Navigating Through Technological Landscapes
Views of people with dementia or MCI and their significant others

Lena Rosenberg
NAVIGATING THROUGH TECHNOLOGICAL LANDSCAPES

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ABSTRACT

The general aim of this thesis was to increase knowledge about people with MCI or dementia and their significant others, particularly as users of everyday technology and assistive technology (AT). The overall aim included increasing knowledge about the interactions between people with MCI or dementia and their significant others, and technology.

In Study I the psychometric properties of the Everyday Technology Use Questionnaire (ETUQ), when used with older adults with and without cognitive deficits, were investigated using the Rasch rating scale model. Study II compared the perceived relevance of and difficulty in using everyday technology, measured with the ETUQ, in people with mild-stage dementia, people with MCI, and older adults without known cognitive impairment, using one-way ANOVA analyses. In Study III, actions and driving forces of the agents involved in the process of introducing AT to people with dementia were explored, using a case study methodology combined with grounded theory. Study IV explored and described how significant others of people with dementia related to technology, and their readiness to use AT together with the person with dementia, using a grounded theory approach with focus groups and individual interviews.

The findings of Study I suggested that the ETUQ demonstrates acceptable validity in terms of internal scale validity and person response validity, when used in this population. The ETUQ showed sensitivity in detecting differences between three subgroups in perceived difficulties in everyday technology use. Study II showed significant differences in perceived difficulty in everyday technology use between all three groups. Here everyday technology was perceived most difficult by people with dementia, followed by people with MCI, and older adults without known cognitive impairment. It also suggested that older adults with MCI or dementia experienced fewer technology artifacts and services as relevant to their daily lives, as compared to older adults without known cognitive impairment. In Study III, Doing the right thing was the main driving force among actors in this AT intervention process. However, conflicting views appeared of what the right thing to do was, findings suggest that it is important to be attentive to who has decision power, as this person is likely to influence the process profoundly. Study IV’s findings showed that the significant others took a utilitarian perspective on technology, as they refused technology for technology’s sake but showed an overall readiness toward using technology if they considered it to benefit them and their relatives with dementia. Technology was found to be important for keeping an active lifestyle and for creating and maintaining self-images among people with dementia and their significant others.

The thesis contributed new knowledge about the perceived relevance of and difficulty in everyday technology use in older adults, particularly in those with MCI or dementia. Findings also indicate that the ETUQ is a tool that generates valid, sensitive measures of perceived difficulty in everyday technology use, and valuable information about its perceived relevance that may support researchers and clinicians. The thesis contributed new knowledge about the complex situation of a person with dementia and his/her significant others when AT is introduced in the home, suggesting the need of a more flexible and process-oriented procedure with ends-in-view instead of clearly set goals. Significant others of people with dementia were found to be generally ready to adopt technology, although they took a utilitarian perspective. Technology was perceived by them as important for keeping an active lifestyle and for creating and maintaining self-images, which suggests that such conceptions should be considered. Finally, the thesis contributes knowledge of design-related principles and conditions that may be decisive in transactions between people with dementia and technology. It is suggested that what is communicated through the interface of the technology is particularly crucial, as this is likely to guide the person through suitable use, whereas instructions are likely to be forgotten.

Key words: Alzheimer’s disease, assistive technology, cognitive impairment, community living, design, environment, everyday technology, IADL, occupational therapy, older adults, Rasch analysis
LIST OF PUBLICATIONS

This thesis is based on the following publications, referred to in the text by their roman numerals:


IV. Rosenberg, L., Kottorp, A., & Nygård, L. Readiness for technology use with people with dementia: The perspectives of significant others. In manuscript.

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<table>
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<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>AD</td>
<td>Alzheimer disease</td>
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<tr>
<td>ADL</td>
<td>Activities of daily living</td>
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<td>AMPS</td>
<td>The Assessment of Motor and Process Skills</td>
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<td>APA</td>
<td>American Psychiatric Association</td>
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<td>AT</td>
<td>Assistive technology</td>
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<td>ETUQ</td>
<td>Everyday Technology Use Questionnaire</td>
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<tr>
<td>IADL</td>
<td>Instrumental activities of daily living</td>
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<td>ICT</td>
<td>Information and communication technology</td>
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<tr>
<td>MCI</td>
<td>Mild Cognitive Impairment</td>
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<td>MMSE</td>
<td>Mini Mental State Examination</td>
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<td>MOHO</td>
<td>Model of Human Occupation</td>
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<td>OT</td>
<td>Occupational therapist</td>
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<td>VD</td>
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<td>WHO</td>
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Papers I-IV
PERSONAL INTRODUCTION

This research project originates in my own experiences and in inquiries raised by the changes in the technological landscape during the 1990s, when banks and other companies developed a variety of IT and telephone services. These changes led to such companies offering various self-services for the customers, which meant that they became more restrictive in giving individual service. As a result, I saw older adults at the post office being referred to telephone services when they asked for the balances on their bank accounts and I heard their concerns when they had to pay a fee to be allowed to continue paying their bills at the post office. I also heard an older relative saying how difficult answering machines and other telephone services were to understand and to manage.

Later, working as an occupational therapist in geriatrics and in an open rehabilitation clinic for people with traumatic brain injuries gave me experiences of the potentials and challenges of assistive technology, in particular when used by people with cognitive impairment. Experiences such as these triggered my interest in how changes in the technological landscape affected the lives of older adults, as well as in how technology can be used in interventions for these older adults.

As my own attitudes towards technology inevitably have affected how I have carried out the studies in this thesis, it is also reasonable to reflect on myself as a technology user. As I grew up in a middle-class home in Sweden in the 1970s the television set, music player and telephone were the most important everyday technologies for me. The computer technologies belong to my adulthood and are indeed central in my life today. Moreover, being an occupational therapist means that I have adopted a problem-solving attitude towards technology. Reflecting on myself as a technology user and consumer, I would say that my readiness to adopt new technology so far has been sufficient to allow me to adjust my habits to new artifacts and services. However I also recognize that new technologies most often have been introduced into my technological space by people in my close social environment rather than by myself. Thus the importance of the context is also emphasized in my own case as a technology user.
In short, the research questions in this thesis were formed by inquiries deriving from the recognition of fast changes in the technological landscapes and what these might imply for older adults with conditions of mild cognitive impairment (MCI) or dementia living at home. According to Emiliani (2006), the use of everyday technology is increasingly required in today’s society in different tasks such as buying tickets from machines for travel and entertainment, as well as in contacting health care services and social agencies, and using automated telephone services and other information and communication technologies such as television and the Internet. Assistive technology for older adults with MCI or dementia is also an area of growing interest in society. Accordingly, my individual inquiries concerning the experiences of older adults with or without MCI or dementia living in these continuously changing technological landscapes were the starting point of this thesis.

INTRODUCTION

Dementia and mild cognitive impairment (MCI) are common conditions among older adults, with a prevalence of approximately 5.5 million persons diagnosed with dementia in the European Union in 2003, and 27.7 millions worldwide in 2003 (Wimo, Jonsson & Winblad, 2006). A majority of these people live in their own homes with support from friends and family. As the conditions from MCI and dementia influence memory and other cognitive functions, they may have consequences on the prerequisites to handle everyday technology, such as cash machines and automated telephone services and hence also consequences for engagement in occupations in home and society. Further, assistive technology such as time aids and locator devices is seen as one promising possibility for helping people with dementia by compensating for functional losses (Cahill, Begley, Faulkner & Hagen, 2007a; Cahill, Macijauskiene, Nygård, Faulkner & Hagen, 2007b; Cash, 2003; Gitlin & Chee, 2006) and to enhance well-being and safety for both the person with dementia and his or her family (Gitlin & Chee, 2006). Therefore knowledge is needed about relations between older adults, in particular those with MCI or dementia and the technological landscapes with which they live.
In the following, I will introduce the medical conditions of MCI and dementia and the consequences that these conditions may have for those afflicted in everyday life and specifically in everyday technology use.

Older adults with mild cognitive impairment or mild-stage dementia

Dementia

Dementia is a collective name for progressive degenerative brain syndromes, and Alzheimer’s disease, AD, is the most common dementia type with about 60-80% of the cases. Vascular dementia (VD) is considered as the second most common dementia type. Dementia with Lewy Body and Frontotemporal dementia are other types of dementia syndromes. All types of dementias affect the person’s ability to engage in and perform daily occupations (American Psychiatric Association (APA), 2000) which, as stated above, often involve everyday technology use. Commonly used diagnostic criteria to establish diagnoses are DSM-IV-TR (APA, 2000), ICD-10 (World Health Organization (WHO), 1993) and the NINCDS-ADRDA (McKhan et al., 1984). Dementia prevalence increases with age but is not part of normal aging. Further, dementia diseases cause progressive decline in cognitive and functional abilities and the symptoms are often described in three stages; mild, moderate, and severe stage dementia. Instrumental activities of daily living (IADL) are affected early in the course of dementia, whereas impairment in personal ADL (PADL) occur later (Gauthier & Gauthier, 1990; Liu et al., 2007; Morris, et al., 1993).

Mild Cognitive Impairment (MCI)

The term MCI is commonly used to broadly define older individuals whose cognitive impairment is more severe than those typical of normal ageing but not severe enough to warrant a diagnosis of dementia (Petersen, 2004; Petersen & Negash, 2008; Winblad et al., 2004). Reports of population-based prevalence for MCI range from 11% to 17% (Mariani, Monastero & Mecocci, 2007). MCI is associated with a considerably increased risk of developing dementia and a more rapid rate of decline in cognitive function than in persons without cognitive impairment (Boyle, Wilson, Aggarwal, Tang & Bennett, 2006). According to Petersen et al. (1999), MCI is an abnormal condition of cognitive
impairment not severe enough to be classified as dementia. The criteria (Petersen et al., 1999) required normal activities of daily living but later these criteria were modified to accept minor deficits in IADL (Petersen, 2004), which often imply difficulties in activities that include everyday technology use. Even though the diagnostic criteria of MCI require an overall intact ADL ability (Petersen, 2004; Winblad et al., 2004) several studies have indicated that people with MCI do experience difficulties in performing more complex and challenging IADL tasks (Artero, Petersen, Touchon & Ritchie, 2006; Dodge et al., 2005; Giovannetti et al., 2008; Pèrès et al., 2006; Tuokko, M orris & Ebert, 2005) such as shopping and managing finances. However the knowledge of IADL ability among people with MCI is still limited (Nygård, 2003; Nygård & Winblad, 2006; Winblad et al., 2004).

Because of the heterogeneity in people that are diagnosed with MCI, there are ongoing debates whether MCI is a clinically useful concept or not (Ames et al., 2006). Since this is a diagnosis given to older adults with impairments that might have consequences for everyday technology use, the group of people with MCI are together with people with mild to moderate stage dementia the populations in focus in this thesis. The term everyday technology has so far been used in the text above owning to its current relevance in IADL. Further, it has been touched upon that everyday technology is a possible problem area for people with MCI or mild to moderate stage dementia. Next I will clarify how the concepts of everyday technology and assistive technology are used in this thesis.

The concepts of everyday technology and assistive technology

When engaging in occupations people interact with their environment which both everyday technology and people are parts of. In occupations person and environmental aspects may be difficult to separate from each other since they act together in unity and mutually influence on each other (Cutchin, 2004). In order to clarify the point taken in this thesis, different concepts related to everyday technology and assistive technology will here be defined.
Everyday technology

An artifact may be defined as an object that has been intentionally made or produced for certain purposes (Hilpinen, 2004). In this thesis, the concept of everyday technology is chosen to describe technological artifacts and systems present in the context where older adults in today’s world pursue their lives. The concept technology has many different meanings (Bijker, 2006). However, in this thesis it mainly refers to physical objects or artifacts such as telephones and microwave ovens but with the addition of everyday to clarify the reference to technological artifacts that commonly exist in the everyday lives of older adults with or without dementia or cognitive deficits. The term everyday technology was defined by Larsson (2009) based on Hagberg (2008) to mean “technical objects (artifacts and systems) which are used or designed to be used on a daily basis, or more seldom but habitually. The term points towards doing things in the household, doing leisure or in the context of the individuals’ social network”. Part of what is considered as everyday technology in this thesis is sometimes in the literature referred to as domestic technology but with the difference that also technologies outside the home are considered as everyday technology. In addition to everyday technology the concepts of technological landscape and technological room are used to describe technological artifacts and system as a whole. According to Hagberg (2008) technological landscape refers to the landscape of technological artifacts and systems that people will meet within the environment where they move around. When a person is moving around in the technological landscape some parts of the landscape will come within reach while others will not. The technology room is a part of the technological landscape that a person more permanently is in dispose of, for example technology in the person’s home.

Further, there are several theories in the area of technology science about the role of technology in society. According to the theory of social construction of technology (SCOT), technology is made and shaped by human actions which means that technology is constructed by the society (Pinch & Bijker, 1987). This theory is in opposition to technological determinism which sees technology as a governing force in society, that determines human actions and is more or less inevitable and out of control (Pinch & Bijker, 1987). In the present thesis the assumption taken is that technology is socially constructed. This social constructionist perspective does not deny that technology is a
forceful ingredient of modern society, it just acknowledges that the force does not emerge from technology itself but from how it is used, what it is used for and what meaning it is given in our culture and society (Sørensen, 2005).

In more detail, the concept of everyday technology is in this thesis defined as electronic, technical, and mechanical equipment that exists in the everyday lives of older adults, including both well known and more recently developed technological artifacts. This definition was chosen based on the results from research studies (Nygård & Starkhammar, 2003; Nygård & Starkhammar, 2007) and clinical experience that indicated that not only complex communication and information technologies, ICT, but also mechanical, non-electronic technology might present hindrances to people with cognitive impairments. Further it is relevant to not only consider artifacts but also services since people interact not only with physical artifacts but also with services reached with these. For example, text message is a service that is available through a mobile phone; a type of artifact.

**Assistive technology**

Besides everyday technology, *assistive technology* is an important concept in this thesis. According to the Assistive Technology Act of 1998, assistive technology is: "Any item, piece of equipment, or system, whether acquired commercially, modified, or customized, that is commonly used to increase, maintain, or improve functional capabilities of individuals with disabilities" (Assistive Technology Act of 1998). The most common assistive technologies among older adults in Sweden are walkers and canes (Dahlin Ivanoff & Sonn, 2004) but in this thesis the main focus is on assistive technologies targeting the specific consequences of MCI or dementia, i.e. assistive technologies for cognitive limitations such as electronic calendars and reminders, sometimes clinically referred to as cognitive devices. Marshall (1996) pointed out several purposes for assistive technology to play a role in care and support of people with dementia and listed different target areas; technology for stimulation, relaxation, compensation, behavior management, safety, surveillance, control assistance for relatives, service coordination and reminders. Recently, Topo (2009) suggested that technology for communication should be added to Marshall’s list.
The boundaries between everyday technology and assistive technology are blurred and according to the definition used here (Assistive Technology Act of 1998), the same object could in one situation be considered as everyday technology and in another as assistive technology depending of a person’s reasons for having and using the technology. For example an ordinary mobile phone with a large tough screen might be purchased in order to facilitate for a person having difficulties using an ordinary mobile phone and hence according to the definition used here be considered as assistive technology. But the same mobile phone could as well be chosen by a person without particular difficulties and hence be considered as everyday technology.

Despite overlaps in the definitions of everyday technology and assistive technology, in this thesis I found it useful to differentiate between the two concepts due to the fact that some technologies within the concept of assistive technology are prescribed and financed through the Swedish healthcare system and hence processes for providing them may be treated and viewed differently than everyday technology by users, professionals and others. Further we know from the literature that assistive technology may support the user although in some cases it may threaten the person’s self-images and hence be experienced as stigmatizing (Gitlin, 2002; Larsson Lund & Nygård, 2003). Thus because of the differences in provision of everyday technology and assistive technology, and because of the different connotations they might carry, both concepts are used in this thesis although they partly overlap.

Later in this introduction I will return to the subject of assistive technology for people with MCI and dementia but first I will present the basic theoretical framework chosen in this thesis.
Theoretical framework

This thesis focuses on people with MCI or mild-stage dementia and their significant others specifically as users of technology in everyday life. When a person is using, or interacting with technology this takes place in a context in space and time, with or without other persons, in a given place with other physical objects and sometimes also in a system where different technologies are connected to each other such as in a telephone net or water system. To elucidate this complexity, theory is needed.

The basic theoretical framework for this thesis consists of the Model of Human Occupation, MOHO (Kielhofner, 2002), the General Ecological Model of Aging (Lawton, 1986; Lawton & Nahemow, 1973) and Dewey’s transactional model as suggested by (Cutchin, 2004) and as it is applied within occupational therapy. The general ecological model of aging, also referred to as the competence-press model (Lawton & Nahemow 1973), has influenced the field of gerontology research profoundly and it is one of the fundamental theories to have influenced occupational therapy models (Kielhofner, 2002; Law et al., 1996). Occupational therapy is also influenced by Deweys’ pragmatism but has been criticized for not using this philosophy to its full potential mainly through the predominant dualistic view of person and context (Cutchin, 2004; Dickie, Cutchin & Humphry, 2006).

