure resulted in individual data on the number of ETs found relevant (i.e. all items scored 1-6), number of ETs currently used (i.e. all items scored 2-6; data used in Study II), and perceived difficulty in ET use (data used in Studies I-III). The Rasch-generated ETUQ person measures indicate less perceived difficulty in ET use, the higher the measure. The construct *perceived difficulty* in ET use was expressed in Studies I and III as *perceived ability* in ET use, as the latter wording facilitated communicating the findings, and I will mainly use that expression here.

Table 3. Description of the scale steps in ETUQ.

Score	Description	Collapsed in the analysis ¹
6	The ET is used with no hesitation or difficulty at all	
5	The ET is used with minor hesitation or difficulty	
4	The ET is used with frequent/major difficulties	}
3	The ET is sometimes/partly used together with another person	
2	The ET is only used together with another person	}
1	The ET is not used anymore, or has not come into use, even if it is available and relevant for the person	
No score	Non-relevant	

Note: ¹ See the Preparatory Rasch analysis section in Data analysis Study I.

Psychometric testing of the ETUQ has primarily used modern test theory methods, more specifically Rasch measurement models. Unidimensionality, rating scale validity, and person response validity have been supported in studies including adults with and without different cognitive impairments (Fallahpour, et al., 2014; Hällgren, Nygård & Kottorp, 2011), including persons with dementia and MCI (Nygård, et al., 2012; Rosenberg, Nygård, et al., 2009). Studies of inter-rater and test-retest reliability are ongoing, but were not available at the time of this data collection.

Table 4. Items and response categories in FAI.

Activity item	Response categories	Group
1. Preparing main meals	0 Never	A
2. Washing up	1 Less than once a week	
	2 1-2 times per week 3 Most days	
3. Washing clothes	0 Never	B
4. Light housework	1 1-2 times in 3 months	
5. Heavy housework	2 3-12 times in 3 months	
6. Local shopping	3 At least weekly	
7. Social occasions away from home		
8. Walking outside >15 min		
9. Actively pursuing hobby		
10. Driving car / Using public transport		
11. Travel outing / Car ride	0 Never	C
	1 1-2 times in 6 months	
	2 3-12 times in 6 months	
	3 At least weekly	
12. Gardening	0 Never	D
13. Household / Car maintenance	1 Light	
	2 Moderate 3 Heavy / All necessary	
14. Reading books	0 None	E
	1 One in 6 months	
	2 Less than one in a fortnight	
	3 More than one each fortnight	
15. Gainful work	0 None	F
	1 Up to 10h per week	
	2 10-30h per week	
	3 Over 30h per week	

The Frenchay Activities Index (FAI) (Holbrook & Skilbeck, 1983) was used to identify changes in perceived activity involvement. The 15-item FAI interview concerns frequency of performing everyday activities during the past three months (items 1-10) or six months (items 11,14,15), while the response categories in items 12 and 13 instead reflect degree of effort, as can be seen in Table 4. The intention of the developers of the FAI was to include complex everyday activities and activities with a social dimension (Holbrook & Skilbeck, 1983), and the item descriptions stress active participation in planning, organization, and performance. In the FAI interview the data collector also did the scoring based on the participants' responses, using a four-step scale grouped into the response structures A-F (see Table 4). Most often the ordinal FAI scores are totaled, with a maximum of 45 points indicating an active lifestyle. This was the approach used in Studies I and II. However, advantages of using Rasch-transformed FAI measures have been suggested (Lin, Chen, Wu, Yu & Ouyang, 2012), and this approach was adopted in Study III. The FAI person measures in Study III reflect more perceived activity involvement the higher the measure, whereas a high FAI item measure mirrors a more challenging activity where involvement is lower.

The FAI has been extensively evaluated in stroke populations (Lin, et al., 2012; Piercy, Carter, Mant & Wade, 2000; Post & de Witte, 2003), as well as in general populations (Han, et al., 2006; Turnbull, et al., 2000). It has been suggested to have the potential to differentiate activity involvement in controls from persons with MCI and dementia (Nygård & Kottorp, 2014; Nygård, et al., 2012). Reasonable inter-rater reliability has been evidenced with good strength of agreement on a majority of the items in persons with stroke (Post & de Witte, 2003), as has test-retest reliability in a general population aged 16 years or older (Turnbull, et al., 2000).

Psychometric testing regarding construct validity of the FAI has mainly used classical test theory, reporting more inconsistent results. Most often multidimensionality has been indicated, ranging from two to four factors (Han, Lee & Kohzuki, 2009; Han, et al., 2006; Holbrook & Skilbeck, 1983). More recently Rasch models have also been used to validate the FAI, suggesting either a unidimensional construct (Hsieh, et al., 2007; Hsueh, Wang, Sheu & Hsieh, 2004), or a two-factor structure of domestic chores and work/leisure (Lin, et al., 2012). Unidimensionality has been supported by evidence of acceptable item goodness-of-fit in a sample of persons with dementia, MCI, and no cognitive impairments (Nygård & Kottorp, 2014).

To provide information of changes in cognition the *Mini-Mental State Examination (MMSE)* (Folstein, Folstein & McHugh, 1975) was used. This global but brief screening tool was developed to measure severity of cognitive impairment and to capture cognitive change. Cognitive functions covered are orientation to time and place, registration of

words, attention or calculation, recall of words, language, and visual construction. Possible scores range from 0 to 30, with higher scores indicating better cognitive functioning. A four-point (mean 3.7) change has been suggested as clinically important (Burbach, Molnar, St. John & Man-Son-Hing, 1999). MMSE is highly sensitive to moderate to severe cognitive impairments (Tombaugh & McIntyre, 1992), but lacks the sensitivity to efficiently differentiate persons with mild AD or MCI from normal controls (de Jager, Schrijnemaekers, Honey & Budge, 2009). Low as well as high educational levels are known to introduce measurement bias in MMSE (Tombaugh & McIntyre, 1992). However, as it is widely recognized in research and clinical practice, MMSE was used in this thesis to describe the cognitive level of the participants over time. All scores were from MMSE screening performed within six months.

A screening for depression was undertaken by using the *Geriatric Depression Scale*, (*GDS*) (Yesavage, et al., 1982). The Swedish 20-item version of GDS includes yes/no questions (e.g. Are you basically satisfied with your life? Have you dropped many of your activities and interests?). Adverse answers are scored one point, and a total score exceeding five indicates possible depression (Gottfries, Noltorp & Norgaard, 1997). Most validation studies cover the 30- and 15-item versions of GDS, where the latter generally has shown better sensitivity and specificity and is recommended for depression screening in elderly (Mitchell, Bird, Rizzo & Meader, 2010). GDS data have so far only been reported to describe the sample at baseline in Study III, but high GDS scores were also taken into consideration when selecting participants for Study IV.

Data collection Study IV

The settings for the qualitative interviews in Study IV were the homes of the participants, based on their wishes. To allow collection of rich in-depth data on how persons with cognitive decline relate to technology in everyday life, yet avoid lengthy and potentially tiresome interviews, at least two sessions were planned for each participant. An interview guide was used, which had been pilot-tested with a cognitively healthy older adult to ensure that the question areas prompted reflections relevant to the aim of the study. The guide was based on the theoretical framework (Kielhofner, 2008) and focused in the first interview on activities, interests, habits, and roles that were important in the daily lives of the participants, why these were important, how the participants managed to carry out these activities and habits and fulfill these roles now, and on changes in these – actual and/or anticipated. The point of departure in the second interview was important activities that the participants had talked about in the previous interview, now exploring how they related to use of current and potential future technology in these activities, and their views of themselves as users of technology in

daily life. Each participant was interviewed twice. The total of 12 interviews, which lasted from about half an hour to an hour and a half, were audio recorded and later transcribed verbatim by research assistants.

DATA ANALYSIS

In Studies I-III different quantitative approaches were used to identify, explore, and describe functional change over time after MCI diagnosis, focusing on ET use and activity involvement. Study IV used a constant comparative method to explore how older adults relate to technology in everyday life at present and for the future, while facing cognitive decline. Below the analytic procedures in each study are described.

Data analysis Study I

To explore patterns of functioning over time in MCI the analysis in Study I was performed in three stages. First a preparatory Rasch analysis of the raw scores generated from the ETUQ interviews was conducted. This was followed by the primary pattern-oriented analysis, taking data regarding perceived ability in ET use, activity involvement, cognitive functioning and all background variables into consideration. Diagnostic outcomes in the patterns identified were examined. Finally the person-oriented approach was contrasted with group level analysis to analyze change in and relations between the main variables.

Preparatory Rasch analysis

A Rasch rating scale model was used to convert the ETUQ raw scores used in Studies I and II into linear person measures, expressed in log-odds probability units (logits), and to examine the validity of these (Bond & Fox, 2007). This was necessary as the ETUQ is constructed to take individual preferences and needs regarding ET use into account, by only scoring items perceived as relevant by the person. Thereby, the number and challenge of ET items assessed differ between persons, and the raw scores need to be transformed into test-free measures to make comparisons between persons possible. A test-free measure of ability is regarded to be independent of which selection of items is used for measuring (Wright & Linacre, 1987). Version 3.61.1 of the WINSTEP software program was used in this analysis (Linacre, 2009).

As a first step the *rating scale validity* of the ETUQ, when used for two years in this MCI sample, was examined. Guidelines for optimization of the effectiveness of the rating scale categories include ensuring (a) at least 10 observations of each category, (b) logical order of advancing average measures based on how categories successively reflect more ability, and (c) that outfit *MnSq* is less than 2.0 (Linacre, 2004). Criteria (a)

and (c) were met in the analysis of the ETUQ scale, but not criterion (b). Consequently, the scale steps in ETUQ that showed to be disordered were collapsed to achieve monotonically advancing category measures. After collapsing scale steps 1 and 2, and steps 3 and 4 (see Table 3), the mean person measures within each response category increased in the desired ascending order. Hence, in the subsequent analyses person measures from a four-category ETUQ scale was used.

To ensure *person response validity* in the generated ETUQ person measures, a goodness-of-fit analysis was also conducted. In this analysis the response patterns from the participants were tested against the underlying assertions in the present Rasch model, which were: (a) the easier the ET, the more likely it is to be managed by any person, and (b) the more able the person, the more likely he/she is to manage harder ETs compared to a less able person. Unexpected responses not matching these assertions, i.e. questioning person response validity, are in a Rasch analysis identified by goodness-of-fit statistics expressed as infit and outfit mean square (*MnSq*) and standardized *z*-values. We considered infit *MnSq* most important to evaluate, as infit problems imply a greater threat to validity than outfit problems. This is because the infit *MnSq* is more sensitive to response patterns to items with difficulty matching the ability of the person. Outfit *MnSq* is instead sensitive to response patterns to items with difficulty far from the person's ability (Linacre, 2002). Criteria used for acceptable goodness-of-fit of the ETUQ person measures were therefore an Infit *MnSq* value of 1.4 logits or less (Wright & Linacre, 1994) associated with *z*-value 2.0 or less (Bond & Fox, 2007). Misfits in 5% of the persons can be expected to occur by chance without questioning the validity of the responses (Bond & Fox, 2007). However, only four of the 129 person measures (3.1%) slightly exceeded the criteria set, which supported the validity and continued use of the ETUQ person measures in the analysis.

