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**ASSISTIVE TECHNOLOGY  
AS COGNITIVE SUPPORT  
IN EVERYDAY LIFE  
FOR PERSONS WITH DEMENTIA OR STROKE**

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# ABSTRACT

The overall aim of this thesis was to expand the knowledge base for a better understanding of how persons diagnosed with dementia or stroke become users of assistive technology for cognitive support in everyday life.

In **Study I**, identified difficulties in everyday life related to cognition were matched with a specific type of modifiable context-aware assistive technology with the aim of identifying what types of tasks the assistive technology could support. The findings showed that the assistive technology in focus was judged to be able to initiate the performance of specific tasks and to inform about upcoming events, to support the completion of an already initiated task or to remind the user in a specific location or after specific actions. It was judged as less supportive in the area of communication, handling electronics and doing more complex activities with many steps.

In **Study II**, four persons who had experienced a stroke had one type of modifiable context-aware assistive technology, with individual customisations, installed in their homes for a six-month period. The participants were interviewed with the aim of examining how the assistive technology influenced their everyday lives. The findings showed how routines developed with support from the assistive technology influenced the participants towards increased control of their everyday life, created daily structure and supported them in regaining social contacts. The spouses cooperated in the use of the assistive technology and were alleviated from responsibilities to some extent.

In **Study III**, ten persons, who had an early stage of Alzheimer's disease, were followed on their way towards becoming users of assistive technology which was individually chosen to match their needs, desires and goals. The participants were interviewed to acquire descriptions of how they become users of the assistive technology and to examine how they experienced the use of the assistive technology. Four significant junctures were identified at which decisions influencing whether the person became a user of the assistive technology or not were made. The junctures were related to how the initial decision was made, how routines were adjusted to the assistive technology, whether the users trusted the assistive technology and whether the participants felt an increased sense of capacity when using it. As users, the participants perceived how time and effort were saved, how worries and stress decreased and how their sense of safety increased, which enabled them to perform their valued activities.

In **Study IV**, experiences from the assistive technology interventions presented in the previous studies were examined with the aim of identifying features in the assistive technology that affected the usability and usefulness of it.

The findings identified eight themes, including features that promoted or impeded the task performance and goal achievement, that is, the usability and usefulness of the assistive technology. They were related to the use during task performance, the preparation and customisation of the assistive technology, and the impact of faulty assistive technology.

The findings in the thesis provide new knowledge about how a person, who experiences cognitive impairments due to a stroke or a dementia disease in the early stage, becomes a user of assistive technology. These findings can be of use in the provision of assistive technology for cognitive support and for future research.

It was apparent that to become a user of the assistive technology, it was of great importance that the task intended to be supported by the assistive technology is connected to a valued goal that the potential user has a desire to achieve, and moreover that the assistive technology can enable the person to achieve that goal, not only to perform the task in target.

In the findings, for some persons to become users of assistive technology the significant others were identified as being of great importance. Features in the assistive technology that promote usability and usefulness were identified. The usefulness of the assistive technology was shown to be closely related to the matter of trust and sense of safety. The findings implied the importance of having a user-centred perspective, also concerning the social and physical context, when planning for the provision of assistive technology to the potential user.

## LIST OF PUBLICATIONS

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## LIST OF ABBREVIATIONS

AD	Alzheimer's disease
AT	Assistive technology
CAPM	Comprehensive Assessment of Prospective Memory
COPM	Canadian Occupational Performance Measure
GPS	Global Positioning System
HAAT	The Human Activity Assistive Technology
ICF	The International Classification of Functioning, Disability and Health
ISO	International Organization for Standardization
MMSE	The Mini Mental State Examination
MOHO	The Model Of Human Occupation
MPT	The Matching Person and Technology model
NEAC	The National Ethics Advisory Committee
n.d.	No date
OARS	The Older American Resources and Services
OMFAQ	The Older American Resources and Services Multidimensional Functional Assessment Questionnaire
PEO	The Person-Environment-Occupation model
PDA	Personal Digital Assistant
WHO	The World Health Organization

# 1 INTRODUCTION

## 1.1 PERSONAL INTRODUCTION

During my fourteen years as a clinical occupational therapist I met several people who experienced cognitive impairment after a stroke. It was evident that the difficulties derived from their cognitive impairments hindered them in their everyday life but still, there was little I could do to alleviate these difficulties in terms of provision of assistive technology. The assistive technology then consisted mainly of simple electronic calendars or of some basic reminders. Technology for people with dementia consisted almost solely of cooker timers used during the later stages of the disease. Other types of assistive technology for cognitive support for people with dementia had not been thought of at that time.

In 2012, the scene is completely different. Technological progress has made technology more capable, more available and more manageable from year to year and as a result of this progress, there have been huge expectations that technology would have a positive impact on the lives of people who need cognitive support.