Person-environment interaction

In the first two studies in this thesis, the General Ecological Model of Aging (Lawton & Nahemow, 1973) and MOHO (Kielhofner, 2002) served as the theoretical framework. The General Ecological Model of Aging (Lawton & Nahemow, 1973) covers the interplay between persons and their environments. The person is defined in terms of a set of competences and the environment is defined in terms of demands. The interaction between the two components, the personal competence and the environmental demands, generates the outcome of adaptation (Lawton & Nahemow, 1973). Similarly in MOHO (Kielhofner, 2008) occupation is suggested to arise within an individual and is afforded or constrained through the individual’s interaction with the environment. According to the environmental docility hypothesis (Lawton & Simon, 1968; Lawton & Nahemow, 1973) individuals with less capacity are less likely to competently manage an environment.
where the demands are high. For example, when technology is complex it can result in
greater environmental demands, but the environment, in terms of technology, can just as
well provide new opportunities if the capacities of the individual and the design of the
technology are in balance (Lawton, 1986). This linear and deterministic view has been
criticised by many scholars during the years and questioned also by Lawton himself
(Scheidt & Norris-Baker, 2003). Over the years, Lawton expanded and revised the model
to encompass a larger complexity but still with focus on causal determination. According
to Scheidt and Norris-Baker (2003) Lawton acknowledged that, philosophically speaking,
people and environments are parts of each other and hence cannot be viewed as separate.
Although, in order to be able to study outcomes of person-environmental interactions,
Lawton meant that we need to speak of and measure them as separate to each other
(Scheidt & Norris-Baker, 2003). This is in opposition to Cutchin (2004) and Dickie et al.
(2006) who propose that we need to view persons and environments as co-constitutive,
i.e. entities that move through each other and shape each other in order to enable a more
holistic and dynamic understanding of human-environmental transactions.

MOHO (Kielhofner, 2002) has been used in this thesis as it aims to explain and
understand people’s motivation for, patterns in and performance of occupations in
everyday life. In contrast to the The General Ecological Model of Aging (Lawton &
Nahemow, 1973), MOHO focuses on occupational performance as the outcome from
person-environment interactions. According to MOHO components besides ability, such
as environment, values, habits, interests and roles, influence a person’s performance
(Kielhofner, 2002) and, consequently, also the use of everyday technology and assistive
technology in everyday life. However, MOHO, among other occupational therapy
models, has been criticised particularly owing to the dualistic view, focusing on person
and environment as separate entities rather than on the relationship itself (Dickie et al.,
2006). Further, occupational therapy models have also been criticized for being
individualistic and not serving understanding when focusing on people’s actions in a
bigger context (Dickie et al., 2006). Hence the theory of transaction (Cutchin, 2008) has
been suggested as an alternative perspective for understanding occupation (Dickie et al.,
2006). Because of the focus on relations between person and environment in study III and
IV, the theoretical framework from study I and II was considered to be inadequate and
therefore the transactional perspective as described above (Cutchin, 2004, 2008; Dickie et al., 2006) was applied in study III and IV.

The concepts of occupation and adaptation

Engagement in everyday occupations is a vital part of human life and essential to health (Law, 2002; Wilcock, 1993) and hence also to people who have MCI or dementia (Alzheimer’s Society, 2005). Having an active lifestyle has even been suggested to protect older adults from developing dementia (Fratiglioni & Qiu, 2009; Wang et al., 2009). According to the American Occupational Therapy Association (AOTA) (1997) occupations are meaningful activities with contextual, temporal, psychological, social, symbolic, cultural, ethnic and/or spiritual dimensions. Occupations reflect the unique characteristics of a person and a person is to some extent defined by the occupations in which he or she engages. A person’s preferred occupations may change over time, depending on different factors or circumstances in his or her life. When performing occupations the use of objects e.g. everyday technology is common. According to Kielhofner (2002) both the intrinsic properties of the objects, for example how they are designed, and the person’s skills to use these as well as the environment in which they are used, will affect the performance.

Occupation is in occupational therapy theory often described as providing a link between an individual and his or her context. Such definitions imply an individualistic view of the person meaning that occupation is initiated and formed mainly by the individual (Dickie et al., 2006). If we instead think of occupations as transactional relations, the view of occupation as “self-action” or “interaction” becomes problematic since it implies a dualistic view of person and context. Rather, occupation might be viewed as a transaction joining person and situation (Dickie et al., 2006). Further, viewing occupations as transactional relations means that we also have to include the temporal and spatial dimensions of these (Dickie et al., 2006). Further, according to Kielhofner (2002), participation, over time, results in adaptation and its components, identity and competence. In MOHO (Kielhofner, 2002, p. 121) adaptation is defined as “the construction of a positive occupational identity and achieving occupational competence
over time in the context of one’s environment”. According to Haak, Fänge, Iwarsson and Dahlin Ivanoff (2007) problems in adaptation may lead to the person lowering the demands on the quality of the performance or stop performing the occupation. Similarly, Nygård and Borell (1998) found that people with dementia sought rest in performing highly valued occupations as long as possible but when this was not possible anymore they limited their occupational performance in attempts to minimize harm to their identities. However, the concept of adaptation (adaptation-to-environment) has been questioned as it suggests a process where individuals, driven by motivation, adapt to their environment. Instead of adaptation-to-environment the transactional perspective suggests the reconstruction of situations. This means that when people experience a problematic situation they will coordinate elements and actions in the situation in order to remake the situation to a new whole with new meaning in order to bring back harmony. Due to instability, these processes of actions, involving individuals or groups, are continuously taking place, and harmonious situations are thus only occurring temporarily (Cutchin, 2004). Cutchin (2004) have with the concept place integration suggested a reconstruction of the concept of adaptation-to-environment. With these considerations in mind, the concept of adaptation is used in this thesis although acknowledging the construction and reconstruction of situations as suggested in the Deweyan perspective (Cutchin, 2004).

Everyday technology use among older adults

There are many assumptions regarding how people in general should age and there is even an expression “successful aging” referring to older adults ageing without disabilities, with high cognitive and physical capacity and an active lifestyle (Rowe & Kahn, 1997). Further, to age in place at home is assumed to imply good ageing and the home has been identified as very important to older adults (Dahlin Ivanoff, Haak, Fänge & Iwarsson, 2007; Haak et al., 2007; Lilja, 2000; Oswald & Wahl, 2005). One prerequisite for having an active lifestyle is the use of everyday technology since this is required in a wide range of activities in both home and society (Czaja et al., 2006; Emiliani, 2006). However, Czaja at al. (2006) found older and middle aged adults to have lower perceived self-efficacy with respect to computer use and higher computer anxiety than younger adults. In addition, functional decline from what often is called normal aging might influence the use of everyday technology. For example, Hayase et al. (2004) examined changes in ADL
performance ability across the lifespan and found a gradual decline in ADL ability from the years of 50 and through to the end of the life span studied. Further, age related decline in for example vision, hearing and tactile sensation (Hooper, 2001) might have negative influences on older adults’ ability to use everyday technology.

Nevertheless, information and communication technologies (ICT), assistive technology and home modifications provide possibilities for older adults to age in home (Gitlin & Corcoran, 1996; Gitlin, 2002). One among several stereotypes of older adults as technology users is that they are resistant to try new technologies but little evidence for this have been found in research (Östlund, 2005). Rather the generations that are aging today have taken part in extensive technological changes adopting new technological artifacts and services during their life span (Östlund, 2005). However, non use of different technologies has been observed among well elderly due to ambivalence and non-relevance (Selwyn, 2004; Larsson, 2009). Another reason for non use of ICT might be related to that older adults often are retirees and hence are excluded from the labour market. This means that they do not have access to the main arena of technical development, training and support (Östlund, 2005). An additional reason for non use might be high age: Larsson (2009), for example, found high age itself to be a factor for not upgrading the technology room in a sample of people over the age of 85.

In conclusion, the use of everyday technology among older adults has been acknowledged as important for inclusion in today’s society but except from studies focusing on the use of ICT, we have very limited knowledge of older adults as technology users. To avoid stereotypes, research focusing on the use of technology and the perspectives of older adults as technology users has been called for (Östlund, 2004). Here the use of everyday technology among older adults in general has been discussed. Now I will move over to review the literature about the importance of, and the conditions for, everyday technology use among people with MCI or dementia.
Everyday technology use in people with MCI or dementia

In a literature review, Egan, Hobson and Fearing (2006) concluded that engagement in occupation among people with dementia has been acknowledged to maintain identity and provide a sense of usefulness and enjoyment. This is in accordance with Öhman and Nygård (2005) and Phinney, Chaudhury and O’Connor (2007) who found engagement in occupations in people with AD to be important to them in order to maintain ordinary patterns of everyday life and facilitate their experience of connection and belonging in the world as well as autonomy and identity. To be engaged in occupations also allowed them to experience and demonstrate certain characteristics of their identity that reflected the person they used to be, thus sustaining a sense of continuity. These studies show that providing opportunities for engagement in occupation among people with dementia is highly important. However, consequences from MCI and dementia have a negative impact on the opportunities to engage in occupations.

The knowledge of how MCI influences performance of occupations is sparse but slower speed of task performance in IADLs has been seen in individuals with MCI as compared with healthy controls (Wadley, Okonkwo, Crowe & Ross-Meadows, 2008) which might have an impact of the possibilities to interact with everyday technology which often requires a certain pace (Nygård, Starkhammar & Lilja, 2008). As discussed before, in spite of the diagnostic criteria for MCI, people with MCI show restrictions in IADL compared to older adults without cognitive impairment (Wadley et al., 2007; Toukko et al., 2005; Pérès et al., 2006). Several of the IADLs that people with MCI have showed restrictions in are those that often require the use of everyday technology, such as telephone use, transportation and handling of finances (Toukko, et al. 2005; Pérès et al., 2006). Similarly Perneczky et al. (2006) found not only cognitive abilities but also the ability to perform everyday tasks to be reduced in people with MCI.

Unlike MCI, the diagnoses of dementia require problems in IADL and already in mild-stage dementia, ability to perform IADLs such as household activities and shopping is affected (Liu et al., 2007). Cognitive functions that often are reduced in dementia, such as the ability to recognize or identify objects, abstract thinking, planning and carrying out
complex tasks (APA, 2000), are often required in everyday technology use. Further, Oakley, Duran, Fisher and Merritt (2003) found ADL motor performance skills, which are also needed in technology use, to be affected among people with AD, also among those that were generally high functioning. These findings suggest that occupations involving the use of everyday technology might be more difficult for people with dementia to actually perform than for older adults that are not afflicted by dementia. In an empirical study aiming at identifying difficulties in and hindrances to the use of everyday technology among people with mild to moderate stage dementia Nygård and Starkhammar (2007) found several aspects that hindered or made the use of everyday technology difficult. Conditions related to the person with dementia were for example memory deficits, deficits in attending to multiple aspects, sensitivity to stress and lack of embodiment of technology. They also found limitations in the person’s knowledge of the technologies and their potential, and communication problems when using technology, e.g. when sequencing actions in line with the demands of the technology (Nygård & Starkhammar, 2007).

Further, decreased ability to initiate activities often affects occupations among people with dementia and is one problem often reported by significant others (Egan et al., 2006; Landes, Sperry, Strauss & Geldmacher, 2001). According to Cook, Fay and Rockwood (2008) people with mild to moderate AD showed decreased frequency of initiation of IADLs, leisure and social activities. Furthermore, when using complex everyday technology artifacts and services such as a DVD player or a computer, certain skills are needed to anticipate outcomes and adapt to changing situations. Cooke, Fisher, Mayberry and Oakley (2000) found increased difficulty in such ADL process performance skills related to ‘knowing what’, e.g. finishing up the tasks, clarifying situations appropriately, noticing own problems and responding appropriately to solve those problems in occupation. These ADL process skills are also highly relevant when interacting with everyday technology and reduced such skills will likely have a negative impact on the interactions with everyday technology as well.
The conditions for using everyday technology among people with MCI and dementia have here been discussed. Further, engagement in occupation among people with MCI or dementia as well as in other older adults has been acknowledged as important (Egan et al., 2006; Graff et al., 2006; Phinney et al., 2007; Vernooij-Dassen, 2007; Öhman & Nygård, 2005). However the knowledge of the interplay between people with MCI or dementia and their environment, including aspects such as other people, everyday technology, AT etc. is limited. To better understand these relations, it is important to also acknowledge the resources of people with MCI or dementia, in order to know how to best support them.

Resources and support from others

Reports of resources in people with dementia seem to be obscured by concerns for their well-known vulnerability (Bond & Corner, 2001) but a few studies have reported self-initiated strategies for problem-solving and other resources. From a literature review based on studies of people with dementia’s own perspective on their illness de Boer et al. (2007) presented a more nuanced picture of people with dementia than the usual; a picture of people actively using both emotion-oriented and problem-oriented strategies to deal with the disease. Other empirical studies have also shown that people with mild stage dementia use self-initiated response strategies to compensate for dementia problems. For example, Clare (2003) and Clare, Goater and Woods (2006) found that people with dementia use strategies to deal with perceived changes in functional capacity in order to maintain normality and to protect their identities. Coping strategies used by people with dementia have been found to change over time (Clare, Roth & Pratt, 2005) and, according to Harman & Clare (2006), not always being successful, thus in need of continuous adjustment. Examples of self-initiated strategies used by people with dementia mentioned in the literature are the use of visual and written prompts, (Nygård & Öhman, 2002; Preston, Marshall & Bucks, 2009), humor (Nygård & Starkhammar, 2003; Preston et al., 2009), social support such as help from family members (Gillies, 2000; Nygård & Öhman, 2002; Pearce, Clare & Pistrang, 2002; Preston et al., 2009) and relying on routines and habits (Nygård & Starkhammar, 2003; Nygård & Öhman, 2002; Preston et al., 2009). According to Nygård (2004), the rich variety of response strategies that were found in the daily activities of people with dementia were applied intuitively and
characterized as ‘common sense behavior’, hence suggesting a potential to be supported by caregivers.

Taken together, research has shown that people with dementia have recourses that could be built upon in supportive interventions. However, interaction with everyday technology artifacts and services that are new to the person might require learning new skills, but it is well known that the ability to learn new things decrease when cognitive impairment increase. However, research has found that people with dementia have limited, but still promising, potentials to adapt and learn (Davis, 2005; Flynn et al., 2003; Grandmaison & Simard, 2003). Learning and adapting has been found to be possible also in technology use (Hofmann et al., 2003; Lekeau, Wojtasik, Van der Linden & Salomon, 2003; Nygård, 2008; Orpwood et al., 2007) which suggests that people with MCI or dementia have some potential to adapt and learn to use technology that are new to them even if little is known about this.

A very important recourse in dementia care is the significant others. According to statistics from Sweden in 2005 the majority of people with dementia in Sweden (about 78 000) lived in their ordinary home and received care or help from family members such as a spouse or children. Approximately two-thirds of the caregivers were spouses and one-third were children (Wimo, Johansson & Jönsson, 2007). The same pattern is seen in, for example, the United States (National Academy on an Aging Society, 2000). The burden of giving care to a relative with dementia has been acknowledged in research (Etters, Goodall & Harrison, 2008). Despite that most of the research into family caring has focused on physical and emotional burden of the caregiver, a few studies focus on their resources as support to engagement in occupations at home. Phinney (2006) and Vikström, Borell, Stigsdotter-Neeley and Josephsson (2005) found that families of people with dementia use a variety of supportive strategies to help their relatives with dementia to remain involved in daily activities, through creating a supportive environment. According to Phinney (2006) these strategies were enacted to support the identity and autonomy of the individual and to maintain family values and practices. Considering the importance of engagement in daily occupations for people with dementia, caregivers’ supportive strategies such as those found by Vikström and colleagues (2005) and Phinney (2006) seem to be highly important recourses to acknowledge.
Yet another type of recourse available for persons with dementia is the physical environment, and an overview of environmental interventions such as home modifications and assistive technology will be presented below.

Home modifications and assistive technology for people with dementia and their significant others

The home is found to be very important in old age (Haak et al., 2007; Lilja, 2000; Oswald & Wahl, 2005) and according to today’s health policies older adults should be able to stay in their own homes as long as possible (National Board of Health and Welfare, 2007). According to Sibely et al. (2002) people with mild-stage dementia can maintain living at home with appropriate support. Home modifications and assistive technology interventions have been suggested to provide support for people with dementia to avoid or delay nursing home placement (Cash, 2003; Gitlin & Corcoran, 1996; Spruytte, Van Audenhove & Lammertyn, 2001). However home modifications must be individualized to fit to the particular home situation (Gitlin & Corcoran, 1996) since subjective experiences of the home environment may have important implications for which modifications that are accepted by families or individuals with dementia (Gitlin, 2002).

In interventions, involving the situation at home with both the person with dementia and eventual significant others, it has been recommended to view and treat the person with dementia and the significant other as one client (Vikström, 2008). Moreover, clinical interventions that address both the person with dementia and the caregiver are reported to give the largest and most positive effects (Schultz & Martire, 2004). According to Gitlin (2002) it is important to develop a collaborative approach with the person with dementia and the caregiver and to keep in mind that the intervention must work for all people in the household when delivering home modifications or assistive technology.

Assistive technology

As discussed earlier AT is suggested to have a potential to enhance the situation of people with dementia and their significant others in terms of independent living, safety, autonomy and quality of life (Cahill et al, 2007b). However the knowledge of the potential of AT in the context of dementia is still limited and the research carried out so
far is not sufficient to draw general conclusions of the benefit from AT solutions or the cost-effectiveness of these (Topo, 2009). In the following, I will summarize literature on AT for people with dementia, mainly focusing on studies where the person has dementia in mild to moderate stages, still live at home and is an active user of the AT as this is the main target population of this thesis. According to a literature review (Topo, 2009) such studies are currently biased towards studies focusing on residential living, severe dementia and caregivers’ experiences.