Primary pattern-oriented analysis

In Study I a person-oriented approach guided the next step of the analysis. The underlying theoretical perspective in this approach is holistic and interactionistic, emphasizing that the functioning and development of individuals depend on several simultaneously operating factors (Bergman, Magnusson & El-Khoury, 2003). This view encourages analysis where each individual's pattern of data across variables is the basic unit of analysis.

To explore how perceived ability in ET use, activity involvement, and cognitive function interacted in patterns of stability or change over time, individual longitudinal case plots for each variable were created in SPSS (Statistical Package for Social Sciences). The ETUQ person measures and total scores from FAI and MMSE were first

converted into standardized z -values, to facilitate visual comparisons across variables. This visual inspection approach was chosen as the sample size was considered too small for cluster analysis (Bergman, et al., 2003), and was inspired by earlier longitudinal small sample research (Ekstam, Uppgard, Von Koch & Tham, 2007). The means of the individual standard errors (SE) generated by Rasch analysis were used when calculating the standardized z -values, as well as when establishing limiting values for objective and consistent categorization of when a true change was evident in the longitudinal case plots (Kazdin, 2010). In the visual categorization of the case plots, performed independently by two of the authors to ensure reliability, strict guiding criteria for categorizing the case plots as ascending, stable, fluctuating, or descending were used.

The pattern-oriented analysis started with cross-tabulating these four predefined types of case plots for ETUQ and FAI, as the relation of ET use and activity involvement over time was our main interest. This resulted in a 16-cell table where participants were found in nine of the cells, ranging from one to eight persons in each cell. Thereafter the other variables under study (MMSE, disease progression, gender, age, educational level, living conditions, and support at interview) were added to each person's profile, and these profiles were explored through comparisons within and across the nine cells. The main characteristics found pointed to three main patterns of functioning in the sample. Proportions for different diagnostic outcomes at year two were calculated for these patterns as well as for the whole sample. Chi-square statistics (using Fisher's exact significance test, with alpha 0.05) were also computed to examine the relation between conversion to dementia and the patterns of functioning identified when dichotomized as stable/ascending and fluctuating versus descending.

Group level analysis

To complement the person-oriented analysis in Study I, paired t -test was used to compare differences in the sample between baseline and two years on ETUQ, FAI, and MMSE. Additionally, Spearman's rho was used to examine the correlation at baseline between the main variables ETUQ and FAI. Spearman was chosen as the FAI scores were skewed and at ordinal data level (Campbell, Machin & Walters, 2007).

Data analysis Study II

Study II empirically investigated five predefined assumptions regarding factors potentially influencing the amount of ET used over two years' time; these factors were perceived ability in ET use, activity involvement, cognitive and diagnostic status, age group at baseline, and educational level.

ETUQ person measures from the same Rasch analysis as in Study I were used, including the 10 additional ET items of *food processor*, *credit card at gas station (pay with code)*, *electronic key*, *self-service check-out station in store*, *Skype*, *washing machine in laundry room*, *cell phone: MMS*, *cell phone: alarm*, and *cell phone: camera*. By including these, some recent ETs emerging after the development of the ETUQ were also taken into consideration. The outcome variable in Study II was the proportion of ETUQ items used. This proportion was calculated for each person by dividing the number of ETs currently used by the total number of ETs assessed. All responses where ETUQ items were scored 1 (*The ET is not used anymore, or has not come into use, even if it is available and relevant for the person*) was removed from the analysis. The number of ETs used ranged from 11 to 73 over the two-year study time. Due to the additional ET items mentioned above the total number of ETs assessed ranged from 92 to 96.

The proportion of ETUQ items used as well as use of different types of ET were first investigated by descriptive statistics. Standard competition ranking was performed in Excel to describe ETs with the most and the fewest users at baseline and at two years, and ETs with the largest increases and decreases in the number of users over two years.

Using SPSS, a mixed-linear-effect model (Fitzmaurice, Laird & Ware, 2004) was thereafter applied to investigate the time effect of perceived ability in ET use, activity involvement, cognitive and diagnostic status, age group at baseline, and educational level on the outcome variable proportion of ETUQ items used. Inherent in all longitudinal analysis is that between-individual as well as within-individual variation and measurement error impact correlations in each measure repeated over time. Mixed-linear-effect models are efficient in handling correlated data, variations in responses between and within individuals, and unbalanced data where the number of observations differs between subjects (Fitzmaurice, et al., 2004). All predictors were added as time-dependent variables in the model, except age group at baseline and educational level, which were time-independent. A stepwise removal of the least significant variable followed, with alpha set to 0.05. The Bayesian information criterion (BIC) in “smaller is better” form (Weiss, 2005) was used when fitting the model, i.e. to assist the choice of an appropriate covariance structure. Bonferroni correction was applied in multiple comparisons.

Data analysis Study III

Study III aimed to investigate involvement over four years in a range of everyday activities, and to provide new knowledge about the associations over time of perceived ability in ET use and perceived activity involvement. As in Studies I and II, a

preparatory Rasch analysis was conducted using the WINSTEPS software, this time involving four-year data from FAI and ETUQ (see Figure 1). Mixed-linear-effect modeling and differential item functioning (DIF) were used to investigate overall and item-specific activity involvement respectively. Furthermore, person measures from FAI and ETUQ were correlated.

Preparatory Rasch analysis

As in Studies I and II, proper rating scale functioning was first ensured for ETUQ and now also for FAI. In ETUQ the scale steps were collapsed in the same way as in the former analysis, into a four-category scale (Table 3). For FAI a partial credits model (PCM) was used in the Rasch analysis, as the response categories of FAI are divided into six groups (A-F) with different response structures, as shown in Table 4. A PCM examines the category function of a scale with items separated into groups with similar response structures (Linacre, 2000). As the FAI scale steps 2 and 3 were disordered in group D, they were collapsed in that group, resulting in the desired overall monotonically advancing mean category measures in all groups.

For person response validity of ETUQ and FAI the same criteria for acceptable goodness-of-fit were used as in Studies I and II, i.e. infit *MnSq* value of 1.4 or less (Wright & Linacre, 1994) associated with *z*-value 2.0 or less (Bond & Fox, 2007). For both ETUQ and FAI more than 95% of the person measures met these criteria. The Rasch assertions tested in the goodness-of-fit analysis for FAI can be formulated as (a) the easier the FAI activity, the more likely it is to be performed frequently by any person, and (b) the more able the person, the more likely he/she is to frequently perform more difficult FAI activities, compared to a less able person. However, as the response structures vary between FAI activities (see Table 4), comparisons of changes in frequency are mainly meaningful within each item.

In a Rasch analysis the *unidimensionality* of a scale can also be examined, testing to what extent the items included all support the underlying construct that is intended (Bond & Fox, 2007). Goodness-of-fit statistics generated for the items can be used in this procedure. Unidimensionality of the items in FAI (item fit) were examined using stricter criteria than for person fit, as is recommended (Wright & Linacre, 1994). These higher expectations on the items are due to the fact that the difficulties of the items are expected to continue into the future when encountered by numerous persons, while the person abilities are expected to change. Thus, infit and outfit *MnSq* values beyond the range of 0.6-1.4 associated with *z*-values beyond ± 2.0 were judged to indicate misfitting items (Bond & Fox, 2007). All items in FAI met these criteria. Thus, the preparatory Rasch analysis in Study III yielded valid FAI person measures indicating overall level of

perceived activity involvement among the participants in the sample, and valid FAI item measures indicating level of perceived activity involvement for specific items.

Analysis of activity involvement

Four-year data on FAI person measures were thereafter used when investigating the time effect on overall activity involvement in a univariate mixed-linear-effect model. This model has been described in the Data analysis Study II section. In Study III it was performed using the same alpha, correction for multiple comparisons, and information criterion, but fitted to a different covariance structure.

Next trajectories of involvement for each activity item in FAI were examined. To detect whether specific items presented less activity involvement over time than expected, differential item functioning (DIF) in relation to time was examined. In this analysis we controlled for potential changes in the mean FAI person measures over time to capture actual DIF (Petersson, Lilja, Hammel & Kottorp, 2008). Standardized z -value comparisons were calculated between consecutive time points as well as from baseline to year four for each FAI activity item. As a descending activity involvement over time was assumed in the sample (Nygård, et al., 2012), we used $z \geq 1.65$ as significance level to test the one-tailed hypothesis of “This FAI item demonstrates no actual DIF (i.e. not less activity involvement than expected) beyond statistical randomness”.

Correlations

Finally, correlations between FAI and ETUQ person measures at all waves were examined, using Pearson with Cohen’s guidelines for interpretation of effect size, i.e. 0.1 small, 0.3 medium, and 0.5 large. A medium effect size in the social sciences corresponds to effects “likely to be visible to the naked eye of a careful observer”, whereas a large effect size is noticeably larger (Cohen, 1992). The level of significance was set to 0.05.

Data analysis Study IV

The analysis of interview data in Study IV was guided by the grounded theory approach elaborated by Kathy Charmaz, which is influenced by symbolic interactionism. This theoretical perspective has pragmatist roots, and stresses the fundamental role of dynamic action and interaction in the construction of society, reality, and self, as well as of meaning (Charmaz, 2006). Additionally, Charmaz adopts a constructivist perspective in her view of how experiences and interpretations of reality are constructed by participants as well as researchers involved in a study (Charmaz, 2006; Morse, et al., 2009). Taking this ontological and epistemological standpoint means that data is seen as

constructed rather than discovered, and the researcher's analysis is viewed as an interpretive understanding rather than searching for an objective truth. This viewpoint informed our choice of grounded theory approach in Study IV.

As recommended in grounded theory, analysis and collection of data was carried out in tandem (Charmaz, 2006; Glaser & Strauss, 1967). Directly after the initial interviews, field notes were taken and each audio recording was listened through. Transcription of interview data, initial coding, and inclusion of new participants thereafter took place in parallel. The NVivo software was used to facilitate the analysis.

In qualitative analysis it is important to be aware of the risk of unintentionally forcing the data at hand into codes and categories that originate from the researcher's preconceptions, rather than being grounded in data (Charmaz, 2006; Glaser & Strauss, 1967). For example, my preconceptions regarding what drives occupational choices in human beings are influenced by MOHO (Kielhofner, 2008), and the question guide was developed from that perspective. Thus, sensitizing concepts from MOHO, such as interests and habits, served as the point of departure. To avoid forcing data into codes derived from that theoretical framework, the initial coding was performed line-by-line or sequence-by-sequence with the ambition to construct codes that were close to the data, capturing actions, and when helpful using the participants' own words in what are known as in-vivo codes (Charmaz, 2006). The whole analytic process was characterized by constant comparisons, e.g. of data with data, data with existing codes, and new codes with existing codes (Hallberg, 2006). Short descriptions of each code were made to facilitate these comparisons, which spurred merging or splitting of codes. In parallel, longer memos were written to capture early analytic ideas. When the initial coding was completed for all data, questions that highlighted the aim of the study from different perspectives were posed to the data to create an overview of the data at hand, and to help focus the analysis on how the participants related to technology in their doings at present and for the future. Data answering these questions were extracted, sorted, and discussed among the authors. Mind-mapping, where each participant's views on and ways to relate to technology were outlined, was also used to further create an overview and focus on the data regarding technologies (Charmaz, 2006). These steps helped to identify significant leads in the analysis. By continued comparisons of the codes and properties within these leads, three distinct, yet related, categories were identified, which characterized the participants' ways of relating to technology.