Backed up by prior experience it was very encouraging to see that research in the field of assistive technology had shown that people with cognitive impairment could benefit from this technology. With these promising results there was a need to take additional steps in research. Now, it has become important to shift attention from only focusing on what the technology can do to compensate for cognitive impairments in a general sense and instead focus on how persons, who are diagnosed with, for example, stroke or dementia, can make an anticipated positive change in their everyday life in line with their desires and needs with support from the technology. Research in this relatively new field of research is of crucial importance if the assistive technology support to persons who are diagnosed with dementia or stroke is to be as advantageous and effective as possible. With more new knowledge, it would be possible to gain a better understanding of whether the great expectations that society has for the future can actually be met in real life. By aiming to contribute new knowledge into this area of research, this thesis intends to examine how persons diagnosed with dementia or stroke become users of assistive technology for cognitive support in everyday life.

## 1.2 TECHNOLOGY AS A MEANS OF COGNITIVE SUPPORT

The point of departure for this thesis is the fact that the continuous progress of technology, for example, related to communication technology or home surveillance, has come to a point at which technological solutions seem to have the capacity, not only to support people in general, but also to address difficulties related to cognitive impairments to a much higher extent than ever before.

This progress has raised hopes that technology can be a means to enable the participation in valued activities and in society for persons who previously to a great extent have been hindered from taking part in the everyday life that many people take for granted, that is, people with cognitive impairments (Emiliani, Stephanidis & Vanderheiden, 2011). The importance, for all people, to engage in valued activities and to participate and be in charge in one's life situation has been viewed as being a central focus in occupational therapy (Law, 2002). In accordance with the perspective of occupational therapy it has been stated that *"all people need to be able or enabled to engage in the occupations of their need and choice, to grow through what they do, and to experience independence or interdependence, equality, participation, security, health and well-being"* (Wilcock & Townsend, 2008, p.198).

To be able to enable people with cognitive impairments to engage in occupations of their need and choice, a plausible way might be to involve technology. There are huge expectations concerning how technology can support persons, especially elderly persons, with or without cognitive impairments. It is hoped that people may be able to age in their own homes to a higher extent with so-called smart home technology (Pigot et al., 2003), which focuses on safety and health for the inhabitant with support from monitors (Bharucha et al., 2009; Demiris & Hensel, 2008; Ricker et al., 2002) or videophones (Coradeschi et al., 2011). Electronic tracking devices have also provided hope around the enhancement of safety especially for persons diagnosed with dementia (Landau, Auslander, Werner, Shoval & Heinik, 2010; Robinsson et al., 2010) even if the use of tracking devices has evoked ethical dilemmas about issues such as integrity (Landau, Werner, Auslander, Shoval & Heinik, 2009). The possibility of providing individualised interfaces has been anticipated and welcomed, since this could enhance accessibility in many fields for persons with cognitive impairment (Vanderheiden, 2007). There is a vision that the greater majority of people could have access to information and communications services despite, for example, different



types of disabilities (Schneiderman, 2000) and further, that this can lead to increased social inclusion (Abascal & Nicolle, 2005). Thanks to the decreased size of the items, the use of the technology has become more accessible in different contexts, and the possibility to have a constant electronic companion for cuing, reminding and guiding concordance with context and routines (Bharucha et al., 2009; Vanderheiden, 2007) can become a reality.

This thesis focuses on people who are diagnosed with stroke and dementia and who experience cognitive impairment. In Europe, approximately 9 million people have a dementia disease (Wimo, Winblad & Jönsson, 2010) and 72 % (Lesniak, Bak, Czepiel, Seniow & Czlonkowska, 2008) of the 1.1 million people who suffer a stroke every year (Truelsen et al., 2006) still have cognitive difficulties one year after the incident. The number of persons with a dementia diagnosis is growing, since people are living longer and the prevalence of dementia increases with age (Jorm, Korten & Henderson, 1987). In recent years, the diagnoses of dementia have been given at an earlier stage of the disease (Carpenter et al., 2008; Petersen, 2009). This situation implies that many people might have the potential to benefit from using assistive technology. It is of importance to examine further how the progress of technology can meet the desires related to how people in these groups can engage in everyday life and to participate in society. With the aim of the thesis focusing on how people with stroke or dementia become users of assistive technology this introduction will address: who the potential users are, what technology is available and what previous knowledge there is about using assistive technology for cognitive support.

### **1.3 PERSONS WITH DEMENTIA OR STROKE IN EVERYDAY LIFE**

When dementia or stroke occur, it often results in a profound change in everyday life for both the persons who have been afflicted of the diseases (Becker, 1993; Steeman, Dierckx de Casterlé, Godderis & Grypdonck, 2006) as well as their families (Thommessen et al., 2002). Common cognitive impairments due to stroke are deficits in attention, short-time memory and language, orientation of time and executive functions (Lesniak et al, 2008) and decreased awareness of the disease (Hartman-Maeir, Soroker, Oman & Katz, 2003), and cognitive impairments related to dementia are gradual onset of memory impairment, aphasia, apraxia, decreased visuospatial and temporal ability, decreased executive functions (American

Psychiatric Association, 2000; Cummings & Cole, 2002) and decreased awareness of the disease (Clare, Roth & Pratt, 2005).