When considering AT for people with dementia living at home, there are AT aiming to be used by either the person with dementia, by the significant other or by both parts. AT aiming to be used by people with dementia themselves are scarcely developed (Topo, 2009) and has so far been used mainly to compensate problems related to temporal disorientation, through for example electronic calendars and memory notebooks (Nygård & Johansson, 2001; Schmitter-Edgecombe, Howard, Pavawalla, Howell & Rueda, 2008; Topo et al., 2007) and safety, through for example stove timers (Nygård, Starkhammar & Lilja, 2008; Starkhammar & Nygård, 2008; Nygård, in press). However a few attempts have also been made to develop AT to enhance the quality of life for people with dementia by, for example, designing easy-to-use technology for accessing music (Orpwood et al., 2007; Topo et al., 2004). According to Topo (2009) studies of AT for people with dementia focusing on problems in communication, social inclusion, lack of meaningful activities or stimulation are still lacking.

Safety problems have shown to be an area where significant others of people with dementia often ask for technical solutions (Kinney, Kart, Mur doch & Ziemba, 2003; Rialle, Ollivet, Guigui & Hervé, 2008). Rowe, Lane & Phipps (2007) reported on the development of a home monitoring system which main goal was safety and to improve caregiver sleep through preventing the person with dementia to leave the home unattended. However, no outcome reports have yet been found. Further, tracking through cell phones with the use of GSM (Global System for Mobile communications) and GPS (Global Positioning System) have been suggested as possible devices for people with dementia and their significant others to solve safety problems without restricting the person with dementia (Miskelly, 2005; Rasquin, Willems, de Vlieger, Geers & Soede,
2007). However, there are debates on the ethics in tracking of people with dementia (Cahill, 2003; Hughes & Louw, 2002; Plastow, 2006; Welsh, Hassiotis, O’M ahoney & Deahl, 2003) with contrasting perspectives among researchers. Moreover Robinson et al. (2007) found that contrasting perspectives can lead to conflicts in decision-making concerning a person with dementia who wanders and that decision-making regarding the use of assistive technology is complex and associated with considerable ethical conflicts. According to Topo (2009) both formal and informal caregivers tend to emphasize safety issues and hence it is important to capture different perspectives when studying the need for AT in people with dementia and their significant others.

Except from AT aiming to be used by the person with dementia, an additional area where technology has been suggested to have a potential is in giving psychosocial support to significant others who care for persons with dementia. Such interventions are targeted towards the significant other but are supposed to also be beneficial to the person with dementia since they may reduce the risk of early nursing home placement which is associated with caregiver burden (Gaugler, Kane, Kane & Newcomer, 2005; Y affe et al., 2002). Technology-based interventions targeting significant others of people with dementia have shown promising results in alleviating distress and depression (Eisendorfer et al., 2003; M ahoney, Tarlow & J ones, 2003) but according to M ahoney and colleagues (2003) the intervention effects was dependent on characteristics of the significant other and hence not all significant others benefited from the intervention. Attempts have also been made to support access to formal and informal support services for caregivers to persons with dementia and to enable significant others to participate in online discussion groups (Finkel et al., 2007; M agnusson et al, 2002). However in a systematic review of randomized trials where support to caregivers of people with dementia had been studied, no evidence for effectiveness in technological information and support-based interventions were found (Thompson et al., 2007).

Suggestions for successful AT-interventions

Despite few empirical studies with AT conducted in the homes of people with dementia (Topo, 2009) some suggestions have been made of how to achieve success in interventions with AT for people with dementia and their significant others. Firstly,
introduction of the technology at an early stage of the disease has been suggested (Cahill et al., 2007b; Rasquin et al. 2007). Secondly, no new learning should be required on the part of the person with dementia and the importance of familiarity is emphasized (Cahill et al. 2007a) Thirdly, the design of the technology has been pointed out as crucial (Bharucha et al. 2009; Cahill et al., 2007a; Gilliard, 2001). For example, Orpwood, Faulkner, Gibbs & Adlam (2003) recommended that AT should provide few choices to the user, have contrasting colours and high visibility to meet the needs of people with dementia. Also, AT with high levels of technical difficulties have been reported to have the lowest level of use and perceived usefulness (Bjørneby et al., 2004; Cahill et al. 2007b). Finally, the use of AT by the person with dementia was in some cases in the ENABLE project influenced by the availability of a caregiver that reminded the person with dementia about the AT and sometimes also demonstrated product use (Cahill et al. 2007b). The development of AT to be used by people with mild to moderate stage dementia living at home is in its infancy and it has been pointed out by several authors that there is a need for the development of simple and non-stigmatizing AT that meets the needs of the person with dementia and their significant others (Bharucha et al., 2009; Bjørneby et al., 2004; Cahill et al., 2007a; Gilliard, 2001; Topo, 2009).

In summary, AT for people with dementia is currently mainly used to compensate for functional loss mainly in the areas of temporal disorientation and safety problems (Nygård & Johansson, 2001; Nygård, Starkhammar & Lilja, 2008; Schmitter-Edgecombe et al., 2008; Starkhammar & Nygård, 2008; Topo, 2009; Topo et al., 2007) and to support caregivers through technology based psychological interventions (Eisendorfer et al., 2003; Finkel et al., 2007; Mahoney et al., 2003; Magnusson et al, 2002; Thompson et al., 2007). Generally there is great trust in that AT has the potential to enhance safety, independent living and autonomy for people with dementia and to enhance quality of life for both people with dementia and their significant others. The knowledge of how AT best should be introduced and provided is sparse and research focusing on AT for people with mild to moderate stage dementia living at home that takes environmental issues into consideration has recently been called for (Topo, 2009).
In order for people with impairments due to MCI or dementia and their significant others to be able to benefit from interventions such as AT prescription, the availability of sensitive ADL/IADL assessments is important. In the next chapter, I will discuss ADL and IADL assessments for the use with people with MCI and dementia and briefly describe the development of a new assessment of everyday technology use that has been used in the first two studies in this thesis.

The development of Everyday Technology Use Questionnaire

Development of more sensitive assessment methods that may detect changes in complex ADL/IADL ability in people with MCI or preclinical dementia that for example can enable early interventions have been requested (Bodine & Scherer, 2006; Hancock & Larner, 2007; Jefferson et al., 2008; Nygård, 2003; Pérès et al., 2006; Winblad et al., 2004). Since IADL tasks in general are more complex than ADL tasks, assessments of IADL may be likely to detect early limitations in MCI. The Assessment of Motor and Process Skills (AMPS) has shown to be sensitive when assessing older adults with and without AD (Hartman, Fisher & Duran, 1999). However, even though AMPS includes some activities that imply the use of everyday technology, it does not specifically measure competence in everyday technology use. For sensitive assessment, the item or task selection in an instrument is crucial, and new ADL instruments may need to incorporate more complex and culturally relevant items, such as everyday technology use, than the traditional ADL scales do. Such instruments may then detect subtle changes in ability (Nygård, 2003; Nygård & Winblad, 2006).

To our knowledge, there is no assessment that measures the perceived difficulties in everyday technology use. In order to systematically gather such information and achieve a basic comprehension of perceived relevance of and difficulty in technology use in older adults with MCI or dementia, the Everyday Technology Use Questionnaire (ETUQ) was developed. According to Kielhofner (2008) people have perceptions of their own ability to perform certain tasks. These perceptions are formed by earlier experiences, values, needs and norms in the environment. Hence it is valuable to capture each person’s own perceptions when assessing difficulties in everyday technology use.
The ETUQ was developed as a questionnaire by researchers at Karolinska Institutet (Nygård, 2002) in collaboration with clinical occupational therapists (OT) who met in discussion groups to identify items relevant to cover the construct of everyday technology in a population of older adults. According to the Joint Committee on Standards for Educational and Psychological Testing (American Educational Research Association, 2002), such a participatory approach is preferably used in the design of new assessments, items, and scoring procedures. A wide range of everyday technology artifacts and services were included to cover the range of electronic, technical, and mechanical equipment that commonly exists in the more narrow technology room and the wider technological landscape of older adults, including both well known and more recently developed technological artifacts and services. Well known technologies were included in the ETUQ based on the findings of a study where people with dementia, who lived alone, were found to have considerable difficulties in carrying out tasks with their ordinary telephone (Nygård & Starkhammar, 2003). The everyday technologies chosen for inclusion in ETUQ were the result of common sense agreement between clinicians and researchers of what everyday technology is, rather than a decision from a theoretical standpoint, in line with the ambition to enhance clinical relevance.

Conclusion of introduction

Living in today’s technological landscapes requires continuous adjustment to everyday technology artifacts and systems in order to manage daily life since everyday technology is used in a wide range of activities both in home and society (Czaja et al., 2006; Emiliani, 2006). The value of having an active lifestyle in old age (Fratiglioni & Qiu, 2009; Wang et al., 2009) and the importance of engagement in activities for people with dementia has been acknowledged in the literature (Egan et al., 2006; Phinney et al., 2007; Öhman & Nygård, 2005). However, hindrances that people with MCI or dementia might experience in performing occupations have been described, involving interaction with everyday technology (Nygård & Starkhammar, 2007). Furthermore, non use of technologies has been observed among well elderly due to age-related aspects, ambivalence and non-relevance (Selwyn, 2004; Larsson, 2009) and research focusing on the use of technology and the perspectives of older adults has been called for (Östlund, 2004). Accordingly, difficulties in everyday technology use and non relevance of
technology might be experienced by older adults diagnosed with dementia or MCI as well as by older adults without cognitive impairment. In spite of common assumptions and hypotheses about technology use among older adults, no systematic studies of difficulties in the use of everyday technology and the perceived relevance of everyday technology has been conducted among older adults with or without cognitive deficits.

Generally there is great trust in society that assistive technology has the potential to provide support to people with dementia and their caregivers (Cash, 2003; Gitlin & Chee, 2006; Spruytte et al. 2001) but the knowledge about how this may be achieved is sparse (Cahill et al., 2007a) and research evaluating the use of assistive technology for people with mild to moderate stage dementia living at home has recently been called for (Topo, 2009).

Finally, significant others of people with dementia are central in dementia care services since a majority of people with dementia in Sweden and other countries live in their ordinary home and receive care or support from family members (Wimo et al., 2007). It is commonly supposed that support from technology is wanted (Bodine & Scherer, 2006). However the knowledge about the readiness among significant others of people with dementia to use and adjust to technology in their everyday life together with their relative with dementia is also sparse.
RESEARCH AIMS

General research aim

The overall aim of this thesis was to increase knowledge about people with MCI or dementia and their significant others, particularly as users of everyday technology and assistive technology. The overall aim also includes increasing knowledge about transactions between people with MCI or dementia and their significant others, and technology.

More specifically, the aim was to investigate the perceived relevance of, and difficulties in the use of everyday technology among older adults with and without cognitive deficits and how to measure these constructs. The aim also included increasing knowledge about the transactions involved in the interplay between technology and older adults with MCI or dementia, and their significant others.

Specific research aims:

- To evaluate aspects of validity and reliability i.e. internal scale validity, person response validity and person separation of the Everyday Technology Use Questionnaire with a sample of older adults with and without cognitive impairment or dementia (Study I).

- To compare the perceived relevance of and difficulty in using everyday technology in people with mild-stage dementia, people with MCI, and older adults without known cognitive impairment (Study II).

- To explore the actions of the different persons and their driving forces in the process that starts when an AT is brought into the situation where a person with dementia and other significant persons pursue their everyday lives (Study III).

- To explore and describe how significant others of people with dementia relate to technology, and their readiness to use assistive technology in their daily life together with the person with dementia (Study IV).
METHODS

Design

Different methodological approaches were used in this thesis in order to develop knowledge about people with MCI or dementia and their significant others as technology users, and to explore the ongoing transactions within their technological landscapes. For an overview of research approaches and methods used in this thesis, see Table 1.

Table 1. Overview of research approach and methods of data collection and analysis in the four studies included in the thesis

<table>
<thead>
<tr>
<th>Study I</th>
<th>Study II</th>
<th>Study III</th>
<th>Study IV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus</td>
<td>Investigating psychometric properties of ETUQ(^1) in a mixed sample of older adults</td>
<td>Comparing three groups in relevance of, and perceived difficulty in everyday technology use</td>
<td>Exploring driving forces in the process of AT(^2) implementation to persons with dementia</td>
</tr>
<tr>
<td>Research approach</td>
<td>Modern test theory and instrument development</td>
<td>Grounded theory, multiple case study</td>
<td>Grounded theory</td>
</tr>
<tr>
<td>Methods of data collection</td>
<td>Self/proxy reported relevance and perceived difficulty in using everyday technology collected with ETUQ(^1)</td>
<td>Open-ended interviews and observations</td>
<td>Focus group interviews and individual open-ended interviews</td>
</tr>
<tr>
<td>Analysis</td>
<td>Rasch rating scale model</td>
<td>Rasch rating scale model, ANOVA, post-hoc Bonferroni</td>
<td>Grounded theory approach</td>
</tr>
</tbody>
</table>

\(^1\) Everyday Technology Use Questionnaire, \(^2\) Assistive technology
Participants and criteria for selection

The population of main interest in this thesis was older adults with MCI or dementia in a mild to moderate stage, still living in their own homes, and their significant others. However, older adults without known cognitive impairments were also included for comparisons in Studies I and II. An overview of participants' characteristics is presented in Table 2.

Table 2. Overview of participants' characteristics at the time of inclusion in data collection

<table>
<thead>
<tr>
<th>Study I</th>
<th>Study II</th>
<th>Study III</th>
<th>Study IV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants</td>
<td>Total n=157</td>
<td>Total n=13</td>
<td>Total n=16</td>
</tr>
<tr>
<td>a) with mild-stage dementia (n=34)</td>
<td>Case 1 (n=3) 1 PWD(^2) (Ingrid), 1 significant other, 1 professional</td>
<td>Significant others to PWD(^2): 9 spouses, 5 adult children, 1 son-in-law, 1 neighbor</td>
<td></td>
</tr>
<tr>
<td>b) with MCI(^1) (n=30)</td>
<td>Case 2 (n=4) 1 PWD(^2) (Harry), 2 significant others, 1 professional</td>
<td>Ind int(^3) (n=4)</td>
<td></td>
</tr>
<tr>
<td>c) without known cognitive impairment (n=93)</td>
<td>Case 3 (n=6) 1 PWD(^2) (Karin), 1 significant other, 4 professionals</td>
<td>a) Focus group 1 (n=4)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>b) Focus group 2 (n=3)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>c) Focus group 3 (n=5)</td>
</tr>
<tr>
<td>Sex</td>
<td>Total 66/91 (42/58)</td>
<td>Total 2/11</td>
<td>Total 5/11</td>
</tr>
<tr>
<td>n men/women</td>
<td>a) 16/18 (47/53)</td>
<td>Case 1) 1/2</td>
<td>Ind int(^3) 1/3</td>
</tr>
<tr>
<td>(% men/women)</td>
<td>b) 13/17 (43/57)</td>
<td>Case 2) 1/3</td>
<td>a) 1/3</td>
</tr>
<tr>
<td></td>
<td>c) 37/56 (40/60)</td>
<td>Case 3) 0/6</td>
<td>b) 0/3</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>c) 3/2</td>
</tr>
<tr>
<td>Age, years</td>
<td>Total 74 7.60 (55-98)</td>
<td>Total 56 (26-91)</td>
<td>Total 63 (45-78)</td>
</tr>
<tr>
<td>Mean, SD (range)</td>
<td>a) 73, 8.34 (55-87)</td>
<td>PWD(^3): 85 (79-91)</td>
<td>Ind int(^3) 63 (55-78)</td>
</tr>
<tr>
<td></td>
<td>b) 74, 6.86 (59-87)</td>
<td>Significant others: 63 (55-78)</td>
<td>a) 65 (45-76)</td>
</tr>
<tr>
<td></td>
<td>c) 74, 7.59 (60-98)</td>
<td>Professionals: 38 (26-51)</td>
<td>b) 71 (66-75)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>c) 57 (49-64)</td>
</tr>
</tbody>
</table>

\(^1\)Mild cognitive impairment; \(^2\)Person with dementia; \(^3\)Individual interviews
Participants in Studies I and II

In Studies I and II the sample consisted of 157 community-living people, aged 55 years and older. According to Linacre (1994), a sample size of approximately 150 people is suggested to generate stable item calibration (99% CI 0.5 logits). Of the 157 participants included, 34 were diagnosed with dementia, 30 with MCI, and 93 had no known cognitive impairments. Inclusion criteria were that participants should live in their own homes in the community and be engaged in daily life tasks, which meant that their IADLs were not taken over by someone else. Persons with visual disorders that could severely interfere with the use of everyday technology were excluded. Participants with dementia and MCI were recruited in collaboration with personnel at memory and dementia investigation units. These participants had, before inclusion in the study, been diagnosed by a physician in accordance with established criteria for dementia; DSM-IV (APA, 2000), ICD-10 (WHO, 1993) and NINCDS-ADRDA (McKhann et al., 1984) and the diagnostic criteria for MCI proposed by Petersen (2004). The participants with no known cognitive impairment were recruited through national retirement organizations in Sweden. The absence of cognitive impairment was based on MMSE scores of 24 or above (Folstein, Folstein & McHugh, 1975).