FINDINGS

PATTERNS OF FUNCTIONING OVER TIME

The exploration in Study I of how perceived ability to use ET and activity involvement together with other variables interacted in patterns of stability or change revealed a variation of functioning in the sample during the two years following diagnosed MCI. The 32 participants analyzed displayed nine different combinations of longitudinal case plots on perceived ability to use ET and activity involvement, as shown in Figure 2. Among these nine case plot combinations, three main patterns of functioning over time were identified – a *stable/ascending*, a *fluctuating*, and a *descending* pattern. The participants distributed evenly in these three patterns, which are color-highlighted in Figure 2 and further presented below.

Perceived ability to use everyday technology (ETUQ)










		Ascending	Stable	Fluctuating	Descending	<i>n</i> (%)
Activity involvement (FAI)	Ascending					1 (3%)
	Stable					23 (72%)
	Fluctuating					5 (16%)
	Descending					3 (9%)
	<i>n</i> (%)	2 (6%)	14 (44%)	7 (22%)	9 (28%)	32 (100%)

Figure 2. How the 32 participants analyzed in Study I were distributed in three main patterns of functioning: a stable/ascending pattern ($n=10$, white cells), a fluctuating pattern ($n=10$, light gray cells), and a descending pattern ($n=12$, dark gray cells).

Note: Persons circled had progressed to dementia at year two.

Stable/ascending pattern

Seven of the 10 persons in the stable/ascending pattern reported stable functioning over time on both ETUQ and FAI. In three persons a stable case plot on one of these variables was instead combined with ascending functioning on the other, as can be seen in Figure 2. The MMSE case plots also generally remained stable for the persons in this pattern, with the exceptions of one person with fluctuating MMSE pattern, and two with a descending tendency, which however stayed within the criteria set for stable case plots. Four persons (40%) within this pattern progressed to dementia within two years; three of these were among the persons suggesting non-stable MMSE case plots. Two persons, on the contrary, showed reverting cognitive symptoms, and were at year two diagnosed “MCI subjective” and “no known cognitive impairment”, respectively. Median age at baseline was 63.5 years among the 10 persons in this pattern, and 80% had an education of more than 12 years.

Fluctuating pattern

Six of the 10 persons in the fluctuating pattern reported fluctuating functioning over time on ETUQ and stable functioning on FAI. Three persons, on the contrary, reported fluctuating FAI and stable ETUQ over time. Only one person reported fluctuating functioning on both perceived ability to use ET and activity involvement (see Figure 2). The MMSE case plots most often descended slightly below baseline, however remaining classified as stable according to our criteria. In two cases MMSE either fluctuated or descended. Two persons (20%) within this pattern progressed to dementia during the study time, while one person reverted to “no known cognitive impairment”. Median age at baseline was 66 years for the 10 persons in the fluctuating pattern, and 20% of them had more than 12 years of education.

Descending pattern

Most common was the combination of descending ETUQ and stable FAI over time, which was shared by eight of the 12 persons in the descending pattern. Three persons in this pattern showed the opposite combination (see Figure 2). Notably, none displayed both descending ETUQ and descending FAI. The FAI scores at year two were generally below baseline scores, but did not reach our limiting criteria for descending case plots. The same was true for the MMSE scores. Seven persons (58%) in the descending pattern had progressed to dementia at year two. Median age was 69.5 years at baseline for persons in this pattern, and 33% had more than 12 years of education.

In Study I, half of the sample perceived fluctuating or descending ability to use ET over time, while activity involvement was non-stable in only 25% of the persons (Figure 2). This variation for ETUQ and relative stability for FAI over two years were, however, not reflected in the group level analysis of these variables in the same study, which exhibited non-significant decreases. Cognitive functioning, on the other hand, showed a significant mean decrease in year two of -1.1 MMSE points (SD 2.12) $p=0.007$, despite MMSE generally being classified as stable according to our criteria.

Diagnostic outcome

Two years after inclusion, 16 of the 32 participants analyzed in Study I (50%) were still diagnosed with MCI, 13 persons (41%) had progressed to dementia, and 3 (9%) showed reverting symptoms. Percentages differ slightly from Study II, where only the 31 persons contributing data at year two were included in the diagnostic outcome calculation. In Study I the highest proportion of persons progressing to dementia (58%) were found in the descending pattern, but the relationship between a descending pattern of functioning and progression was non-significant when statistically comparing the stable/ascending and fluctuating pattern group with the descending pattern group: chi-square ($df=1, n=32$) =2.50, exact $p=0.150$.

In Study III it was found that of the 25 persons still participating at year four, seven (28%) were still classified with MCI, 17 (68%) had converted to dementia, and one (4%) had reverted to “cognitively normal”. Furthermore, an unpublished analysis of the potential of the three pattern groups identified in Study I to predict diagnostic outcome at year four showed that among the seven persons with MCI at year four, four persons (57%) were found in the stable/ascending pattern of functioning in Study I, two persons (29%) were found in the fluctuating pattern, and one person (14%) was found in the descending pattern. Among the 17 persons with dementia at year four, three persons (18%) were found in the stable/ascending pattern (all with dementia already at year two), six persons (35%) were found in the fluctuating pattern, and eight (47%) were found in the descending pattern at year two. The person who had reverted to normal at year four was found in the stable pattern of functioning in Study I.

EVERYDAY TECHNOLOGY USE OVER TIME

Perceived ability in everyday technology use

As indicated above, the mean perceived ability to use ET did not change significantly on a group level between baseline and year two (Study I); the ETUQ person measures showed a non-significant mean decrease of -0.75 logits ($t = -1.567, df=30, p= 0.128$).

Unpublished data shows that between baseline and year four the mean decrease in the ETUQ person measure was -0.83 logits ($t = -1.186, df = 24, p = 0.247$), which means that the changes in perceived ability to use ET were non-significant also over four years.

Amount and type of everyday technology used

The descriptive findings in Study II showed that the amount of ETs in use in the sample was decreasing from a mean of 56% of the ETUQ items in use at baseline to a mean of 50% in use at year two. This decrease was also shown in Study II as a significant overall time effect on the amount of ET used ($F=5.19, p<0.01$). Despite this overall average decrease in number of ETs used in the sample over two years, it was found in Study II that the number of *users* of specific ET items both decreased and increased. In Table 5 the ET items showing the largest *decreases* in number of users are found, and Table 6 displays the ET items showing the largest *increases* in number of users. As can be seen in Table 6, four of the seven ET items showing the largest increases over two years were additional items not included among the 92 regular ETUQ items.

Table 5. ETUQ items showing the largest decreases in the number of users over two years (Study II).

ETUQ item	Users at baseline, <i>n</i> (%)	Users at year two, <i>n</i> (%)	Difference between baseline and year two (<i>n</i>)
Card-opened door lock	18 (58)	7 (22)	-11
Stereo/CD player	22 (71)	13 (42)	-9
Camera, analogue	8 (26)	1 (3)	-7
Cell phone, top up prepaid card	9 (29)	3 (10)	-6
Pedometer	10 (32)	4 (13)	-6
DVD	19 (61)	13 (42)	-6
Stationary push-button telephone	25 (81)	19 (61)	-6
Calculator	27 (87)	21 (68)	-6
Push button to get off bus or open bus door	28 (90)	22 (71)	-6

Table 6. ETUQ items showing the largest increases in the number of users over two years (Study II).

ETUQ item	Users at baseline, <i>n</i> (%)	Users at year two, <i>n</i> (%)	Difference between baseline and year two (<i>n</i>)
Electronic key ¹	1 (3)	9 (29)	+8
Self-service check-out station in store ¹	0 (0)	6 (19)	+6
Clinical thermometer	21 (68)	24 (77)	+3
Electric kettle	17 (55)	20 (65)	+3
Credit card at gas station (pay with code) ¹	7 (22)	10 (32)	+3
Hair curling/straightening iron	3 (10)	6 (19)	+3
Skype ¹	1 (3)	4 (13)	+3

Note: ¹ Not a regular ETUQ item.

Factors explaining the amount of everyday technology used

In Study I the decreases over two years in the perceived ability to use ET and activity involvement were found to be non-significant. However, in Study II we found that perceived ability to use ET and activity involvement significantly contributed to decreasing amount of ET used. In addition to the significant time effect found in Study II on the amount of ET used, four of the six investigated factors – less ability to use ET, less activity involvement, declining cognitive state, and older age group – significantly predicted use of less ET (Figure 3). The most influential factor for explaining the amount of ET used was which age group the persons belonged to at baseline. Persons in the oldest age group (75-84 years) used an average of 14% less ET than persons in the younger age groups (55-64 and 65-74 years). Somewhat unexpectedly, conversion to dementia could not predict less ET used.

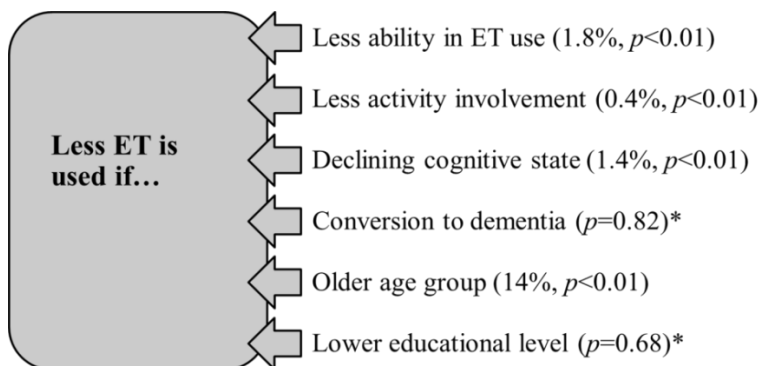


Figure 3. Results from the mixed-linear-effect model in Study II investigating our assumptions of factors potentially influencing the amount of ET used over time.

Note: * Non-significant factor. For non-significant factors only p -value at removal from the model is shown. For significant factors the estimate is also shown, expressed as the change in percentage of the outcome variable – the proportion of ETUQ items used – for each one-unit change in the predictor.

ACTIVITY INVOLVEMENT OVER TIME

Overall activity involvement

In contradiction to the many FAI case plots classified as stable over two years in Study I when a person-oriented approach was used (see Figure 2), findings on a group level in Studies I and III pointed to generally decreasing overall activity involvement over time in the sample. These group-level changes were, however, non-significant during the first two years (Study I). The comparison in Study I of overall activity involvement at baseline and year two showed a mean difference of -1.74 FAI points, SD 5.34; $p = 0.079$. Two years later (Study III), the analysis of four-year data showed a significantly decreasing time effect on overall activity involvement in the sample ($F = 8.745$, $p < 0.001$). Pairwise comparisons in Study III showed significant decreases on the adjusted means of overall activity involvement between baseline and year four (-4.55 logits, $p < .001$); between years one and four (-5.15 logits, $p < .001$), between years two and four (-2.82 logits, $p = .048$) and years one and three (-2.90 logits, $p = .019$). Otherwise the comparisons of means between time points were non-significant.

Item-specific activity involvement

In addition to the above finding of overall decreasing activity involvement over four years' time, the DIF analysis in Study III contributed more detailed information about

stability or change of activity involvement on item level. When adjusting for the descending FAI person measures in the sample, actual DIF indicated descending involvement in seven of fifteen FAI activities (see Table 7). Involvement in all leisure activities descended, and about half of the activities presenting descending involvement were performed outside the home. The eight activities showing stable involvement over four years, despite declining ability in the sample, were *Gardening, Heavy housework, Preparing main meals, Driving car / Using public transport, Washing up, Light housework, Walking outside >15 min* and *Washing clothes*.

Table 7. The FAI items with descending activity involvement listed in the order in which the sample showed significant actual DIF during four years (Study III).

Activity item	Timespan where significant DIF was first found	z-value difference ¹
Travel outing / Car ride	year 1 – year 2	-2.00
Social occasions away from home	year 1 – year 2	-1.65
Actively pursuing hobby ²	year 3 – year 4	-2.02
Gainful work	year 0 – year 4	-2.87
Household / Car maintenance	year 0 – year 4	-1.89
Reading books	year 0 – year 4	-1.87
Local shopping	year 0 – year 4	-1.84

Notes: ¹Cut-off for significant z-value difference: -1.65. ²This item also descended significantly between year 0 – year 4.

ASSOCIATION BETWEEN ACTIVITY INVOLVEMENT AND ET USE OVER TIME

Overall the findings from Studies I-III indicate that involvement in everyday activities and use of ET are associated constructs, and that this association becomes stronger over time in persons with cognitive decline due to MCI.

At baseline, a medium non-significant correlation was found between ETUQ person measures and FAI scores in Study I ($\rho(30)=.33, p=0.064$), and between ETUQ person measures and FAI person measures in Study III ($r(35)=.30, p=0.07$). However, *changes* in perceived ability to use ET and *changes* in activity involvement were rarely

coinciding in Study I, as the distribution of case plots in Figure 2 illustrates; fluctuating or descending case plots on *both* perceived ability to use ET and involvement in activities were largely absent.

In Study II the relationship between activity involvement and ET use was examined from another angle, now highlighting the amount of ET used. The findings from the regression model indicated that activity involvement was one of the significant factors predicting the amount of ET in use over two years' time in the sample, albeit with a small estimate (see Figure 3).

Findings in Study III showed that the association between perceived ability to use ET and activity involvement became stronger over time, as illustrated by the steeper slope of the regression line at year 4 in Figure 4. During the first three years the correlations had medium effect sizes, while the effect size was large at year four.

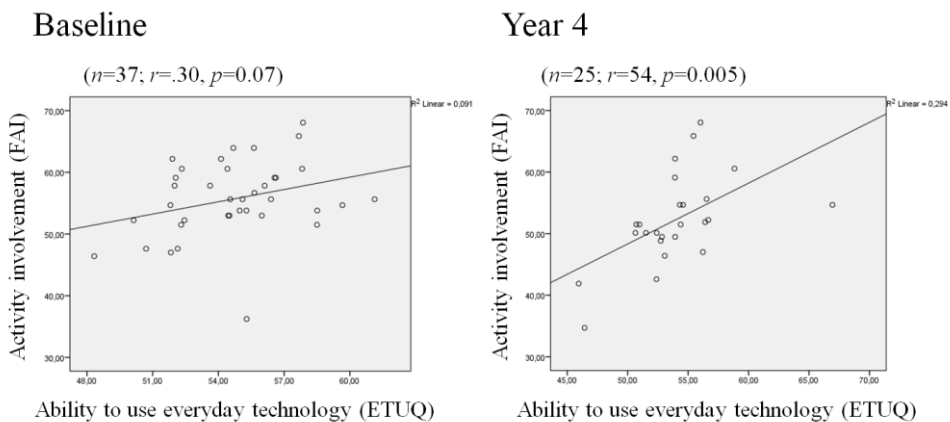


Figure 4. Scatterplots illustrating the stronger association over time between person measures of ETUQ and FAI found in Study III.

RELATING TO TECHNOLOGY IN EVERYDAY LIFE

The analysis in Study IV showed that the six participants' different ways of relating to existing and potential future technology could be described as a continuum including the three categories of *Downsizing*, *Retaining*, and *Updating*. As shown in Figure 5, each category on this continuum included subcategories reflecting actions taken towards existing technology or assumptions made about potential future technology use in everyday life. Some subcategories contained qualities of downsizing, retaining as well

as updating. These floated along the continuum as indicated by the dotted lines in Figure 5, where they are presented in connection with what was interpreted as the main quality.

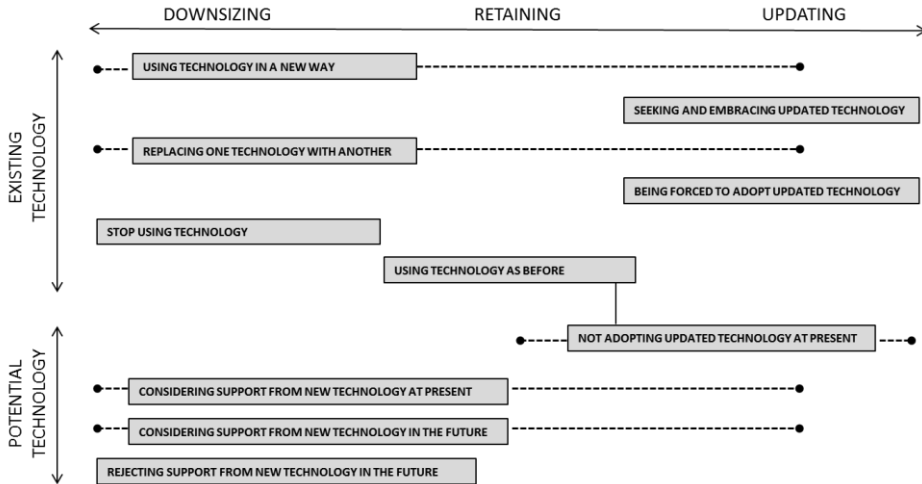


Figure 5. Overview of the findings in Study IV: categories and subcategories describing ways of relating to technology in everyday life.

Multiple conditions in various individual combinations affected how the participants related to technology in present and future doing. These conditions included the perceived need for change, based on the extent to which they currently struggled with or envisioned their own future decline, the importance and habituation of the occupations in question, whether they assumed that technology could support valued occupations, and finally availability of alternative solutions. Trade-offs were also made between desired and adverse anticipated outcomes concerning integrity, safety, facilitating vs. training, impact of the technology on their spouses, and financial costs. Additionally, take-off runs often had to be endured before the hoped-for usefulness of the technologies was realized. Successfully passing these take-off runs was often dependent on support from friends and family. The paradox of having to pass difficulty to achieve simplicity was recurrent and negotiations of the price worth paying were ever-present.

Downsizing

The *Downsizing* category (Figure 5) describes both the participants' ways of relating to doing in general – including for example adaptive approaches such as simplifying by

accepting help from others and sticking to familiar activities – and their ways of relating to technology in everyday occupations. Downsizing actions used towards existing technology included *Using technology in a new way*, *Replacing one technology with another*, and *Stop using technology*. Assumptions made regarding potential technology included *Considering support from new technology at present* or *Considering support from new technology in the future*, and *Rejecting support from new technology in the future*. The latter way of relating to potential technology was common for video-based monitoring, intended to support valued occupations by prompting. At present camera monitoring in one's home was a price no participant was prepared to pay. However, some assumed that they would revise present cautious views should their abilities deteriorate in the future.

Retaining

The category of *Retaining* technology use and doing in everyday life constituted an intermediate, sometimes fragile, situation where participants were *Using technology as before* (Figure 5). These technologies were often everyday objects not considered technologies by the participants, even less thought of as support in everyday occupations. Instead they were self-evident parts of everyday life, often used as before and without reflection. However, some participants also consciously maintained use of certain technologies to retain doing that worked well enough, suggesting a need to preserve a delicate equilibrium to maintain seamless everyday doing.

Updating

Despite the difficulties and needs of downsizing experienced in everyday occupations, a simultaneous *Updating* was evident in the analysis (Figure 5). This category comprised both a strong quest – described in the *Seeking and embracing updated technology* subcategory – and a forced need for renewal and updating of doing and technology used – described in the *Being forced to adopt updated technology* subcategory. Some participants sought updated technologies, while others mainly experienced a push from technology itself which they either struggled with or circumvented. The circumventing way of relating to technology is described in the *Not adopting updated technology at present* subcategory. It was closely linked to a retaining approach.

Importantly, all participants described ways of relating to technology in all three parts of the continuum. That is, in parallel to downsized doing and technology use, all participants also exhibited retained doings and ways to relate to technology, as well as doings and ways of relating to technology suggesting either a quest or need for updating.

GENERAL DISCUSSION

This research project contributes new knowledge of how persons with cognitive decline due to MCI perceive changes in and relate to technology use and occupations in everyday life over time, and also for the future. I will discuss here the main findings from the four studies, divided into the following sections: “Technology use and everyday occupations over time”, “Variability over time of everyday technology use”, and “Technology support in MCI”.

TECHNOLOGY USE AND EVERYDAY OCCUPATIONS OVER TIME

In different ways all studies in this thesis show how use of technology and involvement in everyday occupations may be related over time in persons with cognitive decline due to MCI. The connection between use of ET and everyday occupations has not to our knowledge been investigated prospectively before. The findings of this thesis thus add new knowledge with the potential to guide clinicians in identifying possible key areas to address over time in clients with MCI. On a group level the findings showed that overall activity involvement decreased in the sample over time (Study III), and so did the amount of ET used (Study II). Furthermore, in the four-year data in Study III, overall activity involvement and perceived ability to use ET were shown to become more closely associated over time, which was not as clear in the two-year data in Study I. The qualitative findings in Study IV also suggested that ways of relating to doing and technology were closely jointed, and influenced each other. I will start by discussing how the overall changes on the group level and the association between technology use and everyday occupations over time can be understood. Thereafter, the more variable findings of how persons perceived their ability in ET use will be discussed.

Consistent with how MOHO describes the impact of the environment as possibly both supportive and constraining (Kielhofner, 2008), an underlying assumption in this thesis was that the environmental aspect of ET may both offer opportunities and add challenges in the everyday occupations of persons with MCI. However, based on the fact that extensive cross-sectional research comparing groups with varying levels of cognitive impairment of different etiologies have repeatedly demonstrated that greater cognitive impairment is accompanied by reduced ability to use ET (Fallahpour, et al., 2014; Hällgren, et al., 2014; Malinowsky, et al., 2010; Nygård, et al., 2012; Rosenberg, Kottorp, et al., 2009), we assumed that ET use would generally become more challenging over time for the persons in this MCI sample. Also, earlier findings of less activity involvement in groups with more cognitive impairments (Nygård, et al., 2012) made us assume descending activity involvement over time. These assumptions were in

line with the environmental docility hypotheses, expecting more person-environmental fit problems in persons with less competence (Lawton & Nahemow, 1973; Lawton & Simon, 1968). The longitudinal findings of less ET used (Study II) and less overall involvement in activities (Study III) confirmed our assumptions, and were expected in a sample with cognitive decline.