During data collection, participants in the three groups were asked if they had functional limitations or diagnoses. These data indicated a broad variety of common age-related functional limitations such as back pain and hearing deficits, and diagnoses like rheumatoid arthritis and diabetes were also present in the three groups. Furthermore, the groups were compared for differences in age, sex, and living circumstances (living alone or cohabiting). No significant differences in age (Group 1 vs. 2 t=.69, df=61, p=.49; Group 1 vs. 3 t=.42, df=125, p=.65; Group 2 vs. 3 t=.41, df=120, p=.68), living conditions (Chi Square=.28, df=2, p=.87) or sex (Chi square=.63, df=2, p=.73) were found between groups. In order to capture a broad array of technologies, participants were recruited from urban, rural, and suburban environments. Further characteristics of the participants in Studies I and II are presented in Table 2.
Participants and assistive technology, Study III

In Study III, people with dementia were recruited through OTs working in memory investigation units and outpatient clinics. Inclusion criteria were that the participants should be 55 years or older, diagnosed with MCI or dementia, living in their own homes, and about to receive an AT due to problems from MCI or dementia. In addition to the person with dementia, the main participant, other persons shown to be significant to the situation were included, according to the principles of theoretical sampling in grounded theory (Charmaz, 2006; Glaser & Strauss, 1967).

Altogether three cases (Merriam, 1998) were included with one person with dementia in each case and with a total of 13 participants and six different ATs in the study (for description of the ATs included in the study see Table 3). The three participants with dementia, regarded as the main participants in the study, all lived alone in their own homes and received help from the home help services and from their significant others. They had been diagnosed with dementia between one and two years before inclusion in the study.

Ingrid (Case 1) was diagnosed with AD and experienced dementia-related problems with memory impairment, anxiety, and time perception. She received a Night and Day Calendar (see Table 3). Other persons included in Case 1 were Ingrid’s son, who helped her with everyday matters, and the OT who prescribed the AT. For further characteristics of the participants in Study III, see Table 2. Regrettably, Ingrid died shortly after the data collection was finished.

Harry (Case 2) was diagnosed with VD and experienced memory impairment due to dementia. However, his significant others also reported difficulties with time management and in IADLs such as cooking and washing. Three days a week, Harry visited a senior day centre for people with dementia. Other persons included in Harry’s case were his daughter and a neighbor who helped him on an everyday basis. The OT who prescribed the AT, a Forget-Me-Not-Calendar (see Table 3) for him was also included in the case. At the end of the data collection period, Harry moved from his house into a nursing home for people with dementia.
Karin (Case 3) was diagnosed with AD and experienced memory problems. She also had problems finding her way outdoors. Persons included in the case besides Karin were her daughter, two home helpers, and two OTs. During the period of data collection Karin’s allowance of assistance from the home help services was increased from once a week to several visits every day. Several ATs were tried in Karin’s case; a Memory Message, a Forget-Me-Not-Calendar, a Magnetic Board, a Week Schedule and finally a Night and Day Calendar (see Table 3 for descriptions of ATs).

Table 3. Assistive technology (AT) in Study III

<table>
<thead>
<tr>
<th>AT Introduced</th>
<th>Case</th>
<th>Description of AT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Night and Day</td>
<td>Cases 1 and 3</td>
<td>An electronic calendar that displays the correct day, date and a notation of ‘morning’, ‘afternoon’, ‘evening’ or ‘night’ when connected electrically.</td>
</tr>
<tr>
<td>Calendar</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Forget-Me-Not-Calendar</td>
<td>Cases 2 and 3</td>
<td>An electronic calendar that displays the correct day and date when connected electrically.</td>
</tr>
<tr>
<td>Memory Message</td>
<td>Case 3</td>
<td>A talking clock that gives pre-recorded messages at predetermined times. It also gives information of what day and what time of the day it is.</td>
</tr>
<tr>
<td>Magnetic Board</td>
<td>Case 3</td>
<td>A magnetic board on which it is possible to make a schedule for one week with written text or symbolic pictures for each day.</td>
</tr>
<tr>
<td>MeDose watch</td>
<td>Case 3</td>
<td>A digital watch with hands and six built-in alarms given as a voice, a signal or vibration.</td>
</tr>
<tr>
<td>Week schedule</td>
<td>Case 3</td>
<td>A schedule on paper with a plastic cover that makes it possible to write on the schedule with a whiteboard pen and to erase it.</td>
</tr>
</tbody>
</table>

Participants in Study IV

The inclusion of participants in Study IV followed the principles of theoretical sampling (Charmaz, 2006; Glaser & Strauss, 1967), meaning that the parallel ongoing analysis guided the inclusion. Study IV originated in some of the data collected from the four significant others of the participants with dementia (two daughters, one son, and one neighbor) in Study III. The relatives with dementia of those participants had been diagnosed with dementia about two years before inclusion in Study III, and were between 79 and 91 years old. These interviews are called the individual interviews here.
The main participants in Study IV were significant others recruited for focus group discussions through personnel at an outpatient geriatric clinic. Inclusion criteria were that the participants should be significant others of people with dementia, involved in the everyday lives of the persons with dementia, and willing to take part in discussions in Swedish. Potential participants were invited to focus groups interviews by telephone and by an information letter.

In total, 12 significant others of people with dementia participated in three focus groups. The first focus group consisted of four participants; two wives, one daughter, and one son-in-law. The relatives with dementia in this group had been diagnosed within one year prior to their significant others' inclusion in the study and were between 76 and 87 years old. The second focus group was recruited from a support group for significant others of older adults with cognitive impairments due to stroke and dementia, and hence they knew each other before inclusion in the study. From this existing support group, two wives and one daughter of people with dementia were included. The relatives with dementia in the second group had been diagnosed four to eight years prior to the study and were more severely dementia-impaired than the relatives of the participants in Groups 1 and 3. They were between 81 and 95 years old. Finally, the third focus group consisted of three husbands and two wives of younger people with dementia. This group was characterized by the significant others still working, and two of them had children under the age of 18 living at home. The relatives with dementia in this group had been diagnosed between six months and three years prior to the study and were between 50 and 66 years old.

Altogether 16 significant others of people with dementia were included as participants in the study. The relatives with dementia of those participants were diagnosed with AD (n=8), unspecified dementia (n=3), and Lewy body dementia (n=1), and ranged from 50 to 95 years in age. For characteristics of the participants in Study IV see Table 2.

People with MCI and dementia as research informants

In recent literature, it has been increasingly recognized that people in early stages of dementia may be relatively well aware of their situation and that they are adept at talking about what it means to have dementia (Menne, Kinney & Morhardt, 2002; Nygård, 2006;
Phinney, Wallhagen & Sands, 2002). Nevertheless, verbal skills are affected early in the course of dementia, and the perspectives of people who are afflicted by dementia have generally been ignored in research (Nygård, 2006). According to Burgio and Leon (1997) researchers should not dismiss these data despite difficulties in getting reliable self-reports from people with dementia. When it comes to collecting self-reports from people with MCI, Farias, Mungas and Jagust (2005) and Wadley et al. (2007) found that individuals with MCI did not under-report their functional status, as can often be seen in persons with dementia. There is no gold standard in information sources in research involving people with dementia and both self- and proxy reports have been questioned (Doble, Fisk & Rockwood, 1999; Loewenstein et al., 2001). In this thesis, people with MCI and dementia were included as informants in Studies I, II, and III.

In Studies I and II the data collection with the ETUQ required that the participants had an ability to recall 86 different artifacts and services and reason abstractly about one’s perceived difficulties in the use of each of these. Hence the interview format was considered to be challenging for persons with cognitive impairment, and therefore the main respondents in the groups of people with dementia and MCI (Groups 1 and 2) were planned to be significant others of the people with dementia or MCI. In cases where the interviewer assessed that an interview with the person with MCI or dementia would be ethically preferable and give reliable and rich data, the interview would then be conducted with either this person alone or both persons together. However, during data collection it was discovered that interviews where both parties contributed to the interview (person with dementia or MCI and a significant other) were preferable. If the informants disagreed, the significant other’s response was chosen. Of the total numbers of interviews (n=64) in the groups of people with dementia and MCI (Groups 1 and 2), 50% (n=32) were conducted with the participant together with a significant other, 30% (n=19) was conducted with only the participant, and 20% (n=13) were conducted with only a significant other. In the group of people without known cognitive impairment (Group 3), 100% (n=93) were conducted with only the participant.

In Study III the data collection was adjusted to facilitate participation for the people with dementia, following Nygård’s recommendations (2006), by using a combination of qualitative observations and open interviews and using the context as support.
Data collection procedures

The data collection was the same in Studies I and II. Data for these two studies was mainly collected with the ETUQ. The data collection in Study III was conducted with open-ended interviews and participatory observations, while data in Study IV was collected through focus groups and open-ended individual interviews (for an overview see Table 1).

Data collection instruments, Studies I and II

The Mini Mental State Examination (MMSE) (Folstein et al., 1975) is a 30-item questionnaire that is widely used to screen for cognitive impairment or dementia in older adults (Crum, Anthony, Bassett & Folstein, 1993). The maximum MMSE score is 30, indicating normal cognitive functioning (Folstein et al., 1975). In clinical practice and in research, cut-off scores of 20-24 indicate mild impairment, 15-19 mild to moderate impairment, 10-14 moderate impairment and <10 indicates severe cognitive impairment (Wlodarczyk, Brodaty & Hawthorne, 2004). In Studies I and II the most recent MMSE score was excerpted from the records of the participants diagnosed with dementia (Group 1) or MCI (Group 2). The participants without cognitive deficits were assessed with MMSE before the ETUQ interview was administered. All participants without known cognitive impairment had MMSE scores at or above the cut-off score of 24.

As declared in the introduction, the Everyday Technology Use Questionnaire (ETUQ) was developed by researchers at Karolinska Institutet (Nygård, 2002) in collaboration with clinical OTs. The ETUQ was developed to map out perceived relevance and competence in the use of everyday technology among older adults with MCI or dementia. However during the work with Study II, the construct perceived competence was rephrased to perceived difficulty because the latter was considered to be closer to what was actually measured with the ETUQ. Accordingly, the same construct that is called perceived competence in Study I is called perceived difficulty in Study II.

The version of ETUQ (Nygård, 2002) that was used in Studies I and II in this thesis comprises 86 items representing everyday technology artifacts and services available in the technological rooms and landscapes of older adults in Sweden. The ETUQ is
conducted with an interview, and was designed as a standardized questionnaire with fixed response alternatives consisting of 86 items divided into eight activity areas based on common sense logic, in order to facilitate the interview (see Table 4).

Table 4. The eight activity areas in the Everyday Technology Use Questionnaire (ETUQ), number of items and examples of items in each activity area

<table>
<thead>
<tr>
<th>Activity Area</th>
<th>No. of Items</th>
<th>Examples of Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Household activities</td>
<td>18</td>
<td>Iron, microwave oven</td>
</tr>
<tr>
<td>Activities in the home</td>
<td>15</td>
<td>Television, video/DVD player, computer</td>
</tr>
<tr>
<td>Personal care</td>
<td>5</td>
<td>Razor, electric toothbrush</td>
</tr>
<tr>
<td>Power tools</td>
<td>1</td>
<td>Unspecified</td>
</tr>
<tr>
<td>Accessibility</td>
<td>15</td>
<td>Elevator, code-operated door lock</td>
</tr>
<tr>
<td>Data and telecommunications</td>
<td>18</td>
<td>Cell phone, e-mail, Internet</td>
</tr>
<tr>
<td>Economy and shopping</td>
<td>8</td>
<td>Credit card, Internet banking</td>
</tr>
<tr>
<td>Transportation</td>
<td>6</td>
<td>Automated check-in at airport</td>
</tr>
</tbody>
</table>

The current version of the ETUQ (Nygård, 2002) uses a four-category scale; 4 = Use without difficulty, 3 = Use independently with difficulty, 2 = Use with help from someone else, 1 = Does not use anymore.

Data collection procedures, Studies I and II

The data collection in Studies I and II was performed between 2003 and 2005 in different parts of Sweden. In the dementia and MCI groups (Groups 1 and 2), the ETUQ interviews were carried out by 10 registered occupational therapists working at the memory investigation units in their clinical work. In the group of people without known cognitive impairment (Group 3) the interviews and MMSE assessments were carried out by five students at Master’s or Bachelor’s level at the Occupational Therapy program at the Karolinska Institute in Stockholm. All the data collectors had, previous to the study, been trained in the administration and scoring of the ETUQ in a half-day seminar. The data collectors also received continuous feedback and guidance during the period of data collection.
In every interview, which took about 30-45 minutes to complete, each of the 86 items was scored by the data collector based on the information given by the participant and/or his or her significant other. At first, the data collector asked if the item was perceived as relevant for the participant. Non-relevance could mean that the technology was not accessible or that the participant did not use or never had been interested in using this technology, even though it was accessible. If relevant, the four-category rating scale, described earlier, was used for scoring perceived difficulty of each item. Items that were not relevant to the person were left blank. Owing to these procedures, data received from the ETUQ represent the participants’ use of the technology that was perceived as relevant for them.

Data collection procedures, Study III

Data was collected in Study III through observations and in-depth interviews (Kvale, 1996; Nygård, 2006) in repeated sessions in the homes of the main participants (the persons with dementia) between September 2006 and February 2008 by the first author (LR). The data collection aimed to capture the different perspectives of the different actors involved in the process in each case. In order to achieve this, flexibility was needed and different sources of data were used; face-to-face interviews, observations, and telephone interviews. Of the 35 data collection sessions, six were telephone interviews.

The first data-collection session in all three cases took place before the persons with dementia had received the AT that their OTs were about to prescribe. At this session the informants’ expectations of the AT as well as perceived problems in everyday life and earlier experiences, interest, and habits related to everyday life of the person with dementia, were documented.

In the second session the person with dementia and the OT were observed during installation and introduction of the AT in all three cases. The third session took place when the person had had the AT in the home for one or two weeks. The following sessions of data collection were directed by circumstances in each case and questions raised in the parallel analysis.
The number of data-collection sessions and the period of data collection in each case ranged from four sessions over 20 days in Ingrid’s case (Case 1), to 8 sessions over 13 months in Harry’s case (Case 2), and 23 sessions over 15 months in Karin’s case (Case 3). In Karin’s case different AT solutions were tried and therefore the data collection was more extensive than in the other cases.

Data collection procedures, Study IV

The individual interviews were conducted by the first author (LR) between September 2006 and February 2008 within the data collection of Study III, and encompassed eight open interviews (Kvale, 1996) with significant others. Four of them were conducted in the homes of their relatives with dementia and four as telephone interviews. An initial comparative analysis (Glaser & Strauss, 1967) of these interviews informed us when the interview guide for the focus groups was designed. This interview guide consisted of open questions covering the participants’ experiences of technology use, views of technology, ideas and experiences of AT as support for both people with dementia and his/her significant others, and ethical reflections connected to technology.

Five sessions with three different focus groups were conducted between January and September 2008 at places that were chosen to facilitate for the participants. All the focus group sessions were led by LR with assistance from an experienced OT, who took care of practical arrangements and kept field notes during sessions (Morgan & Kreuger, 1997). Each session lasted between two and three hours (1.56h – 2.48h) including refreshment breaks. In the latter part of the second session in Groups 1 and 2 and in the latter part of the session with Group 3, the research assistant showed pictures of a selection of AT and gave a brief description of their purposes and functions. The ATs presented in the sessions were devices for planning and reminders, cell phones, and a remote control. This was a means to stimulate concrete discussions of AT for people with dementia and their significant others, as the participants were unaware of ATs for this group or only knew of a few.
Data analyses

Data analyses, Study I

In Study I, an application of a Rasch rating scale model was used to examine the unidimensionality of the ETUQ (Bond & Fox, 2001). Because the statistical use of sums of ordinal scores can be questioned (Fisher, 1993; Wright & Linacre, 1998) the Rasch computer programs are used to convert the raw scores from a test or a questionnaire into equal interval measures.

The Rasch rating scale model was chosen for the following reasons. First, the items included in the ETUQ were assumed to vary in difficulty. The Rasch rating scale model takes into account the actual challenge of each item scored and adjusts the final person ability measure based on differences in item challenge (Bond & Fox, 2001; Wright & Stone, 1979). Second, as the perceived relevance and use of everyday technology is related to context and personal characteristics, it is important that a measure generated from a test can handle a situation when all people may not be tested on similar items but can still be compared with each other (i.e. test equation) (Wright & Stone, 1979).

Applied on the construct of difficulty in everyday technology use, the basic assertions in a simple Rasch model for estimation of a person’s abilities and items difficulties are as follows: (1) the less difficult a technological artifact or services is to use, the more likely it is to be used without difficulty by all people than are technological artifacts and services that are more difficult to use, and (2) the more competent the person is in using technological artifacts and services, the more likely it is that he or she uses more difficult technological artifacts and services without difficulty than does a person who is less competent. The Rasch analysis aims at investigating if the responses generated when the persons are assessed on the items perceived as relevant for them follow what was expected according to these assertions. If the responses fit the assertions in the model, the raw scores can validly be transformed into linear measures and the scale can be considered to have acceptable psychometric properties (Bond & Fox, 2001).
Several aspects of psychometric properties of a scale can be investigated with Rasch analysis. In this study, the rating scale properties, internal scale validity, person response validity, and person separation reliability of the ETUQ were investigated using the WINSTEPS Rasch analysis software program, version 3.59.1 (Linacre, 2005a).