In contrast, analysis of changes in perceived ability to use ET, presented in the Findings section of this thesis, showed that the non-significant decrease in the ETUQ person measures found in Study I (-0.75 logits, *NS*), also remained non-significant over four years (-0.83 logits, *NS*). This was more unexpected, as it neither fully complies with the cross-sectional studies mentioned earlier, nor with the environmental docility hypothesis. I will return to this finding in the “Variability over time of technology use” section.

A stronger link

The repeated correlation analyses in Study III showed medium positive associations during the first three years between overall activity involvement and perceived ability to use ET. At year four the association became large. That is, four years after detection of MCI a stronger link emerged between ability in ET use and activity involvement, where persons who frequently engaged in everyday occupations generally perceived themselves as more able to use ET, while persons who perceived themselves as less able to use ET were less involved in everyday occupations. The observational longitudinal study design used in Studies I-III does not reveal whether the associations found also imply a causal relationship. To be able to draw conclusions regarding causation, an experimental study design would be needed, where the researchers try to manipulate the participants’ ability in ET use (for example by training in ET use or by customizing specific ETs), while ruling out alternative explanations to potential changes in the participants’ activity involvement (Kazdin, 2010). In view of the study designs chosen in this thesis, the discussion below on potential causal directions should be viewed as a proposal to possible interpretations.

The most likely causal direction in the observed association between perceived ability to use ET and involvement in activities might be that if a person finds many ETs challenging to use, this poses hindrances to engaging in activities where ET use is an integral part, leading to withdrawal. In Study III, it may be that increasing difficulties in using ETs encountered in the technological landscape, such as cash machines (ATM), self-service checkout stations in stores, or credit cards with codes, contributed to the declining involvement in *Local shopping*, and that increasing challenges in using power tools in part underlie the declining involvement in *Household / Car maintenance*. This

causal direction is a common assumption, however seldom empirically tested (Czaja, et al., 2006; Kottorp & Nygård, 2011; Malinowsky, Nygård, et al., 2013; Mitzner, et al., 2010; Rosenberg, Kottorp, et al., 2009; Slegers, et al., 2009).

However, the opposite causal direction is also plausible in some situations. A person who withdraws from an activity for other reasons than difficulties in ET use might as a consequence use the ET involved in that activity less regularly. This may eventually lead to reduced ability to use the ET, as infrequent use has been shown to contribute to making an ET difficult to manage for persons with cognitive impairments (Nygård, 2008b; Patomella, et al., 2011). Examples pointing to the probability of such two-way causal directions between ability in ET use and activity involvement were found in Study IV, in the downsizing sub-category of *Stop using technology*. In the case of Brita, her son and daughter-in-law had lived in the same house as Brita and her husband for the past month. Brita had previously used internet banking when handling the bills, but as her son had noticed that this had become difficult for her, he offered to take over responsibility for the bills, which Brita accepted. That is, in this case challenges occurring in ET use caused reduced activity involvement for Brita. In another situation the causal direction seemed to be the reverse. After moving into the house, Brita's daughter-in-law had taken over many household chores, so that Brita stopped using many household technologies. Brita explicitly stated that she perceived no problems in using those ETs, but she did not need to use them anymore as someone else had taken over the chores. However, it is likely that the vacuum cleaner, dish washer and washing machine will become more difficult to manage for Brita after an extended time of non-use (Nygård, 2008b; Patomella, et al., 2011). Hence, it seems plausible that potential causal directions may differ depending on the situation, and furthermore that changes in ability to use ET and activity involvement may reinforce each other in complex ways. Thus, it was logical to use activity involvement as a predictor when investigating amount of ET used in Study II, but the reverse would have been equally natural.

Despite the uncertainties regarding the direction of a possible causation, the stronger relationship suggested over time between activity involvement and perceived ability to use ET in this sample with MCI is interesting, and deserves a comment. It suggests that as persons in the sample developed more cognitive impairments, the more closely connected their abilities to use ET and involvement in activities became. In other words, at baseline participants with lower perceived ability to use ET seemed to be restricted less clearly in their involvement in activities, and conversely, those with high perceived ability in ET use seemed to be frequently engaging in activities less clearly (Figure 4). This has been indicated before when comparing diagnostic groups in cross-sectional research (Nygård & Kottorp, 2014).

As in the earlier discussion of assumed increasing challenges in ET use over time in persons with MCI, such a mechanism may be understood based on the environmental docility hypotheses (Lawton & Nahemow, 1973; Lawton & Simon, 1968). That is, in persons with less competence the dependence on a supportive ET environment is more pronounced for the adaptive behavior of continued activity involvement, than in those who have more competence. On an inter-individual level, MOHO explains how the environmental impact differs between persons, depending on the unique interaction between a certain environment and the specific characteristics of a certain person (Kielhofner, 2008). In line with the findings on a group level in this sample with MCI, of changing associations between perceived ET ability and activity involvement over time, the environmental impact is also likely to change over time within a person experiencing cognitive decline. As older adults with MCI are likely to possess different abilities over time, and potentially also change beliefs in their own abilities, the same ET may support activity performance and involvement at one time point, but constrain activity involvement at another, for example in a stressful situation (Malinowsky, Almkvist, Nygård & Kottorp, 2012).

Applying the notion of changing environmental impact to the present sample would entail that at baseline – when all participants had MCI – those who were challenged by ET were still able to find alternative ways to continue involvement in activities. They would do this by circumventing ET use, for example, or by working their way through the difficulties with the ET to eventually find a solution, making continued activity involvement possible. Such ways of relating to technology in everyday occupations were described in Study IV, in situations where take-off runs had to be endured while learning to use updated technology before the usefulness of the ET eventually was realized in their occupations. However, at year four – when a considerable portion of the sample (68%) had developed dementia – those who perceived less ability in ET use clearly also engaged less in activities, and vice versa, resulting in a stronger association. This suggests that over time the challenge posed by ET had become a major obstacle in everyday occupations. Accordingly, an important task for health care professionals meeting this client group is to address both ET use and activity involvement in follow-ups after detection of MCI, and be prepared to intervene.

Interestingly, findings from a study using another format of data gathering contradict this suggested mechanism of increasingly stronger associations between ET use and everyday occupations in cognitive decline. When instead using performance-based assessment of IADL in groups with MCI or mild AD and correlating measures of IADL process and motor performance skills to self-reported ability to use ET, stronger associations were on the contrary found in the MCI group than in the AD group (Ryd, et

al., 2015). One possible explanation raised was that persons with dementia might have overestimated their ability in ET use. Yet, similar to the findings in Study III in this thesis and to findings from the study comparing the associations of ability in ET use and activity involvement in controls, persons with MCI, or with dementia (Nygård & Kottorp, 2014), the study by Ryd and colleagues does support the notion that ET use and IADL are associated constructs, both of which are important to address in persons with cognitive impairments.

This association has also been evidenced in persons with acquired brain injury, where perceived difficulties in using ET was found to be related to perceived limitations in ADL ability, as well as to reduced likelihood of returning to work (Larsson Lund, Nygård & Kottorp, 2014). Furthermore, in persons with acquired brain injuries, perceived ability in ET use and perceived ADL ability have together with their interaction variable been shown to explain both the experience of overall participation, and participation in specific domains such as family role and autonomy indoors (Fallahpour, Kottorp, Nygård & Larsson Lund, in press). This also extends current empirical evidence of the impact of impaired ET ability to incorporate participation problems, which is regarded as a key area for occupational therapy interventions (Kielhofner, 2008; Law, 2002).

Descending leisure – an area to address

In Study III longitudinal involvement in the 15 everyday activities in FAI was also investigated more in detail, on the item level. The rationale for this was that knowledge regarding which activities are likely to be affected early in MCI is valuable for clinicians meeting these persons, as it may facilitate early detection of areas where support is warranted. Furthermore, vague functional changes in MCI might presage conversion to dementia (Luck, et al., 2012; Peres, et al., 2008) and are thus important to identify, as the importance of early detection of dementia has been emphasized (Alzheimer's Disease International, 2011). The results from the DIF analysis in Study III suggested some activities where descending involvement were early exhibited in the participants. I will now discuss these findings, highlighting the finding of early descending involvement in leisure activities and possible connections to ET use in such activities.

In this MCI sample, two activities performed outside the home were the first to show more pronounced decrease in involvement compared to the other activities. Between year one and year two, involvement in *Travel outing / Car ride* and *Social occasions away from home* descended more than involvement in the other FAI activities (Table 7). The latter item includes, for example, social leisure activities, and going to the movies, theater, or restaurant with friends. Despite the fact that these two activity items did not

exhibit significant DIF over the whole four-year period, this initial withdrawal from doing social activities outside the home is worth taking notice of. These activities together with *Actively pursuing hobby* and *Reading books* captured a descending involvement in leisure activities among the participants over time. Leisure activities have earlier been shown to be sensitive to changes in cognitive status (Arrighi, et al., 2013; Yeh, et al., 2011). Furthermore, leisure activities have gained much interest in epidemiological research, investigating the potential protective effect of engaging regularly in social, cognitively demanding, and physical activities. Associations between involvement in such activities and reduced risk of incident dementia (Fratiglioni, Paillard-Borg & Winblad, 2004; Wang, Xu & Pei, 2012) and MCI (Geda, et al., 2012; Geda, et al., 2011) have been suggested, but the protective effect of cognitive activity in later life still needs to be further tested (Alzheimer's Disease International, 2014).

Reluctance to engage in hobbies and increased social isolation have, in contrast to other IADLs, been shown more associated with initiative problems than with performance problems in persons with early dementia (Giebel, Challis & Montaldi, 2014). The declining involvement in leisure could be due to the fact that former hobbies and leisure activities with social components become increasingly challenging early during cognitive decline, for example due to perceived stigma (Alzheimer's Disease International, 2012; Burgener, Buckwalter, Perkhounkova & Liu, 2013). An alternative explanation might be that as other more pressing everyday activities such as shopping, meal preparations, and housework become more challenging, persons with cognitive decline choose to withdraw from former leisure activities perceived as possible to avoid, to save energy. Yet another interpretation is that the indicated withdrawal from social occasions away from home and travel outings supports the disengagement theory (Cumming & Henry, 1961). Further research is needed to clarify the underlying mechanisms behind the observed withdrawal, and also how it is experienced by persons with MCI, even though it is suggested that the withdrawal impacts negatively on quality of life for persons with early dementia (Giebel, et al., 2014). Based on the findings in Study III as well as on the accumulating evidence about the protective effects of leisure activities against cognitive decline (Wang, et al., 2012), considering potential needs of support for continued leisure activities in MCI and AD is an important area for occupational therapists. This seems relevant regardless of the direction of causation between involvement in leisure activities and cognitive functioning, as valued leisure activities and togetherness may have the potential to contribute to joy and well-being (Bath & Deeg, 2005; Kleiber, Hutchinson & Williams, 2002).

However, interventions focusing on leisure among persons with cognitive decline living at home are scarce (Smith & Mountain, 2012). For example, a systematic review of the

effects on quality of life, health, and wellness for persons with dementia, of interventions in the areas of BADL, IADL, leisure, and social participation, could only identify one intervention study focusing on leisure among community-dwelling persons with dementia. Most studies targeting leisure were conducted in care facilities (Letts, et al., 2011). Interventions targeting leisure appear underrepresented, in view of the fact that social and leisure activities have been identified as frequently unmet needs for persons with early dementia living at home (Phinney & Moody, 2011; Wherton & Monk, 2008).

In the past decade the possibilities for technology to contribute to a meaningful leisure and social connectedness for persons with cognitive impairments have gained interest. Off-the-shelf ICTs such as tablets have been suggested as one potential way to provide meaningful leisure activities and facilitate social interactions for persons with early dementia living at home (Lim, Wallace, Luszcz & Reynolds, 2013; Smith & Mountain, 2012). This is in line with findings from Study IV, where several examples were present of the important role that ET may play in social and leisure activities. Importantly, ETs such as email, cell phones and tablets both challenged and supported social activities for the participants, and the challenges sometimes prompted new ways of relating to the technology. For example, to reduce the difficulties they experienced when using ET in communicating with others, Brita and Caesar downsized their doing by replacing one technology with another. In Brita's case this entailed replacing use of email by using the telephone instead, and Caesar in turn switched from a standard cell phone, to using a simplified senior mobile. By these downsizing shifts to more easy-to-use ETs they were able to maintain and even broaden their ways of communicating with others. Furthermore, the leisure activity of using a music-streaming service was highlighted as very important for Eric, one of the younger participants in Study IV. Creating playlists of his own had evolved into an engaging hobby that included appropriating and learning several new ETs. This exemplifies that ET at the right level of challenge has the potential to support and widen valued interests in persons with MCI.

Use of social internet-based activities such as Facebook, Skype, and blogs has been highlighted as a promising area for interventions aimed at promoting opportunities for social connections among healthy older adults (Larsson, Nilsson & Larsson Lund, 2013; Nyman & Isaksson, in press). Older adults not used to the online social context appreciated individualized support when familiarizing themselves to this new means of socializing (Larsson, et al., 2013). However, despite enriching life by a sense of increased belonging and complementary togetherness with others, internet contexts may also evoke resistance in older adults due to fear of losing integrity (Larsson, et al., 2013; Nyman & Isaksson, in press).

In Study II, Skype was among the ETs that had increased most in number of users over two years in this MCI sample followed (Table 6). Even though the increase was modest, with three new users at year two (13% of the sample), this finding, together with the findings in Study IV of a quest for updating and renewal in some participants, indicate that some persons with MCI or early dementia also want, need, and are able to incorporate updated ET. This is important for significant others and health care professionals meeting this group to keep in mind and be prepared to support. Even if the participants refrained from some doing and stopped using some technologies, new engaging occupations were also taken on, widening the activity repertoire, sometimes including incorporating new technologies. To conclude, based on the above discussed findings in Studies II and IV, and the findings in Study III, suggesting declining social and leisure activities over time in persons with MCI, research is needed to explore if and how social internet-based activities may also be a feasible way to promote online togetherness for this group of older adults.

It is important to bear in mind that despite the above evidence from primarily group level findings, persons with MCI constitute a heterogeneous group – both regarding trajectories of functioning (Study I) and ways of relating to existing and potential technology (Study IV). In the next section I will discuss how this heterogeneity showed over time in the technology use of the sample.

VARIABILITY OVER TIME OF EVERYDAY TECHNOLOGY USE

The discussion of variability of ET use first addresses the changes in the technological landscapes and rooms over time in this sample. Thereafter, I will discuss the findings regarding how challenging the participants found use of ET to be over time.

Varying amount and types of everyday technology used

By prospectively studying the amount and types of ET used in a sample of older adults with MCI, this thesis is the first to describe longitudinal changes in the technological rooms and landscapes (Hagberg, 2008) in this population. Changes in these, as perceived by each person, were captured with a questionnaire covering a wide range of ETs common in the homes and surroundings of older adults (Rosenberg, Nygård, et al., 2009). In line with earlier cross-sectional research (Czaja, et al., 2006; Nygård, et al., 2012; Rosenberg, Kottorp, et al., 2009; Ryd, et al., 2015) findings in Study II suggest decreasing amount of ET to be used over time in persons with MCI, and also contribute information about factors affecting this decrease. Belonging to the oldest age group – born in the mid-1920s and early 1930s – was the most influential significant factor. Clinically significant decrease in ability to use ET, less activity involvement, and

declining cognitive state as captured with MMSE would also contribute to the use of less ET. Thus, these factors are important for health care professionals to keep track of in persons with MCI, as changes occurring simultaneously might indicate need of support.

However, in contrast with the significant time effect over two years in amount of ET items used (Study II), a sub-set of the sample more often showed stable or even increasing change scores for the number of ET items in use over four or five years (Study IV). This shows that there was variability within this MCI sample over time concerning changes in amount of ET in use. The participants in Study IV were among those in the longitudinal sample who remained stable at MCI diagnosis for the longest period of time or even reverted to normal, which may account for the retaining and updating ways of relating to technology described by them, in parallel with the more expected downsizing approaches.

On the other hand, and in line with earlier research (Nygård, et al., 2012; Rosenberg, Kottorp, et al., 2009), findings from the regression model in Study II indicate that diagnostic state could not significantly predict the amount of ET used. One potential explanation to this may be the consistent overlaps found between diagnostic groups in the earlier studies regarding ability to use ET, despite significant differences between groups (Malinowsky, et al., 2010; Nygård, et al., 2012; Rosenberg, Kottorp, et al., 2009). These overlaps also tell us that on an individual level, diagnostic state does not necessarily reveal level of ET ability, and vice versa (Malinowsky, 2011; Rosenberg, 2009). Rather, in line with how MOHO explains occupational choices (Kielhofner, 2008), the findings in Study IV point to the fact that the motivating force of a strong personal interest in a specific occupation, and the availability of support from the social context can enable persons with MCI to seek and embrace new technology despite challenges. Thus in some areas they could widen their technological rooms while simultaneously downsizing them in other areas. The importance of motivation when striving to learn to use a new technology has also been shown previously in research including persons with cognitive impairments (Larsson Lund, Lövgren-Engström & Lexell, 2011; Lindqvist, Nygård & Borell, 2013). Study IV adds new insights into the breadth of ET updating some persons with MCI engage in spontaneously, i.e. not as a part of an intervention.

As earlier longitudinal data on amount and type of ET items used by persons with MCI or dementia is lacking, it is difficult to compare the findings in Study II to other research. A yet unpublished study used the ETUQ items as the point of departure and compared ETUQ data of relevance from two different periods of time (2003-2005 and 2008-2009) in two different samples of older adults with and without known cognitive

impairment (Malinowsky, Kottorp, Patomella, Rosenberg & Nygård, submitted). Their findings show that a vast majority of ETUQ items (especially ICT items involving cell phones and computers) were perceived to be relevant by *more* users over time, pointing to the increasing presence and importance of ET in society. Interestingly, relevance was increasing *more* in groups with MCI or dementia than in healthy older adults between the two time periods, which suggests that the presence in the technological landscape of for example ICT in everyday activities is over time becoming less challenging to new groups with cognitive decline, as they too have become more habituated to these specific ETs.

However, the findings of Study II in this thesis, where the same sample of older adults were followed prospectively, indicate that this habituation generally may not suffice over time to maintain use of ET. Rather, the findings on a group level in Study II are in line with earlier findings of less ET found to be relevant in groups with more cognitive impairments (Nygård, et al., 2012; Rosenberg, Kottorp, et al., 2009). On the other side, findings in Study II and IV also show that on ET item (Table 6) and individual level, adoption of updated ET artifacts and services such as self-service check-out stations in stores, Skype, music-streaming applications like Spotify, and online cross word puzzles on tablets, does occur among some persons with MCI, which is important to bear in mind for health care professionals meeting this group. These findings, together with the findings of increasing numbers of persons with cognitive impairments becoming users of ICT (Malinowsky, et al., submitted), and other research (Larsson Lund, et al., 2011; Nygård, 2008b; Verdonck & Ryan, 2008) signal that already available ETs such as cell phones, computers, and tablets should be viewed by occupational therapists as potentially useful platforms for compensatory solutions for persons with MCI or dementia.

Varying perceived ability in everyday technology use

While the amount of ET in use decreased significantly during the first two years in this sample (Study II), the perceived ability in ET use on a group level did not, neither over two (Study I), nor four (data shown in the Findings section in the thesis) years. This finding was slightly unexpected, as earlier cross-sectional studies have repeatedly shown significantly less perceived ability in ET use in groups with more cognitive impairment (Kottorp & Nygård, 2011; Nygård, et al., 2012; Rosenberg, Kottorp, et al., 2009).

A possible explanation for the non-significant changes in perceived ability to use ET is that the variations identified in Study I might have continued over the four-year study time. Fluctuations in a variable are likely to bring about non-significant results over time on a group level, although the true picture might be that the variable of interest develops

in a patterned way along diverse pathways over time for different persons (Bergman, et al., 2003). This was in fact the main finding in Study I, where three patterns of functioning – mainly composed of longitudinal case plots of perceived ability to use ET and activity involvement – were identified during the first two years following detection of MCI.

These findings have at least two important implications for clinicians and researchers. The first is that the different patterns found imply that the need of support regarding ET use and activity involvement is individual and likely to change over time for a majority of people with MCI. Thus, repeated clinical evaluations targeting both these aspects are called for. The significance of this suggestion is also supported by the stronger associations over time between these aspects found in Study III, and is in line with recent recommendations (Jekel, et al., 2015).

The second implication is that we should avoid treating persons with MCI as one group when analyzing change processes, but rather elaborate on person-oriented statistical methods in analyzing data. However, this requires larger sample sizes, as do attempts to find explanations to the stable/ascending, fluctuating and descending patterns identified.

Even though Study I suggests three distinct patterns of functioning over time in persons with MCI, we can only speculate on how different variables operate together within these patterns. Tendencies in the data in Study I suggest that younger age and more years of education might be associated with a more stable pattern of functioning and vice versa, which is in accordance to earlier research (Artero, et al., 2008; Kivipelto, et al., 2006). The fluctuating pattern of functioning is more difficult to interpret. Imprecise assessment (Salthouse, 2007) or varying awareness in the participants (Frank, Lenderking, Howard & Cantillon, 2011) cannot be ruled out, but it is also possible that the fluctuations represent true variability in ability to use ET and activity involvement, potentially indicating cognitive decline, as has been suggested earlier (Malinowsky, et al., 2012). Further research is needed to explore the causes of the variations in the fluctuating pattern of functioning.