The first step in the analysis was to evaluate the psychometric properties of the rating scale used, following Linacre’s guidelines (2004). The guidelines pointed out as essential by Linacre (2004) were followed. These are: a) at least ten observations per category are essential to achieve stability in the measures generated, b) the average measure for each category should advance monotonically with category order, and c) outfit mean squares ($MnSq$) less than 2.0 ($MnSq<2.0$) are essential to achieve measure accuracy (Linacre, 2004).

After analyzing the rating scale, the internal scale validity and person response validity were investigated. The WINSTEPS program generates goodness-of-fit statistics for items and persons expressed as $MnSq$ and standardized $z$ values. These indicated the degree of match between the expected responses of the Rasch rating scale model and actual responses on the ETUQ, i.e. the difference between what is expected and what is observed (Bond & Fox, 2001).

In this thesis, items and persons with $MnSq$ less than 1.4 (Wright & Linacre, 1994) with an associated $z<2.0$ (Linacre, 2002) were considered to meet the criteria for goodness-of-fit. At least 95% of items and persons should demonstrate goodness-of-fit to the model in accordance with previous research (Nilsson & Fisher, 2006; Patomella, Tham & Kottorp; Petersson, Fisher, Hemmingsson & Lilja, 2007). The goodness-of-fit statistics are expressed in both infit and outfit statistics. The infit statistics are weighted relatively more for performances of persons who are well targeted to the item value. The outfit statistics are not weighted and are therefore more sensitive to outlying scores (Bond & Fox, 2001; Linacre, 2002). Because this was the first study evaluating the psychometric properties of the ETUQ, both infit and outfit statistics were used in order to get detailed information (Smith, 2000).

Further evaluation of the unidimensionality among the ETUQ were conducted through a Principal Component Analysis (PCA) (Linacre, 1998). The criteria set for this analysis were that at least 60% of the total variation in the data should be explained by the first
variable (i.e. perceived difficulty in everyday technology use), and that any additional factor should not explain more than 5% of the total variation (Linacre, 2005b).

Finally, person separation index statistics were examined to determine the ETUQ’s ability to separate the distribution of persons into different levels of perceived difficulty in everyday technology use (Bond & Fox, 2001). In this thesis, we used the criteria of a reliability index of 0.8, associated with a person separation index of 2.0, to differentiate the sample into at least three groups of persons that distinctly differ in perceived difficulty in everyday technology use (Fisher, 1992).

Data analyses, Study II

The data analysis in Study II was performed in two steps. The first step was to compare the perceived relevance of the item in the ETUQ between the three groups. To do a one-way ANOVA was applied with the dependent variable being the proportion of the total numbers of items in the ETUQ that the participants perceived to be relevant to their life situations.

The second step was to compare the perceived relevance of the item in the ETUQ between the three groups and application of one-way ANOVA was performed with the dependent variable being the ETUQ measures generated from the Rasch analysis.

Further, Post-hoc Bonferroni procedures were used in both steps of the analysis in order to determine between which groups a significant difference was present. The critical p-value for all statistical analyses was set at p<0.05. To further evaluate the degree of differences between groups, effect sizes (d) were calculated. According to Cohen (1988), an effect size of 0.8 or more is defined as large, an effect size between 0.8 and 0.5 is moderate, and 0.2-0.4 is small.

The ANOVA and Post-hoc Bonferroni statistical analyses procedures were conducted using the Statistical Package for the Social Sciences (SPSS), version 13.0 software program.
Data analyses, Studies III and IV

Analysis of data in Studies III and IV was continuously carried out throughout the data collections, following the recommendations of Glaser and Strauss (1967). The digitally recorded interviews were listened to several times and thereafter transcribed verbatim. The transcripts were then inserted into the AtlasTi software in order to facilitate the analysis by structuring the material.

Thereafter, open coding of the transcripts was conducted with an emphasis on the ongoing transactions between participants and environments (Study III) and the essence in the discussions (Study IV). The codes were given names close to the data and as the analysis proceeded the codes were continuously compared and merged with other codes. Parallel to the coding procedures, memos were written where theoretical ideas and new questions raised in the analysis were developed (Glaser, 1978). Each interview was first analyzed separately and subsequently compared to the other interviews in the same study. In Study IV an initial analysis had been conducted with the individual interviews prior to the focus groups. Those individual interviews were reconsidered in the analysis after the coding procedures of the five focus group sessions. The individual interviews were now reread line by line and coded with focused coding (Glaser, 1978), which meant that these data were given codes that had been conceptualized from the focus groups data. Focused coding was also used in Study III. After the coding procedures of data from Cases 1 and 2, interviews and field notes from Case 3 where first read line-by-line and then analyzed with focused coding (Glaser 1978). The focused coding in Studies III and IV mostly confirmed the emerging categories from the data that had been analyzed earlier, but also resulted in somewhat revised properties of the categories, requiring us to go back in the data and look for new incidents (Glaser & Strauss, 1967). This back-and-forth process, where categories were constantly compared to data and to each other, continued throughout the analytical processes of both Studies III and IV. Emerging categories and their properties were also continually discussed in the groups of authors and in seminars with fellow researchers to further increase the validity of findings.
FINDINGS

The aim of Study I was to evaluate aspects of validity and reliability i.e. internal scale validity, person response validity and person separation of the Everyday Technology Use Questionnaire with a sample of older adults with and without cognitive impairment or dementia.

The findings in Study I indicate that the three-category rating scale is preferable to the four-category scale that was first evaluated in the ETUQ. The four-category scale (4 = Use without difficulty, 3 = Use independently with difficulty, 2 = Use with help from someone else, 1 = Does not use anymore) demonstrated category disorder so that categories 2 and 3 could not be distinguished from each other. Categories 2 and 3 were therefore combined into one category: Use with difficulty. The three-category scale (3 = Use without difficulty, 2 = Use with difficulty, 1 = Does not use anymore) was acceptable according to the essential criteria and was hence chosen for subsequent analyses (see Table III).

Table III. Summary of results in Study I of psychometric properties of the Everyday Technology Use Questionnaire (ETUQ)

<table>
<thead>
<tr>
<th>Analysis</th>
<th>Results from the analysis of the Everyday Technology Use Questionnaire (ETUQ)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Four-category rating scale</td>
<td>Not acceptable; rating scale did not meet the essential criteria since category disorder was found in categories two and three.</td>
</tr>
<tr>
<td>Three-category rating scale</td>
<td>Acceptable; rating scale met the essential criteria.</td>
</tr>
<tr>
<td>Internal scale validity</td>
<td>Acceptable; 95% of items (82 of 86) met the criteria(^1).</td>
</tr>
<tr>
<td>Person response validity</td>
<td>Acceptable; 97% of participants (152 of 157) met the criteria(^1).</td>
</tr>
<tr>
<td>Principal Components Analysis (PCA)</td>
<td>Acceptable; 62% of the total variation was explained by the first variable, and the second factor explained 1.7% of the variation.</td>
</tr>
<tr>
<td>Person separation</td>
<td>Acceptable; reliability index of 0.81 associated with a person separation index of 2.09.</td>
</tr>
</tbody>
</table>

\(^1\)criteria of goodness-of-fit to the Rasch rating scale model
Taking the infit and outfit statistics into consideration, both items and participants demonstrated acceptable goodness-of-fit to a Rasch rating scale model, indicating acceptable internal scale validity and person response validity (see Table III). Furthermore, the principal components analysis (PCA) revealed that the first component (here called competence in everyday technology use) accounted for 62% of the variations in the data set, further supporting unidimensionality among the ETUQ items (see Table III). A reliability index of 0.81 associated with a person separation index of 2.09 indicated that the ETUQ was able to differentiate the sample into at least three groups of persons that distinctly differ in perceived difficulty in the use of everyday technology (see Table III). However, 21 participants (20 without known cognitive impairment and one with MCI) received the highest score on all items, resulting in a ceiling effect in these participants’ measures, meaning that ETUQ could not estimate their abilities. This indicates that the everyday technologies included in ETUQ at the time of the study may be too easy for older adults without cognitive impairment but well suited for older adults with MCI or dementia, for whom it was originally developed.

The result also contributed an item map of 86 technological artifacts and services, arranging all items in order of difficulty. A representative portion of the scale is shown in Table IV.

In summary, the findings from Study I indicate that ETUQ demonstrates acceptable evidence of validity in terms of internal scale validity and person response validity to be used for comparing groups of older adults with and without cognitive deficits in perceived relevance and competence of everyday technology use. ETUQ was also found to be sensitive enough to detect differences between subgroups of everyday technology use along the scale.
Table IV. Items perceived to be most and least difficult by the participants (n=157) in Study I.

<table>
<thead>
<tr>
<th>Perceived as most difficult</th>
<th>Cell phone services (other than phone call and text message) (32) 1.76</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Cell phone: text message (23) 1.72</td>
</tr>
<tr>
<td></td>
<td>Rotary dial telephone (63) 1.64</td>
</tr>
<tr>
<td></td>
<td>Self service check-in at airport (16) 1.49</td>
</tr>
<tr>
<td></td>
<td>Tools (94) 1.48</td>
</tr>
<tr>
<td></td>
<td>Pay phone (67) 1.30</td>
</tr>
<tr>
<td></td>
<td>Internet banking (22) 1.29</td>
</tr>
<tr>
<td></td>
<td>E-mail (45) 1.22</td>
</tr>
<tr>
<td></td>
<td>Curling tongs (24) 1.16</td>
</tr>
<tr>
<td></td>
<td>Internet (40) 1.08</td>
</tr>
<tr>
<td></td>
<td>Stove (134) -1.04</td>
</tr>
<tr>
<td></td>
<td>Radio (132) -1.05</td>
</tr>
<tr>
<td></td>
<td>Coffee machine (122) -1.06</td>
</tr>
<tr>
<td></td>
<td>Push-button telephone (133) -1.17</td>
</tr>
<tr>
<td></td>
<td>Television set (136) -1.29</td>
</tr>
<tr>
<td></td>
<td>Queue number system (133) -1.35</td>
</tr>
<tr>
<td></td>
<td>Flushing device at public toilet (88) -1.64</td>
</tr>
<tr>
<td></td>
<td>Elevator (132) -1.82</td>
</tr>
<tr>
<td></td>
<td>Door opener (123) -1.87</td>
</tr>
</tbody>
</table>

The aim of Study II was to compare the perceived relevance and difficulty of using everyday technology in people with mild-stage dementia, people with MCI, and older adults without known cognitive impairment.

It was found that the use of everyday technology may be more challenging for older adults with MCI or mild-stage dementia as compared with older adults without cognitive impairments. The group of participants with dementia received the lowest mean measures and hence demonstrated the highest mean level of perceived difficulty in everyday technology use, followed by people with MCI and people with no known cognitive impairment (see Table V).
A less expected finding was that the group of people with MCI differed clearly from the people without known cognitive impairment with moderate effect size (p<.001) (see Table V), because people with MCI are, according to the literature, not supposed to perceive manifest problems in IADL. Although the three groups differed in mean perceived difficulty with moderate to large effect sizes (see Table V) in the use of everyday technology use, there were overlaps between groups indicating that perceived difficulty of everyday technology use must be individually considered rather than presupposed as a conclusion drawn upon a person’s diagnosis.

Table V. Mean measure of the ETUQ for each group and p-values for differences between the groups (n=157).

<table>
<thead>
<tr>
<th>Groups</th>
<th>Measure in logits, mean Range (SD)</th>
<th>Mean difference (CI 95%)</th>
<th>Significance p-value</th>
<th>Effect size d</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 2 vs. 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Persons with mild-stage dementia (Group 1) n=34</td>
<td>.73 - .94 - 2.39 (.90)</td>
<td>.98 - (.31-.1.64)</td>
<td>p&lt;.001</td>
<td>1</td>
</tr>
<tr>
<td>Group 3 vs. 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Persons with MCI(^1) (Group 2) n=30</td>
<td>1.71 - .39 - 3.80 (1.06)</td>
<td>.67 - (.11-.1.22)</td>
<td>p&lt;.01</td>
<td>.59</td>
</tr>
<tr>
<td>Group 3 vs. 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Persons without cognitive deficits (Group 3) n=93</td>
<td>2.38 - .30 - 4.0 (1.16)</td>
<td>1.65 - (1.11-.2.17)</td>
<td>p&lt;.001</td>
<td>1.51</td>
</tr>
</tbody>
</table>

\(^1\)Mild Cognitive Impairment
Table VI. Perceived relevance of the 86 items included in the ETUQ for each group and p-values for differences in perceived relevance between the groups (n=157).

<table>
<thead>
<tr>
<th>Groups</th>
<th>Perceived relevance</th>
<th>Mean difference</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>mean n of items</td>
<td>(CI 95%)</td>
<td>p-value</td>
</tr>
<tr>
<td></td>
<td>n of items (SD)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>range n of items</td>
<td></td>
<td></td>
</tr>
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<tr>
<td>Group 2 vs. 1</td>
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</tr>
<tr>
<td>Persons with mild-stage dementia (Group 1) n=34</td>
<td>40.18</td>
<td>2.55</td>
<td>p=.91</td>
</tr>
<tr>
<td>(Group 1) n=34</td>
<td>23 – 65</td>
<td>(-3.35-8.33)</td>
<td></td>
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<tr>
<td>(9.92)</td>
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<tr>
<td>Group 3 vs. 2</td>
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<tr>
<td>Persons with MCI¹ (Group 2) n=30</td>
<td>42.67</td>
<td>-15.82</td>
<td>p&lt;.001</td>
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<tr>
<td>(Group 2) n=30</td>
<td>27 – 67</td>
<td>(10.92-20.71)</td>
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<td>(10.78)</td>
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<tr>
<td>Group 3 vs. 1</td>
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<tr>
<td>Persons without cognitive deficits (Group 3) n=93</td>
<td>58.48</td>
<td>18.31</td>
<td>p&lt;.001</td>
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<tr>
<td>(Group 3) n=93</td>
<td>35 – 77</td>
<td>(13.63-22.98)</td>
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<td>(9.13)</td>
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¹MCI=Mild cognitive impairment

Furthermore, participants with mild-stage dementia or MCI experienced fewer everyday technology artifacts and services to be relevant to their daily lives, as compared with participants with no known cognitive impairment (see Table VI). The ten technologies that were perceived as most relevant and least relevant of the participants are listed in Table VII.

Finally, through the comparison of perceived difficulty in using everyday technology in older adults with mild-stage dementia, MCI, and without known cognitive impairment, the ETUQ measures were additionally validated in relation to an external variable, i.e. cognitive decline, supporting further evidence of validity of the ETUQ measures for these samples.
Table VII. Items perceived to be most and least relevant by the participants (n=157) in Study I.

Relevance of the 86 items in ETUQ perceived by participants (n=157). Number of participants who found the item to be relevant (n) %.

<table>
<thead>
<tr>
<th>Perceived as most relevant</th>
<th>Television set (136) 88</th>
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<tbody>
<tr>
<td></td>
<td>Vacuum cleaner (135) 86</td>
</tr>
<tr>
<td></td>
<td>Stove (134) 85</td>
</tr>
<tr>
<td></td>
<td>Push-button telephone (133) 85</td>
</tr>
<tr>
<td></td>
<td>Queue number system (133) 85</td>
</tr>
<tr>
<td></td>
<td>Radio (132) 84</td>
</tr>
<tr>
<td></td>
<td>Elevator (132) 84</td>
</tr>
<tr>
<td></td>
<td>Sliding doors (131) 83</td>
</tr>
<tr>
<td></td>
<td>Revolving doors (131) 83</td>
</tr>
<tr>
<td></td>
<td>Remote control for TV (130) 83</td>
</tr>
<tr>
<td></td>
<td>Internet (40) 25</td>
</tr>
<tr>
<td></td>
<td>Cell phone: other services than phone call and text message (32) 20</td>
</tr>
<tr>
<td></td>
<td>Ticket machine (26) 17</td>
</tr>
<tr>
<td></td>
<td>Curling tongs (24) 15</td>
</tr>
<tr>
<td></td>
<td>Cell phone: text message (23) 15</td>
</tr>
<tr>
<td></td>
<td>Internet banking (22) 14</td>
</tr>
<tr>
<td></td>
<td>Burglar alarm (18) 11</td>
</tr>
<tr>
<td></td>
<td>Fax machine (18) 11</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Perceived as least relevant</th>
<th>Self service check-in at airport (16) 10</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Digital tuner for television (14) 9</td>
</tr>
</tbody>
</table>
The aim of Study III was to explore the actions and driving forces of the different persons – here called the actors – in the process that started when an AT was brought into a situation where a person with dementia and other significant persons pursue their everyday lives. Specific interest was focused on the unfolding interactions in order to discover what they led to, and how the AT intervention corresponded to the situation of the person with dementia.

The findings showed how doing what is right was the main driving force in the process for the different actors in the three cases, and this was considered the core category. However, what was considered to be the right thing to do in a situation could be different for different actors. Although actions were based on what each different actor believed to be the right thing to do, these could still be conflict within the situation. When there were conflicting ideas concerning what the right thing to do would be, it became clear that the actors differed in decision power and that the ideas of the person with decision power influenced the process most profoundly. The core category was built up of three categories. The first category, the choice of problem and selected AT solution is driven by the actors' views of what is the right thing to do, showed how the steps of the process in which problems and solutions were formulated were governed by the actors' views of the right thing to do in the situation. The actors' motives for doing what they saw as the right thing in a situation seemed to be guided by their various views of the person with dementia, and by their awareness of available AT and the potentials of these. These factors influenced which problems the actors chose – or did not choose – to respond to by introducing AT.