It could be that the amount of ET in use is a variable capturing a change process that is more uniform in older adults with cognitive decline – and in older adults in general (Larsson Ranada & Hagberg, 2014) – than does perceived ability in ET use. Future research, preferably including “amount of ETs in use” as a variable in pattern analyses, is needed to answer this question.

TECHNOLOGY SUPPORT IN MCI

The findings in Study IV highlighted the complexity of the participants' ways of relating to technology and doing in everyday life, also with regard to the potential they attributed to technology as support. Consistent with previous research (Melenhorst, et al., 2006; Mitzner, et al., 2010; Peek, et al., 2014; Wahl & Mollenkopf, 2003), multiple conditions and trade-offs affected the participants' choices to downsize, retain, and update their technology use and doing. Study IV added new insights to how ways of relating to technology and doing could contain qualities from different parts of the downsizing-retaining-updating continuum at the same time, and also made clear that older adults with MCI relate to technology and doing in a multitude of ways along this continuum.

Sometimes the participants used existing ET in a new way, with the intention of supporting a downsized doing. However, using new features in existing ET as a support was described only for ICT, such as using reminder alarms in the cell phone more frequently, shifting to direct debit and electronic invoices in the internet bank, and starting to turn on the GPS in the smartphone while taking a walk in the woods. Implementing these support functions in existing ICT oftentimes implied challenging take-off runs, often depending on support from others to be successful. This exemplifies how the complexity in ICT both offered opportunities (Linden, et al., 2011) and added challenges (Patomella, et al., 2011) to the participants, more often than did less complex ETs. Continuing to use ETs like the radio, the gas grill, and other household technologies as before, commonly supported retained doing. Thus, findings from Study IV show that, in addition to ICT, familiar ET can also be seen as an important environmental resource for persons with MCI, despite offering less flexibility. It was clear that some participants used this retaining approach consciously, deliberately avoiding updating, to retain doing that worked well enough.

The need to endure take-off runs before a hoped-for usefulness of updated and unfamiliar technology is not surprising; it is an experience shared by most people. It illustrates the fact that investment in time and effort and need to overcome frustration is often inherent in adoption of new technology, before it is incorporated into the habits of the user (Melenhorst, et al., 2006). It has been suggested that for older adults in general, these efforts are less decisive than the perceived benefits when choosing whether or not to adopt technology innovations (Melenhorst, et al., 2006). Considerable inconveniences can also be tolerated when starting to use an AT, as long as it helps the user to achieve valued goals (Krantz, 2012; Lindqvist, 2012). However, in Study IV the take-off runs at times seemed to be a persistent and unsettling factor, obviously overriding the benefits. For example, Frida's worries before the introduction of a number of ICTs at her workplace even made her son suggest that she should give up her part-time job and

retire. This illustrates a situation with obvious clinical implications. Occupational therapists have skills in assessing the match between a client's capacity and the demands and opportunities of the environment, and in identifying and giving advice regarding possible modifications (Kielhofner, 2008). As has been suggested within the field of acquired brain injuries, it is important to consider the demands and supportive opportunities of technology at the workplaces of working persons with MCI as well (Larsson Lund, et al., 2014). We also need to increase addressing the costs and take-off runs associated especially with use of ICT in persons with MCI.

There was variance in the extent to which the participants in Study IV regarded prompting technology involving monitoring as potentially supportive for valued occupations, and those who were positive tended to consider this possibility only further ahead in time. Thus, for persons with MCI, timing for the introduction of future AAL technology aimed at supporting valued everyday occupations is a potential dilemma, in view of proposed advantages of early introduction of new technologies for persons with cognitive decline (Lindenberger, Lövdén, Schellenbach, Li & Krüger, 2008). Despite the fact that the participants could see some benefits in prompting technologies, their concerns and complex trade-offs regarding integrity issues and potential loss of capacities if simplifying their doing with technology indicate conflicting views, which is in accordance with earlier research. Studies examining acceptability of video-based AAL systems have reported a gap between accepting the systems and actually being willing to use them (Cardinaux, et al., 2011). Furthermore, ambivalent feelings have been described in healthy older adults, who typically felt good *and* bad about potential future monitoring sensors, rather than good *or* bad, in relation to independence versus security, privacy versus intrusion, and whose interests the technology served (Boström, Kjellström & Björklund, 2013). These findings point to the importance of involving the end users early when developing technology aimed at supporting their everyday life (Peek, et al., 2014).

On the other hand, findings in Study IV showed how some participants already used, or could consider using, existing ETs such as smartphones and tablets in new ways to downsize their doing. In light of the increasing use of ICT like these in older adults (Malinowsky, et al., submitted; Statistics Sweden, 2013), these findings support the idea that smartphones and tablets may be feasible platforms for future AAL technologies in this group. Building cognitive support on existing technology solutions has been suggested to have several advantages, and is a strategy that is gaining ground (de Joode, et al., 2010; Greenhalgh, et al., 2013; Lim, et al., 2013; Linden, et al., 2011; Procter, et al., 2014). The technologies are already accessible off-the-shelf, and used by people in general in the society (Smith & Mountain, 2012) which has obvious economic

advantages (Emiliani, Stephanidis & Vanderheiden, 2011). Importantly, by building on ETs that signal “normality” the solutions may also better fit a desired self-image and way to present oneself to others for a person with MCI or dementia (Kielhofner, 2008; Larsson Lund & Nygård, 2003; Nygård, 2008b).

METHODOLOGICAL CONSIDERATIONS

Sampling

A limitation in Studies I-III is that no comparison group was recruited. This hampers comparisons between the perceptions of older adults with MCI regarding changes in ET use and involvement in activities over time, and changes perceived in healthy aging. This should be considered in future longitudinal studies. Furthermore, the choice not to include persons with MCI due to other reasons than possible prodromal dementia (e.g. stroke, Parkinson’s disease, depression), resulted in loss of statistical power, and also delimited generalizability to persons with MCI who may potentially progress to dementia. However, this also made the sample easier to compare with other MCI samples in the literature, where most research so far has been carried out at memory clinics and aimed at identifying, describing, and starting to treat persons with MCI due to possible dementia development. With the new DSM-5 criteria of mild neurocognitive disorder, future research including samples with more mixed etiologies is to be expected (Sachs-Ericsson & Blazer, 2015).

The power calculation at initial sampling was based on detection of group differences in perceived ability to use ET from an earlier cross-sectional study, where this MCI sample was compared to groups with dementia and controls (Nygård, et al., 2012). Despite the fact that the study was potentially underpowered for some statistical analysis (Schafer & Graham, 2002), it was decided to follow this MCI sample prospectively in Studies I-III due to the lack and importance of longitudinal research on ET use in MCI. The suspicion that the study might lack the power to detect significant differences over time was later confirmed. A retrospect recalculation, based on the actual two-year changes on the ETUQ person measures in Study I, suggested that a sample size of $n=98$ would have been needed for beta 0.84 with two-tailed tests and alpha 0.05. Thus, type II error (i.e. not detecting actual changes) may account for some non-significant group-level findings in Studies I-III. Still, the findings from this thesis, with ET use and activity involvement as primary outcomes, suggest that changes in these variables are not descending as predictable and continuous over time as hypothesized. Maybe alternative hypotheses for sub-groups with MCI regarding everyday functioning over time need to be developed and empirically tested in larger samples.

In Study IV the intention was to supplement the longitudinal quantitative information in Studies I-III from ETUQ, FAI, and MMSE, with qualitative data on how persons with MCI relate to technology in everyday life. That is, only persons in the sample followed prospectively with current, or relatively recent, experience of living with MCI, were eligible for sampling to Study IV. Despite also considering those who had progressed to dementia or reverted to normal cognition after year two, the sample size in Study IV was restricted to only six participants. Although the sample presents variation regarding age, gender, marital status, vocational background, and interest in ET, inclusion of participants with yet other circumstances might have contributed a richer variation in the identified ways of relating to technology. However, it is not the number of participants but the credibility, originality, resonance and usefulness of a qualitative study that determine its value (Charmaz, 2006). Study IV describes detailed and varied experiences of relating to technology and doing among persons with MCI, and challenges stereotyped images of persons with cognitive decline, which may provide useful insights to persons meeting this group. Theoretical sampling to saturate the categories of downsizing, retaining, and updating was not possible to adopt based on current conditions, although it might have given further insights into how these categories are related and what they mean to persons with MCI (Charmaz, 2006).

Use of self-reported data

To highlight the perspective of the persons with MCI on changes in technology use and everyday life occupations, this thesis used self-reported data from semi-structured questionnaires and in-depth interviews. This approach, as all approaches to gather data, has both advantages and limitations (Jekel, et al., 2015).

Research has shown that persons with MCI as well as persons with dementia may vary in awareness of and ability to reliably provide information regarding their everyday functioning (Frank, et al., 2011; Roberts, Clare & Woods, 2009). This may have affected the results in Studies I-III. For example, varying awareness may have contributed to the fluctuating case-slopes found in Study I regarding perceived ability to use ET and activity involvement. However, others have reported that persons with MCI do not seem to underreport functional deficits (Farias, Mungas & Jagust, 2005). The ETUQ interview is designed to support concrete reasoning regarding use of different ET items, with probing questions that may facilitate recall. The ability of the participants to report concrete problems in everyday life is supported by the case plots in the descending pattern of functioning (where 58% had conversed to dementia), which correspond well to the expected pattern. Furthermore, in the qualitative interviews the participants provided rich data with developed reasoning regarding their views on how existing and

potential future technology might support their everyday occupations, or not. The interviews contain many examples of the participants' insights in present, and also potential future, challenges in everyday doings and technology use, related to their cognitive impairments. Taken together, the above indicate a relatively good reliability and validity in the data underlying the findings in this thesis, but some overestimation of everyday functioning cannot be ruled out, especially in the later waves in Study III.

Performance-based IADL assessment has been suggested as favorable and more likely to detect subtle differences between controls and persons with MCI or dementia (Jekel, et al., 2015). It can be argued that the many fluctuating and descending case slopes in Study I show that also the questionnaire-based self-report approach with ETUQ was sensitive enough to detect subtle overall change in ET ability. Furthermore, the questionnaire-based approach of ETUQ was considered most appropriate to capture changes in the breadth of ETs used in persons with MCI, and also their overall perceived ability in using ET. Clearly, an observations-based approach would not allow consideration of the same multitude of ETs across various situations and contexts. Previous research indicates that older adults with cognitive impairments report to a relatively large extent *perceived levels of ET difficulty*, congruent with *observed levels of ET difficulty* ($r=0.63$; $p<0.001$) (Malinowsky, Kottorp, et al., 2013). However, despite being clearly related, the constructs of perceived and observed levels of ET difficulty were found not to be identical. For example, recall bias was suggested in complex items used less frequently, as these were perceived as less difficult to use than they were observed (Malinowsky, Kottorp, et al., 2013). Thus, in clinical practice, a combination of screening for difficulties in ET use with ETUQ could preferably be combined with an observation-based assessment (Malinowsky, et al., 2011) to gain deeper understanding of the actual reasons to potential difficulties to manage ET.