The second category, the actors' experiences and views on the situation influence the role of the AT and how it is placed and adjusted, showed that the role given to the AT, where it was placed, and how it was adapted, were all influenced by the actors' experiences and views of the situation. The influential aspects were opinions about the current strategies of the person with dementia, how and when the actors thought the AT should be used, as well as what the AT communicated to the actors regarding use and potentials.

Finally the third category, the persons' problems and needs are little by little being altered in order to match the potential of the AT, showed as a risk scenario that could occur given the following course of events. This was: 1) The process developed
differently than the actor with decision power had presupposed; 2) the actor with decision
power acted by introducing support aiming to facilitate the use of the AT for the person
with dementia; and 3) the support was in line with the actor with decision power’s ideas
of AT use, and not those of the user with dementia.

In conclusion, it was found that doing the right thing was the main driving force of the
actors, although their views of what was right were sometimes in conflict. The actors’
different views influenced the process, and the potential risk scenario exemplifies how
profoundly the view of the one who had decision power influenced the process.

The aim of Study IV was to explore and describe how family carers of people with
dementia relate to technology, and their readiness to use assistive technology in daily life
together with the person with dementia.

The findings showed three types of conceptions of technology among the significant
others of persons with dementia: 1) a utility perspective on technology, 2) the significance
of technology for keeping an active lifestyle, and 3) technology as maintenance of self-
images. An overall positive attitude and readiness towards using technology in their roles
as significant others were found, however, taking a utility perspective on technology,
meaning that they generally refused technology for technology’s sake. The significant
others considered their perspectives as differing from those of younger people, including
a self-chosen distance to new technologies such as computers. A societal press to adopt
new technology was also experienced among the significant others. Still, if they
considered technology to be beneficial to their relative with dementia or to themselves in
their roles as significant others, they were open to trying technology solutions. Safety was
considered most important despite dilemmas of integrity and the right of the person with
dementia to remain active.

The findings also showed that the significant others highly emphasized an active lifestyle
for being healthy in old age, and that they considered technology to have both positive
and negative impact on health, depending on who used it and for what purpose. Engaging
in challenging tasks involving technology use could on the one hand be considered an
opportunity to health-promoting exercise in everyday life and on the other hand as
entailing a risk of weakening the person’s abilities if it made a task too easy.
Consequently the significant others felt that assistive technology should preferably compensate for a person’s lost abilities, but not be used only to facilitate tasks. Technology was also shown to have significance for the creation of and the maintenance of self-images among both the significant others and their relatives with dementia. Maintenance of the self-image of the relative with dementia was one reason for the significant others to adapt technology in order to enable their relatives with dementia to use it.

Several conditions for incorporation of technology in the situation of persons with dementia were found. These included 1) experiencing a need, 2) integration into habits, 3) simplicity, 4) intelligence and automatic functions, 5) flexibility, and 6) being non-stigmatizing.

Firstly, an experienced need of the technology was considered a necessary starting point. Secondly, the integration of new technology in habits and the use of habitual activity patterns were considered important conditions for successful incorporation of technology into daily life. Thirdly, simplicity, meaning lack of demands on the user, such as requiring the user to perform a chain of actions, make choices, or remember codes, was also considered an important condition for incorporation. In addition, it was considered important that the technology did not ask too much of the significant others either.

Furthermore, technology with intelligence and automatic functions was considered helpful in preventing and correcting errors if it was pliable for the user. Flexibility for making individual settings was considered favorable, but flexibility was also considered to be challenging and potentially aggravating. Finally, the findings revealed that technology needs to be non-stigmatizing and perceived as acceptable and attractive to the user, which often meant both the person with dementia and the significant other.
GENERAL DISCUSSION

The findings in this thesis have contributed new knowledge about the perceived relevance of, and the difficulties in the use of everyday technology among older adults with and without cognitive deficits, and how these constructs can be evaluated. The findings have also contributed new knowledge about transactions involving technology and older adults with MCI or dementia and their significant others. Here I will discuss the main findings from these studies.

Relevance and significance of technology

Perceived relevance of everyday technology

Findings from the four studies in this thesis emphasize that perceived relevance is important to consider when studying the use of everyday technology and assistive technology among older adults. In assessing difficulties in everyday technology use among older adults, there is a great risk of adopting the common conception that use of technology is regarded as desirable and non-use as undesirable (Selwyn, 2003). A methodological choice made in Studies I and II to avoid such a perspective was to assess the persons with ETUQ only on items that they perceived as relevant to them in their everyday lives. This was possible by using a Rasch model (Bond & Fox, 2001) for developing and evaluating the instrument. According to Czaja et al. (2006) and Selwyn (2004), perceived non-relevance of information and communications technology (ICT) are common reasons for non-use. Studies I and II showed that not only perceived difficulty but also perceived relevance was found to be an important aspect to study of everyday technology use. According to the findings of Study II, people with mild-stage dementia considered fewer of the everyday technology artifacts and services in ETUQ relevant than did the group with MCI, who in turn perceived fewer items relevant that did the group of people without known cognitive deficits. A possible explanation for this finding is that people with MCI or dementia may adjust little by little to their experienced limitations in using everyday technology by considering it to be irrelevant to their life situations. It has also been suggested that a way of managing the disabling consequences
of dementia may be to engage only in the most important occupations and to stop performing occupations as they become too challenging (Haak et al. 2007; Nygård & Borell, 1998; Öhman & Nygård, 2005). It is also known that executive functions such as planning and initiation are impaired both in MCI and early in dementia (Feldman et al., 2004; Robert et al., 2008; Tomaszewski Farias et al., 2009). Impaired executive functions often imply lack of initiative, which contributes to declining engagement in occupations in daily life among people with MCI or dementia (Robert et al., 2008). Consequently, if a person has given up a certain occupation due to difficulty or lack of initiative, artifacts used in that occupation may not be perceived as relevant anymore. The progressive nature of dementia is likely to lead to gradual changes in engagement in occupations which might not be recognized by the person, as this change takes place over a long time. However the high amount of perceived non-relevance in the groups with MCI and dementia in Study II may also be a systematic bias in the use of the ETUQ. If persons with cognitive impairment consider everyday technology they can no longer use as being irrelevant to their life situations, it may result in artificially high measures on the ETUQ. On the one hand it is important when using this instrument to avoid having what should be rated as does not use anymore instead being rated as not relevant. On the other hand the concept of perceived relevance might need to be reconsidered in ETUQ in order to allow change in what is perceived as relevant to the person in the actual situation instead of the more external point of view taken in these studies. The result from Study II showing that a potential decline in perceived relevance among people with MCI and dementia might exhibit changes in these people’s everyday technology use that might not be captured in the measure of perceived difficulty. Hence perceived relevance might complement the difficulty measure achieved with the ETUQ.

Conceptions of everyday technology and assistive technology

The findings from Studies III and IV showed different conceptions of everyday technology and assistive technology among the participants that can shed some light on the issues of perceived relevance of technology. First, findings from Study IV showed that the significant others took a utilitarian perspective on technology. This meant that they did not consider themselves to be curious about new technology or interested in
technology for amusement or for technology’s sake, but were open to adopt technology they found to be beneficial to their everyday lives. These findings are similar to those of Larsson (2009) and Östlund (1995), who found the expectation of benefit to be crucial for adoption of technology among older adults. Secondly, interaction with technology was considered to have both positive and negative influence on health, depending on who the user was and what the technology was used for (Study IV). According to Sørensen (2005) the collective domestication (ownership and use) of technology produces norms and expectations that influence the way an artifact is used, the meaning it has, and the possibilities of learning new ways of using and thinking of it. Such collectively developed norms and expectations may explain the conceptions of some more newly developed technologies among the significant others in Study IV. Findings from Study II show that the items in the ETUQ that were perceived as least relevant had entered the technology space or the technological landscape of older adults more recently than had the items that were perceived as most relevant (see Table VII). Five of the items that were perceived as the most relevant in Study II - television set, vacuum cleaner, stove, push-button telephone and radio (see Table VII) - have, according to Larsson (2009) been present in the technology space of the oldest old for a long period of time, approximately 40 to 60 years and were the same artifacts that all participants in Larsson’s study of the oldest old (2009) had possessed and used.

According to Sørensen (2005) people might feel that they have to bring new technologies, for example computers or mobile phones, into their lives due to societal norms concerning technology, even if they do not perceive them to be relevant. With regard to what is communicated to older adults about the importance of having an active lifestyle in old age (Fratiglioni & Qiu, 2009; Wang et al., 2009) it could be assumed that it is important to them to keep up with new technologies. This conception was also found among the older adults in Study IV. Parallel to this assumption that using technology is a part of having an active lifestyle, a more skeptical attitude towards technology was also seen. Several of the significant others in Study IV who were old themselves hesitated to accept help from certain technologies, as they feared that making it easier would impose a risk of weakening the user’s abilities. Hence the significant others thought that the technology might be relevant for their relatives with dementia who really needed it, but
did not consider it relevant to themselves. Even though these persons emphasized both physical and mental exercise no one considered it to be important to do things like washing the dishes or doing the laundry by hand instead of using a dishwasher or a washing machine. Only technologies that were thought to facilitate cognitive abilities, such as the phone book in a portable telephone, were feared. This is interesting as it may reflect the central position that being cognitively alert and thereby healthy has in our society. For example, there are current trends that older adults should stay cognitively active by using computer games to train cognitive abilities. The game industry for older adults is growing, even though there is no scientific evidence for the skills required in the games having generalizability to task performance in everyday life (Leikas & Lampila, 2008). This suggests that the conceptions of technology in relation to keeping an active lifestyle among older adults might be double-edged, with a fear of simplifying tasks too much on the one side and an ambition to use technology as exercise on the other.

Difficulties and potentials in everyday technology use

Even though significant differences regarding perceived difficulty in technology use were found between all three groups in Study II, it is important to note the overlaps indicating that individuals without known cognitive deficits might perceive extensive difficulties in everyday technology use, while people with dementia may perceive little difficulty. Despite the common view on technology as a facilitator, the findings of the four studies together support earlier studies suggesting that everyday technology may also provide hindrances to engagement in occupations in daily life for people with mild-stage dementia (Nygård & Starkhammar, 2003; Nygård & Starkhammar, 2007). Findings from Study II suggest that everyday technology use may be more difficult for older adults with mild-stage dementia as compared with older adults with MCI or without cognitive impairments. Considering the commonly reduced ability in IADLs among people with mild-stage dementia (Morris et al., 1993; Gauthier & Gauthier, 1990; Liu et al., 2007), this is not surprising but is indeed rather an important finding since everyday technology is used in an increasingly wide range of activities in home and society (Emiliani, 2006; Hickman, Rogers & Fisk, 2007). Hence everyday technology might need to be considered both a possible environmental hindrance and a support for people with mild-stage dementia.
In addition, the findings from Study II showed that people with MCI perceived more difficulties in everyday technology use compared with older adults without known cognitive impairment, although less than people with mild-stage dementia. This finding concurs with other studies indicating that people with MCI may have difficulties in performing more complex and challenging IADL tasks (Artero et al., 2006; Dodge et al., 2005; Giovannetti et al., 2008; Pérès et al., 2006; Tuokko, Morris & Ebert, 2005) even though only minor impairment in IADL is accepted within the MCI criteria (Petersen, 2004; Winblad et al., 2004). Everyday technology use is increasingly important to participation in today's society (Czaja et al., 2006), and hence the findings from Study II imply that older adults with mild-stage dementia or MCI may be at risk of exclusion from engagement in IADLs as well as in social and vocational occupations where everyday technology is commonly used. This possible exclusion is essential since continuing with occupations to maintain one's ordinary lifestyle has been pointed out as important to people with dementia (Phinney et al., 2007; Öhman & Nygård, 2005). Furthermore, given that everyday technology may be a possible environmental hindrance to people with MCI or mild-stage dementia this hindrance is obviously being built in today to important institutions in society, such as health care centers, through automated telephone services, and television and radio stations that frequently refer viewers and listeners to their websites.

However, it is important to note that even though the people with dementia and MCI perceived more difficulties in everyday technology use compared to older adults without known cognitive impairment, there were technologies that they used without difficulty. These technologies may promote engagement in occupations and participation in home and society. Particularly in the group of older adults without known cognitive deficits, few perceived difficulties in the use of everyday technology were seen. These are contradictory to findings in other studies concerning perceived difficulties among older adults in general. For example, Larsson (2009) found perceived difficulties in everyday technology use among the oldest old and suggested that age itself might be one explanation. Östlund (1999) discussed that new technology is often first introduced in work places, and therefore retirees are at risk of falling behind. However according to Selwyn (2004) and Östlund (2005) it might also be important to take the more qualitative experiences from technology use at the work place into consideration. Forced or highly
routinized computer use might be less likely to translate into computer use in old age than more creative and enjoyable use. Consequently, more studies are needed about everyday technology use among older adults, acknowledging differences such as age and work-related experiences of technology.

In short, the findings from Study II suggest a process of decreased perceived relevance of and increased perceived difficulties in using everyday technology in MCI, and even more in dementia. Accordingly, when technology is developed or applied to support people with MCI or dementia in daily life, it is important to consider such continuous processes of change as may have important consequences for technology use and hence also for engagement in occupations and participation in home and society. Such processes of change were seen in two of the cases in Study III, and they exemplify the need for a more flexible and less linear approach when technology is introduced to support daily occupations.

Findings from Studies III and IV suggest that significant others’ attempts to adjust the environment to enable continued use, as seen in Study IV, should be supported by health professionals in interventions targeting difficulties in everyday technology use among people with MCI or dementia. Kielhofner (2002) suggested that threats to successful adaptation, such as difficulties in everyday technology use, may require rebuilding of a person’s perceived competence and identity. Hence interventions targeting such problems in adaptation might be important. The findings from Studies III and IV showed dilemmas faced by the significant others concerning everyday technology and assistive technology use among the persons with dementia. This verifies Kielhofner’s suggestion and indicates that both significant others and people with dementia might benefit from supportive interventions targeting technology use. Such dilemmas faced by significant others of people with dementia, and their uncertainty of how to act in the many complex decisions they had to make, have also been pointed out by Chung, Ellis-Hill & Coleman (2008) and Vikström, Josephsson, Stigsdotter Neely and Nygård (2008). However, findings from Study III show how important it is that the support is given with sensitivity and that the client, who might be both the person with dementia and a significant other, is viewed as one agent so that the power is not taken away from them as happened in one case in Study III.
III. To summarize, significant others’ attempts to solve problems connected with everyday technology use among their relatives with dementia may be associated with dilemmas, and may accordingly need support from professionals. However, it is highly important that such support is given with sensitivity in order not to take away the agency from either the person with dementia or the significant other.

Design

In agreement with the literature (Bharucha et al., 2009; Cahill et al., 2007a; Gilliard, 2001), the findings from Studies III and IV showed the actual design of the technological artifacts to be crucial to use and usefulness. Taken together, the four studies in this thesis contribute knowledge about design-related principles and conditions that may be decisive in transactions between people with dementia and technological artifacts and services such as everyday technologies and ATs. In the following, these principles and conditions will be discussed.

Level of challenge

The findings of Studies I and II contributed an item map of 86 artifacts and services arranging all items of ETUQ in difficulty order, as they were perceived by the people in the mixed sample of older adults with and without cognitive deficits. To generate a stable item map of ETUQ, more studies are needed, but a few observations may be made from viewing the order of the items in Study I (see Table VI). First, among the ten most difficult items some common design characteristics can be identified. Six out of ten items are based on computer or mobile phone technology and have relatively recently entered the technology landscape. These are: Cell phone services (other than phone call and text message), Cell phones (text message), Self service check-in kiosk at airport, Internet banking, E-mail, and Internet. The assumption that the use of newly developed artifacts and services is perceived as difficult is in accordance with Nahemow (2000), who states that time spent within an environment lowers the demands of the environment. This might be explained by our sample of participants not yet having developed new habits or adjusted existing habits that are needed to successfully interact with the changing environment (Cutchin, 2007). Hence, this finding from Study I suggests that these items
are difficult for the population of older adults tested with ETUQ in Studies I and II, as they are relatively new to them. Given that experience in using an artifact makes the use easier, these items may receive other positions in the item hierarchy of ETUQ as they become more commonly used by the population tested. An additional explanation for these items being perceived as the most difficult ones is that their design requires that the user perform a chain of actions when using them. This has been acknowledged as an aggravating feature of an artifact (Norman, 2002) and was acknowledged by the significant others in Study IV. This is also supported by the design features of the item that was perceived as easiest of all items in ETUQ - Sliding automatic doors, which require almost no action from the user. Similarly the four items that were placed next in the list of the ten easiest items - Door opener, Elevator, Flushing device at public toilet, and Queue number system - require no sequences of actions. The user can simply locate a button, press it and thereafter respond to the action, which further supports the fact that technological artifacts and services requiring minor action from the user are easier to use than those requiring a chain of actions. These findings correspond to the findings of Lewis, Langdon & Clarkson (2008), who compared two microwave oven interfaces, one with several small buttons and one with two dials, one for power settings and one for timing. The microwave oven with two dials was used more quickly and with less difficulty and error than the model with a large number of buttons, suggesting that a large number of buttons affected the difficulty of use. This is similar to what the significant others in Study IV pointed out when they asked for products with few buttons, preferably only one single button, to be usable for their relatives with dementia.