Reflections on the study of change

In Study I, limiting values for clinically significant changes in ETUQ, FAI, and MMSE were calculated, based on the number of scale steps found within two Rasch-generated individual SEs. These limiting values were used as guiding criteria in the classification of case plots in Study I, and in Study II also used to interpret the FAI estimates of the regression model investigating predictors to amount of ET used. Future research should test whether the suggested 6-point change in FAI for clinically significant change is valid. For ETUQ a 3-logit change was regarded as potentially clinically important, based on differences in an earlier cross-sectional study (Nygård, et al., 2012). This should also be tested further.

As mentioned, type II error or varying awareness over time in the participants may account for the non-significant changes in perceived ability to use ET. Another alternative explanation for the non-significant changes has to do with measurement bias. Possibly inflated ETUQ person measures have been created over time, by a tendency to score items no longer in use as “Non-relevant” (i.e. no score), instead of “This item is not used anymore or has not come into use, even if it is available and relevant for the person” (i.e. score 1). Such scoring would risk disguising a withdrawal from using ETs due to potential difficulties into non-use based on non-relevance. As a Rasch model does not necessarily produce lower measures when fewer items are scored (Bond & Fox, 2007), inflated measures over time might be produced, making perceived ability in ET use appear misleadingly stable on group level. This risk has been discussed in earlier research (Rosenberg, 2009). It is in the present longitudinal data contradicted by the variability found in perceived ability to use ET during the first two years. Yet, the use of scale step 1 of ETUQ may need further clarification during the one-day course provided before administrating ETUQ, and the wording “Non-relevant” may need to be re-considered.

Study III used DIF to investigate whether involvement in specific activities decreased earlier than involvement in others over time in this MCI sample. The analysis suggested early withdrawal from leisure activities and activities performed outside the home, but the reasons for these changes remains unknown. Furthermore, it is important to remember that some of the activities often suggested to be affected early in MCI are missing in FAI, for example managing finances, medication, and using the telephone. That is, the findings are obviously influenced by our use of an instrument not covering these items, or reasons for potential changes. Yet FAI includes other equally important activities, and has the advantage of brief administration. A modified and extended version of FAI has lately been developed by Swedish researchers (Wendel, Ståhl & Iwarsson 2013), aiming to capture self-reported reasons for changes as well as satisfaction with performance. The item using the telephone has been added, but priority was otherwise given to new items regarding outdoor mobility. It may be interesting to consider in future studies including persons with MCI.

Missing data

When performing longitudinal data collection, encountering the problem of attrition and missing data is inevitable. In two-year data in Studies I and II, attrition was about 16%, and in four-year data in Study III 32%. A complication when studying persons with progressive cognitive impairments over time is that missing data might be associated to circumstances connected to the cognitive decline in itself, i.e. dropouts might be

“missing not at random” (Maxwell & Tiberio, 2007). For example, it could be that participants with rapid cognitive decline are more likely to drop out due to an extra stressful life situation, than participants with more stable conditions. Accordingly, those who drop out might perceive more problems related to ET use and activity involvement, than those who stay in the study, which might add attrition bias to the findings. This means that observed values of the persons remaining in the study are at risk of becoming select and unusual relative to the population (Schafer & Graham, 2002). This must be taken into account when interpreting the findings in this thesis, even if also persons with reverting symptoms are found among those who dropped out.

The last known diagnostic states for those who declined continued participation, died, or were excluded during the study time were MCI ($n=6$), AD ($n=3$), frontotemporal dementia ($n=1$), and reverted to normal cognition ($n=2$). For ethical reasons, the participants were assured at recruitment that they were free to withdraw from participation at any time without having to explain their reasons, which delimits information at hand regarding reasons to dropout, and also current diagnosis at dropout.

CONCLUSIONS AND CLINICAL IMPLICATIONS

The findings of this thesis provide new and clinically useful knowledge of how persons with MCI perceive the consequences of cognitive decline over time, regarding involvement in activities and use of ET, and how these aspects are associated over time. The thesis also contributes knowledge of how persons with MCI relate to existing and future technology as potential support in everyday life.

Findings in Study I showed that everyday functioning in persons with MCI is likely to take different pathways the first years after detection of MCI. An even distribution between a stable/ascending, a fluctuating, and a descending pattern of functioning appeared regarding perceived ability to use ET and involvement in activities. The highest rate of conversion to dementia (58%) was found in the descending pattern, but the relation between patterns of functioning (i.e. perceived ability to use ET and involvement in activities) and diagnostic outcome year two was non-significant in this small sample.

Accordingly, recurring follow-ups are needed for persons with MCI of ability in ET use and involvement in complex activities, to detect those with descending and fluctuating patterns of functioning. This is suggested as they likely will be in need of supportive interventions from occupational therapists.

Study II showed that the overall amount of ET used decreased significantly during the first two years following MCI detection. Persons belonging to the oldest age group (i.e. 75 years and older) used less ET than younger persons. Less perceived ability to use ET, less activity involvement, and declining cognitive state as indicated by MMSE also predicted less ET to be used over time. However, neither lower educational level nor conversion to dementia significantly predicted less ET use.

Thus, as knowledge of diagnostic status (reverted, MCI, or dementia) showed to be insufficient to draw conclusions regarding amount of ETs in use, repeated investigation of ET use also seems warranted in persons still diagnosed with MCI, in connection with inquiring whether important activities are affected.

Furthermore, findings in Studies II and IV also indicate that the technological landscapes may widen for some persons with MCI, as new ETs like electronic keys, self-service check-out stations in stores, and Skype start to be used by some of the participants over time.

Thus, inquiring about needs to also use newly developed ETs seems justified for occupational therapists when meeting persons with MCI.

Study III showed that overall activity involvement decreased significantly over four years, suggesting a gradual withdrawal from engaging in activities in persons with MCI. More specifically, the findings of Study III identified descending involvement in all leisure and social activities, as well as in activities performed outside the home.

This suggests leisure and social activities to be an area occupational therapists should address in persons with MCI.

Furthermore, the positive correlations between activity involvement and perceived ability in ET use became stronger over time. At year four – when 68% of those remaining in the study had developed dementia – those who perceived less ability in ET use were also more clearly involved less in activities, and vice versa. This may indicate that over time, the challenge posed by ET had become a major obstacle in everyday occupations.

Accordingly, an important task for occupational therapists is to address both ET use and activity involvement in follow-ups after detection of MCI, and be prepared to intervene.

Finally, findings in Study IV described the participants' different ways of relating to existing and potential future technology and everyday occupations as a continuum of downsizing, retaining, and updating. In complex ways, multiple conditions and trade-offs affected the participants' ways of relating to technology and doing along this continuum. Study IV gave new insights into how downsizing, retaining, and updating could take place simultaneously. It is important for occupational therapists to be aware of the challenging take-off runs persons with MCI may encounter when striving for or struggling with downsizing or updating of technology use in everyday life.

Especially when support is lacking in the social context of these clients, occupational therapists have an important role in identifying possible solutions and modifications that may shorten these take-off runs, which may be needed in any of the areas activities of daily living, play, or productivity. Such solutions may be easier to identify in existing ICT such as tablets and smartphones, but may as well include creative ways of making continued valued occupations possible by circumventing technology use if this has become too challenging.

To conclude, the longitudinal findings in this thesis contribute with new knowledge adding to earlier cross-sectional evidence of the relationship between reduced ability in

ET use and limitations in everyday occupations in persons with cognitive impairments. There exists a treatment gap in relation to the still limited attention given to challenges in ET use after detection of MCI. Findings in this thesis suggest that ET use and everyday occupations among persons with MCI deserve more attention from health care professionals in general, and from occupational therapists in particular. Timely interventions targeting ET use could possibly prevent or limit some of the descending involvement in activities found in this thesis, and support continued valued doing for persons with MCI.

FUTURE RESEARCH

Five-year data is also available for this MCI sample that was initially 37 persons. Despite the even smaller sample size, it might be valuable to replicate the longitudinal pattern-analysis used in Study I of how functioning in everyday life is perceived, but extended to cover the whole study period. This would tell us whether the fluctuating pattern was a precursor to a more descending pattern of functioning, as we hypothesized in Study I. Case plots for the variable “amount of ET items used” could also be interesting to include in such pattern-analysis, as it according to the findings in this thesis seems to capture change in another way than “perceived ability in ET use”.

Furthermore, the findings in Study I suggest a relationship over time between pattern of ET ability/activity involvement and diagnostic outcome, even if this showed to be statistically non-significant in this small sample. Clearly, pattern affinity over time and its relation to diagnostic outcome is relevant to investigate in larger samples. The predictive value of the functional assessments used in the thesis (ETUQ and FAI) is important to study in more depth in the future, especially in relation to the newly proposed diagnostic entity of mild neurocognitive disorder (American Psychiatric Association, 2013a, 2013b).

The fluctuating pattern of functioning identified in Study I raises further questions: Do these fluctuations also show in shorter time-spans? In that case, what are the consequences in everyday life of a fluctuating pattern of functioning? Are these fluctuations predictive of something? And how should support be organized when ability fluctuates? Further research is also needed to explore the potential causes for the variations in the fluctuating pattern of functioning, as discussed earlier.

In a larger sample it would be interesting to include level data and aim for elaborated cross-sectional patterns, predictive of functional and/or diagnostic outcome. Such information may be clinically very useful. Exploring patterns of functioning using longitudinal case plot combinations is informative in research, but the pattern affiliation of the participants in Study I gives limited clinical guidance on an individual level when only level and not slope data is at hand. Thus, cross-sectional predictive patterns of functioning would be more useful in a clinical setting. Despite what is known about the overlaps between diagnostic groups regarding perceived ability in ET use (Kottorp & Nygård, 2011; Nygård, et al., 2012; Rosenberg, Kottorp, et al., 2009) and the findings in Study II of diagnostic state being a non-significant factor, it may be feasible to aim for prediction of diagnostic outcome by such extended pattern-profiles in larger samples.

In Study II, the amount of ET items used was the dependent variable in the regression model, and the findings identified factors that over time affected use and non-use of ET in this sample of persons with MCI. ET use in itself is, however, not the primary outcome of interest; more important is how this ET use together with other factors supports or constrains participation in occupations. Thus, in future research, “amount of ET items used” could instead be used as an independent variable, and aim at identifying how it, together with other variables important for competent ET use, predicts involvement, performance, and participation in valued occupations, or even occupational well-being (Doble & Santha, 2008).

Findings in Study III suggest declining social and leisure activities over time in persons with MCI, which corresponds well to findings including samples with early dementia (Giebel, et al., 2014; Phinney & Moody, 2011). Based on this, and on the need to further explore the continuum of downsizing-retaining-updating found in Study IV, future research can, for example, explore if and how social internet-based activities may also be a feasible way to promote online togetherness for this group of older adults.

In retrospect, it would also have been valuable to have taken the opportunity to perform longitudinal qualitative interviews regarding how the participants in this sample related to technology and doing. This remains to be addressed in future research. A study design following persons with cognitive decline due to MCI over a prolonged period of time, using for example an ethnographic approach, would likely contribute to interesting insights in how the ways of relating to technology in everyday life might change or remain stable over time, and how this might interfere with other aspects of everyday life.

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