Familiarity and habitual patterns

Habits and familiarity are strongly believed to support the performance of tasks (Cutchin, 2007; Kielhofner, 2008) and the five remaining items among the ten easiest support this assumption. Television set, Push-button telephone, Coffee Machine, Radio and Stove are all technologies that may be both simple and complex to use, depending on how they are used. Interestingly, they were all among the items that were perceived as most relevant (see Table VII), likely to be regularly used, and well interwoven into the daily habits of many people (Larsson, 2009). This suggests that technologies that are well incorporated are also perceived to be easier. However according to Blackler (2008), the artifact itself
does not have to be familiar to the user; it is rather the familiarity of the artifact’s interface that is of importance. In Study IV the importance of integration in habits was emphasized as a condition for incorporation of technology for a person with dementia. This is in accordance with Boman (2009), who found that assistive technologies for people with acquired brain injuries should support the persons’ daily routines rather than require the establishment of new routines.

In Study III it was also shown how earlier experiences of the person with dementia influenced what the assistive technology communicated to them regarding application and potential use. What was communicated was highly decisive since it was the usability that the assistive technology communicated directly to the persons with dementia that influenced how it was used in practice, as they had difficulty remembering instructions. It has been pointed out (Cahill et al. 2007a; Orpwood et al., 2007) that new learning should not be required of the person with dementia and that familiarity with the technological artifact should be emphasized. Similarly, in Study IV, the significant others of people with dementia emphasized familiarity in technology so that habitual patterns could be used instead of learning. However, the findings from Study III go beyond issues of new learning and familiarity when focusing on the transactions of the person with dementia and the artifact (Cutchin, 2004). These findings suggest that familiarity may be helpful in guiding the person in using the assistive technology. However, it could also have an opposite influence, depending on what the artifact communicates to the person, as the design of the assistive technology may bring something to mind that misleads the person when using the technology. This suggests that the concept of familiarity might need to be further problematized.

Affordance

The principle of affordance as it has been described by Norman (2002) refers to the action possibilities which are readily perceivable by an actor, and hence affordance suggests how an artifact may be interacted with. According to the principle of affordance, thoughtful design may guide the proper course of actions to be taken when using an artifact, assuming that the artifact signals how it is to be used. The findings in Studies III
and IV suggest that this principle may be especially important when the user has dementia and his or her possibility to rely on memory functions is limited, as this means that a person is a victim of how he or she perceives the affordances when transacting with the artifact. The significant others in Study IV asked for technology that is simple to use and that preferably can prevent and correct errors. This is in accordance with what Bharucha et al. (2009) demanded when they stated that much is left to do in designing technologies and environments that are intelligent, context-aware, unobtrusive, and passive (i.e. require minimal user initiation and maintenance). Based on the results of Studies III and IV, the principle of affordance is suggested to be superior to familiarity when designing for people with MCI or dementia, as the design itself may guide the user through the proper use of a technological artifact or service.

In addition Topo and Kotilainen (2009) stated that the main challenge in designing for people with dementia is to figure out how the affordances are most likely to be perceived by the person with dementia and by assisting people. According to the findings of Study III, figuring out how the affordances are likely to be perceived by the person with dementia and people assisting her or him is crucial for significant others, when they are about to purchase new technology or when professionals such as OTs are about to prescribe or recommend technology for support.

Suggestions of how the principles of universal design might be applied in the context of dementia have been presented by Mäki and Topo (2009). Their suggestions are in concordance with the findings of the conditions for incorporation of technology from Study IV, although labeled somewhat differently. Except for the usability aspects of design, including affordance, the findings from both Studies III and IV showed that the aesthetics of the assistive technologies’ design – for example the way they looked or sounded – determined whether the persons would want to have them in their homes. Additionally, perceived meanings such as competence, stigma, or maturity communicated by assistive technologies are, in accordance with the findings from Studies III and IV, the most important to consider. Aesthetics as well as communicating meanings are included in the concept of emotional design as suggested by Norman (2004). The concept of emotional design suggests that emotions have a crucial role in how people connect to
things. This means that an artifact that a user finds aesthetically pleasing would be more easily adopted than an artifact that is less appealing to the user. According to findings from Studies III and IV this is very important to consider when prescribing assistive technology. The findings from Studies III and IV support the applicability of the principles of universal design for the situation of people with dementia as suggested by Mäki and Topo (2009), with the addition of the importance of also considering aesthetics and meanings.

In summary, this suggests that it is important to consider the familiarity of the interface of an artifact and habits connected to it to find out if it is likely to be perceived as easy or difficult by a specific user. A design that requires a chain of actions might not be well suited to people with dementia. The principle of affordance, i.e. that the product itself guides the user through the correct use, is important to consider when aiming to support people with dementia with everyday technology or AT. Furthermore, the principles of universal design as presented by Mäki and Topo (2009) are in concordance with the findings in this thesis and hence supported, with the addition that users’ emotions should not be left out.

AT-interventions to support people with dementia

There is an ongoing development of AT developed for people with dementia, and the possibility of getting support from AT for people with dementia and their significant others is considered important (Cahill et al., 2007b). AT is believed to increase the possibility for people with dementia to remain in their own homes (Marshall, 1999; Wey, 2006) and to enhance quality of life (Cahill et al., 2007b; Cash, 2003; Sixsmith, Orpwood & Torrington, 2007). However AT that is designed to meet the needs of people with dementia is still sparse (Bjørneby et al., 2004; Orpwood et al., 2007) and knowledge about such products among both professionals and the general public is lacking (Bjørneby et al., 2004; Marshall, 2003). This lack of knowledge was exhibited in the findings from Studies III and IV, where the occupational therapists (Study III), the people with dementia (Study III), and the significant others (Studies III and IV) expressed that they lacked information of available AT for people with dementia. In Study III, this resulted in the problems chosen for solution with AT interventions being restricted by which ATs the
OTs had knowledge and experience of. This finding points to the importance of increased knowledge among professional prescribers about existing ATs and their usability for people with dementia (Cash, 2003), in order to let people with dementia benefit from existing AT when possible, as well as from new ATs that are developed for them.

Findings from Studies III and IV suggest that attitudes towards older adults in general and people with dementia in particular influence which problems are chosen to be solved with AT. Professionals’ (Study III) and significant others’ (Studies III and IV) views of the person with dementia, and which occupations he or she ought to engage in, were shown to influence which AT solution were considered appropriate in each case. These findings suggest that stereotyped images of people with dementia might be in play when AT interventions are discussed or implemented by professionals and significant others. Such stereotypes have been acknowledged when technology is considered for older adults in general (Östlund, 2005) and may, according to these findings, be even more pronounced when a person with dementia is to be the user. According to the literature it is important that needs, wishes and preferences of both the person with dementia and the significant other are acknowledged in AT interventions (Alvin et al., 2007; Bjørneby, et al., 2004). However, conflicting views between different actors within the process of AT implementation have been acknowledged in the literature (Bjørneby et al., 2004; Robinson et al., 2007; Nygård, in press). Similarly, in findings from Study III conflicting views between the different actors became manifest, and in Study IV potentially conflicting views between significant others and their relatives with dementia could be observed through what the significant others reported. According to the findings of Study III, conflicting views might be difficult to capture due to illusory agreement between the different actors, including the professional who is prescribing the AT. Hence it might be necessary, both in research and clinical practice, to go beyond what is explicitly said and also consider driving forces shown in actions taken at the time when problems are met.

Findings from Study IV showed that technology for safety was highly valued by the significant others. This is congruent with the findings of Kinney et al. (2003) and Rialle et al. (2008). According to the findings of Studies III and IV, issues of conflicting views in technology for safety need to be particularly considered. In Study IV technology for
safety was well accepted among the significant others, with little concern for integrity violation or other ethical dilemmas. The significant others took for granted that their relatives with dementia would agree to being tracked by GPS technology as they assumed they would understand that it was for their best. Still the discussions also pointed at tracking technology being a possible threat to integrity to the person who is tracked, which also has been acknowledged and widely discussed in the literature (Cahill, 2003; Hughes & Louw, 2002; Plastow, 2006; Welsh et al., 2003). According to Wey (2006) the assessment for AT for people with dementia should not be based primarily on a risk assessment or even on an assessment of needs, but instead on a comprehensive assessment of the persons’ relationships with their social environments. Considering the findings of Studies III and IV, such assessment needs to comprise available support and resources as well as conceptions of technology and the preferences of the person with dementia and other persons concerned.

There is great hope that AT has the potential so solve problems in the situations of people with dementia (Cahill et al., 2007a; Cahill et al., 2007b; Cash, 2003; Gitlin & Chee, 2006). However, Wey (2006) pointed out that assistive technologies are just tools. Their potentials to enable and empower the user depend largely on the quality of the process of implementation. Findings from Study III give important suggestions for how to increase the quality of the AT implementation process when delivering ATs to people with dementia. The findings showed that the persons with dementia needed to use an AT within their own context in order to discover if and how the AT could be beneficial to them. This goes beyond the recommendations that the AT should be tried out in the same environment that it will be used (Blomquist & Nicolaou, 2007). The importance of follow-up in AT interventions is widely recognized in the literature (Alwin et al., 2007; Blomquist & Nicolaou, 2007), and findings from Study III supports this importance but suggests that the general AT prescription process (Blomquist & Nicolaou, 2007) is far too linear. The findings from Study III showed that this linear follow-up structure did not serve or capture the process that occurred in practice. Therefore they suggest that a more flexible and process-oriented follow-up is needed in AT interventions for people with dementia.
Further findings from Study III suggest that goal setting (clearly set goals) that have been recommended in rehabilitation (Bovend’eerdt, Botell & Wade, 2009) and in occupational therapy practice (Graff, 2008; Kielhofner, 2008; Law, et al., 1998) could be replaced by the concept of ends-in-view (Cuthin, Aldrich, Baillard & Coppola, 2007). Ends-in-view are, unlike goals, vague at the beginning of an action but become clearer through the process of acting because what the actor learns from action helps formulate the end. The process of ends-in-view was seen in practice in Study III when the actors with dementia learnt from their transactions with an AT how they could benefit from it and to what end. Hence the ends-in-view were different from the goals set by the occupational therapist when the AT was prescribed. Hence the AT prescriber needs to be open to having the process develop differently than was originally planned, without considering it a failure. These findings challenge the more linear AT prescription process as suggested by Alvin et al. (2007) and Blomquist and Nicolaou (2007).

In Study III the findings showed that the view of the situation of the person who had the decision power in a case influenced the process profoundly. In this study, the power of decision was held mainly by the significant others or the professionals (i.e. OTs and home helpers), and was thus at risk of being taken away from the person with dementia. These persons acted on their own views of what the actual problem was and how it should best be solved. In Study IV significant others of people with dementia discussed the importance of having an assistive technology device support the users’ self-image and not be stigmatizing. However, when it came to safety, the significant others seemed to be willing to deviate from these principles and reasoned that the end justifies the means, in that safety for their relatives with dementia overshadowed everything else. These findings from Studies III and IV show that people with dementia are at risk of having the power of decision taken away from them when the view of the persons with decision power is enacted through the AT intervention. Furthermore, in Study III a risk scenario was identified where the person with dementia’s problems and needs were gradually altered in order to match the potential of the assistive technology, instead of the assistive technology being adjusted to match the needs and wishes of the person with dementia, as acknowledged in the literature (Topo et al., 2007). This underscores how important it is to pay attention to who has the decision power in each case, as his or her views are likely to govern the process, whether they are in agreement with the views of the person with
dementia or not. This was particularly emphasized in the potential risk scenario when the problems and needs of the person with dementia were gradually altered to match the potential of the AT. The importance of being aware of the influence of the person with decision power was further underscored in that our findings show how the actions taken by those involved in introducing and prescribing AT to people with dementia may be guided by their individual experiences and views on what is right, rather than following recommended guidelines.

Methodological considerations

Each methodological approach taken has strengths and weaknesses that will influence the outcome, and in the following I will discuss the specific approaches taken in this thesis. I will start by discussing how the sampling of participants might have influenced the findings of the different studies. Thereafter I will discuss the data collection, the design of Studies III and IV, and finally make some remarks on the ETUQ.

Sampling

In Studies I and II the three groups in the sample were to be different in terms of diagnostics (i.e. dementia, MCI and no known cognitive impairment) but similar in terms of other characteristics such as age, sex, and living conditions (single living/cohabiting), that were believed or known to influence the issues of study, i.e. perceived relevance and difficulty in everyday technology use, in order to be able to compare the groups. Differences between the three groups in age, sex, and living conditions were checked for. However also other characteristics, such as socio-economic factors and ADL/IADL-ability might be related to the studied variable and could therefore have influenced the findings. In Studies III and IV, the design also implied that the sample had a key characteristic in common, i.e. all participants had dementia (Study III) or were significant others of people with dementia (Study IV) but differed in other characteristics.

In all four studies, the sampling was done in a clinical context, and this had some consequences. Conducting studies in a clinical context or in other natural environments means that it is difficult to have full control over the data collection. The recruitment of
participants to the groups of people with MCI in Studies I and II was conducted in
different memory clinics in Sweden by OTs within their clinical practice. This limited the
possibilities to collect structured data of factors like ADL/IADL ability among the
participants. Information regarding their MMSE status collected from the medical records
was also in some cases inadequate. Similarly, Study III was conducted in a clinical
classification, and accordingly it was necessary to accept a convenience sampling (Patton,
2002) of the main participant, i.e. the person with dementia, while the other participants
were sampled in each case according to the principles of theoretical sampling. Although
the intention was to obtain variation in characteristics such as age, time since dementia
diagnoses, living conditions, and AT prescribed, among the main participants in Study III,
the process resulted in having three participants that had similar characteristics. Despite
these similarities in demographics and in ATs received, the process in each case
developed differently and gave rich data. The sample might reflect the group of people
with dementia who receive AT today, but could also be considered as a limitation.
Consequently it could be questioned whether the findings of Study III are valid for people
with dementia with other characteristics, such as being younger or living together with
someone. Similarly, in Study IV, the focus groups with significant others were sampled
according to the principles of grounded theory. This implied that the sample was not
representative for the population in focus but was sampled in order to generate more data
to refine the categories emerging in the analysis (Charmaz, 2006).

The convenience sampling method used in Studies I and II poses a potential risk that the
participants recruited could have been more active, more interested in, or more familiar
with technology than older adults in general. This risk might have been more evident in
Group 3 (older adults without known cognitive impairment) than in the other groups who
were recruited at memory clinics, as a result of the recruitment at meetings of retirement
organizations. Accordingly, it was pointed out to the OTs and students who recruited
participants in all groups, that variation between participants in presumed interest in and
familiarity with everyday technology should be sought. Despite these precautions, the
sample representativeness could be questioned, and accordingly the generalizability of the
findings to a larger population of older adults with or without cognitive deficits may be
limited.
Moreover, the sampling in all studies in this thesis could be criticized for not paying enough attention to socio-economic factors. According to Statistics Sweden (2008) there were clear differences in 2006 between people with blue-collar backgrounds and former white-collar workers in terms of in access to computer and computer use. In people aged 65-84 years old, 77% of the men and 53% of the women among former white-collar workers had computer access, while in the same age group 34% of the men and 25% of the women of former blue-collar workers had computer access (Statistics Sweden, 2008). These differences may have partly economic reasons but may also originate from the characters of their former occupations (Statistics Sweden, 2008). These statistics show that it is important to include socio-economic factors in sampling criteria when variation in access to and experiences in the use of ICTs is sought. However the studies in this thesis do not solely focus on ICT but rather on everyday technology and AT in general, and socio-economic factors are not expected to impact profoundly on these areas. Nevertheless an uneven sampling in terms of socioeconomics might influence perceived relevance of everyday technology, as has also been suggested by Östlund (2005). This suggests that future studies concerning everyday technology and AT in similar groups should take socio-economic aspects into consideration.

In further reflection on socio-economics, it was shown that the participants’ educational levels and occupations in the third focus group differed from those of the other two groups in Study IV. The participants in the third focus group all had college or university education, and were in addition to a large degree were managers or self-employed. The similarities within the focus group constituted a good climate for open and dynamic discussions, which was important since the group only met for one session. However even though the sample was considered too small to make conclusions based on socio-economics, these factors might have influenced the findings. As the third focus group was sampled because they were significant others of younger people with dementia, it also would have been valuable to recruit a focus group of significant others of younger people with dementia with blue-collar background.
Data collection

Data collection in Studies I and II was conducted in 50% of the cases of people with dementia or MCI with the participant and a significant other together, which was considered to give the most valid data. However, all interviews with the participants with no known cognitive impairment were conducted only with the participants. This might have resulted in less reflective data than data collected with two persons (participant and significant other). Probe questions are essential in ETUQ to receive valid data reflecting each participant’s perceived relevance of and difficulty in using everyday technology, irrespective of type of participants. Collecting data with the ETUQ with only the significant other requires that the significant other is very knowledgeable about the participant’s habits and daily life occupations. Such data was collected for thirteen participants in total (two in the group of people with MCI and eleven in the group of people with dementia). Seven of the twelve participants who received the lowest scores in the ETUQ analysis were participants where a significant other to a person with dementia had been interviewed. This might indicate an underestimation of the participant’s ability, but since no information is available on why these interviews were conducted with the significant other alone, this question remains unanswered.

Findings from Studies I and II showed that the ETUQ managed to separate a sample of older adults with and without cognitive deficits into three distinct groups. The finding that the group of people with MCI could be significantly separated from both the groups of people with dementia and older adults without known cognitive impairment is important as even minor restrictions in IADL have shown to be associated with a higher risk of conversion to dementia (Pérès et al., 2006; Tabert et al., 2002). Further, these findings indicate that the area of everyday technology use is sensitive to early impairments due to MCI or dementia. The very concrete questions asked in ETUQ might have contributed to this sensitivity even though both data collected from people with dementia and their proxies have been questioned (Doble et al., 1999; Farias et al., 2005; Okonkwo et al., 2008; Tabert et al., 2002). Nevertheless the data collection in ETUQ could be improved in the future; a revision of the ETUQ with a time limit added to the question is suggested to further improve the interviews. After such revision, one question asked in the ETUQ might be “Do you have a microwave oven? Have you used it during the last year? Have
you had difficulties when using it?" This addition/specification would possibly further increase the sensitivity of the assessment since it would increase the possibility to capture that people have stopped using certain technologies without having reflected on that.

The data collection in Study III was primarily conducted in the homes of the main participants (people with dementia) by using both in-depth interviews and observations. As the aim was to explore actions and driving forces in the process with focus on the transactions, it was important to acknowledge the actions of the participants and not just what they said. The actions were not always observed at the time they took place, but rather through traces that their actions had left in the home of the person with dementia. Such traces were observed, and questions raised by observing them were asked in the interviews. In cases when there were no natural opportunities to observe the person with dementia interacting with his/her AT, the data collector (LR) tried to create such situations in the conversation with the participant, as actions were considered important data.

Conducting observations and interviews is not possible in the field, in this case in the homes of the people with dementia and the OTs’ office, without interfering with the process studied (Patton, 2002). For example, in the interactions with the participating OTs in Study III the data collector did not want the OTs to feel observed, but rather wanted them to conduct the process as they usually did. Since prescription of AT for people with dementia was new for some of them, the data collector made it clear that she was not an expert on AT for people with dementia. However the researcher’s presence is likely to have influenced the AT prescription process, as it is natural to make extra efforts when being observed.

Focus group methodology is acknowledged as a research method through which both participants and researchers learn (Dahlin Ivanoff & Hultberg, 2006). Data in Study IV indicates that some participants might have joined the study to learn more about AT for people with dementia. Such reasons for participation might lead to the participant not sharing so many personal reflections and experiences, but rather seeking information.
from the group leaders or the other participants. This does not mean that any of the participants in this particular study did not contribute to the focus group discussions, but that for some participants the interest to learn more about ATs seemed to be the main driving force to join.

Design of Studies III and IV

When taking a transactional perspective as in Studies III and IV and aiming to follow a process by studying a situation, one important choice is how to define and limit the situation to be studied. In Study III it was decided to study the process starting when the OT and the person with dementia and/or significant others had agreed on trying an AT for the person with dementia. The OTs who provided the ATs to the people with dementia in the study were initially seen as gatekeepers (Patton, 2002), to get in contact with the people with dementia who were about to receive an AT. However, the OTs and the clinical context where they were working were soon found to influence the process profoundly. As participants were included along with questions that arose in the analysis, the OTs were included as participants in the study. Johansson, Lilja, Park and Josephsson (in press) found that professionals enacted local discourses in their professional practice, which was understood as practicing the good. Inclusion of data like the OTs’ managing or steering documents might have added important knowledge for understanding the framework that the OT had for her work. Such theoretical sampling might have further saturated the core category of Doing what is right drives the process, but this was not accomplished according to the case study design. Saturation was not reached in Study IV either, but the focus group’s data in combination with data from the individual interviews was rich. The theoretical sampling procedures that guided the sampling of the focus groups led to sample groups with different characteristics. However, including groups of people with mild-stage dementia also would have been interesting and valuable to complete the picture, although this was beyond the aim of Study IV.
Methodological remarks on the ETUQ

In the development of ETUQ an important basic aspect was that the persons taking the test should only be assessed on items that they perceived as relevant to them in their daily lives. The persons were also asked in the ETUQ if they had difficulty using their own everyday technologies and not a standardized set of technologies. This meant that the items the participants in Study I and II were assessed on corresponded to slightly different technologies. A radio could, for example, refer to a simple transistor radio as well as a more complex radio cassette recorder. This could be questioned from a strict test development perspective where a more standardized approach might be beneficial, but the approach taking in the development of ETUQ is derived from an occupational perspective that takes the persons’ context including, habits, interests, and roles into account (Kielhofner, 2002). The approach taken increased the possibility for ETUQ to capture more of the complexity in the situation of the person with dementia through asking questions about his or her actual everyday technology, rather than focusing on a fictive standardized set of items.

ETUQ also gives information about the hierarchical difficulty order of the items included. Hence the ETUQ gives information about some of the prerequisites for interaction between older adults and everyday technology, but also leaves important questions unanswered. The scale step 1 (does not use anymore) tells only that the person does not use the technology anymore but not why, or what non-use means to the person. Non-use of a technological artifact or service might imply that the person cannot perform a specific task involving the technology anymore, but it could also be that the person had found another way to do the task without using the technology, or that a new artifact or service has replaced the technology. Thus it is not possible to state that each person who receives low scores on the ETUQ is at risk of being excluded from engagement in occupation.

Furthermore, ongoing changes in society create new technologies and new services reached with technology. These ongoing changes require that an assessment aiming to capture this field must be flexible to changes. Using Rasch methods, it is possible to add new items to an existing assessment (Bray, Fisher & Duran, 2000; Linn et al., 1999). It may also be useful to add common ATs to the existing item selection in ETUQ. This
Ethical considerations

The studies in this thesis were approved by the Research Ethics Committee at K arolinska Institutet.

It is crucial in all research that potential participants are well informed about the study in which they are invited to take part. Therefore those who were invited to take part in the studies in this thesis all received both written and verbal information about the study. They were also informed that they could withdraw their participation in the study at any time, without explanation, and that the participation in the study did not influence their clinical contacts. After having received this information the participants gave their written informed consent to participate. However, when including people with MCI or dementia in research, their informed consent has to be continually established and the participants may need to get repeated information before as well as during the study (Hubbard, Downs & Tester, 2001; Nygård, 2006). This was considered especially important in Study III, where data collection took place in the homes of the participants with dementia and involved several sessions of data collection. The researcher (LR) explained who she was and the reason for her visit every time she visited the homes of the participants. This was also explained during observations and interviews, if the participants seemed to have forgotten the purpose of the visit.

One threat to the integrity of research participants with dementia is that due to the consequences of their disease they may have difficulties setting limits and influencing the data collection situation so that it is agreeable to them, for example in terms of how it corresponds to their ability (Kim, Karlawish & Caine, 2002). To avoid such threats, sensitivity was shown to what the persons with dementia seemed to expect from the sessions, with respect to their personality and dignity (Haak, 2002; Nygård, 2006). For example, one person explicitly stated that she expected the sessions to be strict interview sessions with clear beginnings and ends, while others seemed to appreciate a more informal structure. Similarly, in sessions when both the person with dementia and a significant other were present, the significant other sometimes took the lead in issues like
scheduling the next appointment with the person with dementia. In such situations the researcher tried to let the person with dementia have agency as far as possible (Bjørneby et al., 2004; Hubbard et al., 2003). In Studies III and IV the sessions were recorded with a digital recorder. Every time the digital recorder was turned on the researcher said so and showed this to the participants, with respect to their integrity, even though they initially had approved that the sessions were tape-recorded. In line with this consideration, at the last data collection session in one of the cases in Study III the digital recorder was not used because the participant seemed confused and seemed not to understand when the researcher explained why she was visiting.

The ambition was to practice an approach characterized by flexibility and attentiveness to the individuals in all studies instead of taking a standardized approach in data collection (Haak, 2002; Nygård, 2006). For example, flexibility in terms of what time and place to meet guided the data collection in all studies, so that the participants could choose how to make the participation as non-strenuous for them as possible. With respect to individual differences among the participants with dementia in Study III, a phone call was made before each visit to two of the participants’ homes to make sure that the time that was scheduled suited the participant. It turned out, though, that this approach did not suit the participant with dementia in Case 1, as this phone call made her very anxious. Therefore the researcher, in her case, arrived at the scheduled time without calling ahead.

All studies in this thesis were connected to clinical practice and this brought about certain ethical dilemmas. The access to support from the clinical OT should not, for example, be influenced by participation in the study. Therefore the AT intervention in Study III was clearly separated from participation in the study. This was explained to all participants several times during the study and it also required an agreement between the researcher and her clinical OT colleagues. This agreement made clear that it was the clinical OT who was responsible for the intervention and that the researcher did not intervene. However, based on the agreement the researcher could forward issues or problems addressed in the study to the responsible OT if the participant agreed to that. Balancing between what seemed to be right from a clinical perspective and what seemed to be right from a research perspective was not always easy. Even if the researcher sometimes did not agree with the actions taken by a clinical OT or by the home helpers, they were not questioned. Instead the researcher took the approach of trying to understand the different agents’
points of view. To bring these concerns and dilemmas out in the open, the researcher met with the OTs included in Study III and discussed the findings together with them when the study was finished.

Also in Study IV, issues related to setting boundaries between clinical practice and research came to the fore. Sometimes, for example, participating significant others showed interest in ATs that they came to know about during focus group sessions. In such cases they were referred to a clinic that provided support for people with dementia, and it was verified that they came into contact with an OT who could assist them in questions related to AT.

CONCLUSIONS AND CLINICAL IMPLICATIONS

The findings from Studies I and II showed that everyday technology was perceived as more difficult among people with dementia, in comparison to people with MCI and older adults without known cognitive impairment. Interestingly, those with MCI perceived more difficulties in everyday technology use compared to older adults without known cognitive impairment. Findings also indicated that older adults with MCI or dementia may experience fewer technology artifacts and services to be relevant to their daily lives, as compared to older adults without known cognitive impairment. This suggests that use of everyday technology can be affected early by cognitive decline in older adults.

The findings also showed that perceived difficulty in everyday technology use in these groups may be measured in a valid manner by the newly developed assessment, Everyday Technology Use Questionnaire (ETUQ). The ETUQ demonstrated acceptable evidence of validity in terms of internal scale validity and person response validity when used with older adults with and without cognitive impairments. In addition, the ETUQ was found to be sensitive enough to detect differences between three subgroups in perceived difficulties in everyday technology use along the scale.

The findings also contributed an item map from the ETUQ analysis that shows the difficulty level of the 86 items of everyday technology artifacts and services represented in the ETUQ. This item map, together with findings from Studies III and IV, gives important information about design-related principles and conditions that may be decisive
in the transactions between people with dementia and technological artifacts and services such as everyday technologies and ATs. Altogether, these findings suggest that technologies for people with dementia should be easy to use, flexible, intelligent, non-stigmatizing, and aesthetically appealing to the user. What is communicated through the interface of the technology is crucial, as this is likely to guide the person through suitable use, whereas instructions are likely to be forgotten.

In Study III, Doing the right thing came to the fore as the main driving force among the actors in the process that took place when an AT was introduced to a person with dementia. However, as conflicting views of what was the right thing to do appeared in the situation, this suggests that it is important to be attentive to who has the decision power, as this person was shown to influence the process profoundly. The findings also showed that a more flexible and process-oriented AT prescription process with ends-in-view instead of clearly set goals would better meet the complex and changing situation of the persons with dementia and their significant others.

Finally, in Study IV it was shown that when the significant others took a utilitarian perspective on technology, they refused technology for technology’s sake but showed an overall readiness toward using technology if they considered it to be beneficial to them and their relatives with dementia. The findings from this study also suggest that technology can be important for keeping an active lifestyle and for creating and maintaining self-images, and that such conceptions hence need to be considered.

The findings of the four studies have several clinical implications, primarily concerning older adults with MCI or dementia who are still living in their own homes, and their significant others.

- The ETUQ managed to separate a sample of older adults with and without cognitive deficits into three distinct groups - people with dementia, people with MCI, and people without known cognitive impairment - and showed that difficulties in everyday technology use may be signs of disability in MCI or mild-stage dementia. This suggests that ETUQ is sensitive enough to detect early changes in difficulty in everyday technology for people with MCI or mild-stage dementia. Accordingly, clinical use of the ETUQ may provide clinical information...
about clients with MCI or mild-stage dementia, based on their own experiences of limitations in managing everyday life.

- Based on the findings in this thesis, everyday technology needs to be considered as both potential support and hindrance to engagement in occupations among people with MCI or dementia. Hence it is important to be attentive to experienced difficulties in everyday technology use or non-use that might hinder engagement in occupation and participation in society in these populations. It is also highly important that such environmental hindrances are not built in to health services and other institutions in society by devices like automated telephone services and the Internet.

- The use of everyday technologies that are of certain importance to a client should be supported in order to facilitate valued self-images in the person with MCI or dementia.

- It is important for professionals who meet people with MCI or dementia and their significant others to be aware of conceptions of ET as posing a risk by weakening the user’s abilities to manage technology, because they might influence how AT or other interventions involving technology are accepted.

- In clinical OT practice it is crucial to acknowledge the actual situation of persons with MCI or dementia, including their resources, strategies, habits, and personal preferences, and not to let stereotypes govern which problems should be solved and how to solve them by providing AT or home modifications. To achieve this it might be necessary to take a more reflective position on individual attitudes towards older adults and persons with MCI or dementia.

- It is crucial when designing technology for people with MCI or dementia, and when prescribing AT to people with these conditions, to provide an interface of the technology that supports the user without relying on information that is likely to be forgotten. This may be achieved with an analysis of how the affordances of the technology are likely to be perceived by the person with MCI or dementia and his or her significant others.

- In considering AT for people with MCI or dementia, certain characteristics seem to be preferable. AT should be simple to use and make few demands of the user, i.e. they should be flexible and intelligent, and the AT itself should preferably guide the user through suitable use. Importantly, AT should also be aesthetically
appealing to the user. Possible associations communicated by the AT such as competence, stigma, or maturity may be decisive and should be acknowledged.

- To become useful, AT for people with MCI or dementia should be incorporated into the habitual patterns of the user and should not require that the user adjust to the AT by changing his or her habits. This needs to be particularly considered both in design and when choosing and introducing AT.

- In prescribing AT to people with MCI or dementia, a more process-oriented approach to follow-up is recommended, allowing the user to try out the AT in order to identify potentials and difficulties. Overall, the common AT prescription process seem to be too linear to capture the situations of these clients. By replacing the recommendations of “clearly set goals” with “ends-in-view” the AT prescription process would be allowed to be more flexible. This would imply that a process turning out differently than initially expected does not have to be considered a failure but could hold new possibilities.

- Finally, while it is important to consider both the person with MCI or dementia and possible significant others when providing AT, it is also important to be aware of potential conflicting views, and to reflect on whose agenda is followed and who the client is.

**FUTURE RESEARCH**

The research area focusing on people with MCI or dementia and their significant others as users of technology is important, and needs to be explored further. This thesis has generated new questions that would be interesting to explore in future research.

In this thesis, the ETUQ rating scale was only evaluated on all items taken together. In further development of the ETUQ it would be valuable to evaluate the rating scale for each item (i.e. partial credit model). Such item-by-item analysis of the rating scale could generate additional information about the process of use (or non-use) among the persons evaluated. A differential item functioning analysis (DIF) would also contribute interesting information about whether there are some items that vary in difficulty between subgroups. Are there, for example, some items that people with dementia continue to be able to use relatively easily, although they might demonstrate a higher overall measure on
perceived difficulty? Such analysis could also give important information related to design issues. Both of these suggested analyses (partial credit and DIF) do require larger datasets in order to make valid estimations of the statistical outcomes.

Importantly, the ETUQ needs to be further developed to be useful in a clinical context. It should for example be interesting and clinically relevant to investigate if and how the number of items in ETUQ could be limited without threatening the sensitivity or the validity. This means that the ETUQ needs to comprise a sufficient number of items to meet the different contextual situations of persons to still be relevant, and it needs to comprise items that represent different difficulty levels, in order not to lack sensitivity. Another interesting question concerning the items in ETUQ is if AT could be added to the items in the ETUQ. If so, could ETUQ then be a helpful tool in AT intervention by indicating the difficulty level of different ATs, and in that way guide the professionals?

Some unanswered questions remain about the concept of perceived relevance. If the perceived relevance regarding technology decreases when cognitive impairment increases, as our studies suggest, why is that, and what does it mean? More in-depth studies of what purposes people with MCI or mild dementia would like to have technology for, and what they would like technology to do for them are therefore needed. Longitudinal studies with the ETUQ might also capture the changes in the perceived relevance of and difficulty in the use of everyday technology and explain more about the relationships between these concepts.

Several conditions are suggested for incorporation of technologies that should be further explored and evaluated. Affordances, for example, are suggested to be an important principle in design and especially in design for people with dementia. It would be valuable to better understand how affordances may support use of technological artifacts and services among people with dementia or MCI, and how affordances are understood by these people. Such understanding may explain why some technologies are perceived as easy and others as difficult, and thereby provide guidance for technology design.

Finally, it would be important to investigate how a more process-oriented approach to follow-up of AT interventions in dementia care – one that is more flexible with ends-in-views – could be applied, and what the outcome of such an approach would be.
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