Even if there are some differences between the symptoms, the way in which these symptoms affect everyday life is similar in the two groups. As an example, the risk of decreased awareness of the disability also reduces the persons' ability to perform everyday activities and decreases their safety both for people with dementia (Öhman, Nygård & Kottorp, 2011) and people with stroke (Ekstam, Uppgård, Kottorp & Tham, 2007; Hartman-Maeir et al., 2003). Previous research has shown that persons in both groups can perceive difficulties in planning time (Lindén, Lexell & Larsson Lund, 2011; Nygård & Johansson, 2001), and further, how they experience lack of control and structure, reduced independence and changed social roles (Carlsson, Möller & Blomstrand, 2004; Holst & Hallberg, 2003; Steeman et al., 2005). These changed social roles affect interpersonal relationships, responsibilities (Häggström et al., 2008; Steeman et al., 2005; Viscogliosi et al., 2010) and participation in community life (Viscogliosi et al., 2010). The ability to use technology that is needed in everyday occupations decreases (Lövgreen Engström, Lexell & Larsson Lund, 2010; Nygård & Starkhammar, 2007). Leisure activities are reduced (Carlsson et al., 2004; Clare et al., 2005; Holst & Hallberg, 2003; Viscogliosi et al., 2010) and necessary activities outside the home might be avoided (Brorsson, Öhman, Lundberg & Nygård, 2011; Häggström & Larsson Lund, 2007; Öhman & Nygård, 2005). Household activities and other important activities can be transferred to the spouse (Ekstam, Tham & Borell, 2011; Öhman & Nygård, 2005). An important difference is, however, that persons who have survived a stroke, often suffer from decreased motor ability and mobility (LeBrasseur, Sayers, Ouellette & Fielding, 2006) which also affects their everyday activities. Another difference is that dementia is a progressive disease (Qiu, De Ronchi & Fratiglioni, 2007) and stroke is primarily not a progressive disease. However, the risk for a recurrent stroke within five years is 30 % (Burn et al., 1994), and 25% of all dementias are caused by cerebrovascular disease (Qiu et al., 2007). The significant others also become very affected by both diseases. The increased burden (Thommessen et al., 2002), decreased life satisfaction (Forsberg Wårleby, Möller & Blomstrand, 2004; Thomas et al., 2006) and the chaotic life situation (Wallengren, Segesten & Friberg, 2008) for significant others has been acknowledged previously.

Previous research showed that due to difficulties derived from the cognitive impairments, the persons who have had a stroke (Hägström & Larsson Lund, 2007) or have dementia (Öhman & Nygård, 2005) strive to adapt the way they perform tasks that are of importance to them. They form new routines to be able to perform them (Hägström & Larsson Lund, 2007; Öhman & Nygård, 2005) or try to maintain already existing routines and patterns (Öhman & Nygård, 2005). They strive for autonomy, e.g. by trying to be in command of their lives and performing activities independently of others (Hägström & Larsson Lund, 2007; Öhman & Nygård, 2005). Doing things for others, especially close relatives, was shown to be of great significance (Hägström & Larsson Lund, 2007; Öhman & Nygård, 2005). The spouse and other people can be significant support to enable the person to perform valued activities (Öhman & Nygård, 2005, Ekstam et al, 2011, O'Sullivan & Chard, 2010).

From an occupational perspective, it is of importance to acknowledge how activities for all people are organised according to the preferences and needs in the physical and social context (Kielhofner, 2008). When there is such a profound change in life as a stroke or a dementia disease, there is in many cases a need to adapt routines to the changed abilities, in order to achieve goals related to activities that are of importance based on the needs and desires of the specific person in his/her specific context (Kielhofner, 2008).

The perspective taken in the present thesis is grounded in the occupational perspective of the person. To apply an occupational perspective means here that the persons' needs, desires, goals and abilities are in focus in the study. Traditionally, the medical diagnosis (Alzheimer's disease [AD] or Stroke) would be the basic descriptor in dissertations emanating from a medical university. However, in the present thesis the choice was made to use the terminology of medical diagnoses (AD and stroke) as a way to frame and describe the cognitive impairments present among the participants in the studies.

#### **1.4 ELECTRONIC ASSISTIVE TECHNOLOGY AS COGNITIVE SUPPORT**

The term *assistive technology* (AT) needs to be defined to clarify what products the term includes. One definition of AT is the definition from the Assistive Technology Act (2004) in the US: “...*any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or*

*improve functional capabilities of individuals with disabilities*”. This definition has been commonly used in AT research. It can, however, be regarded as too limiting since it only focuses on the functional capabilities and does not explicitly incorporate activity and participation limitations as possible to provide support for with AT. The domains of activity and participation are of importance for understanding health according to the World Health Organization (WHO) and the domains are included in the International Classification of Functioning, Disability and Health, ICF (WHO, 2008).

In this thesis it was considered important to expand beyond the traditional medical focus on a function, since to overcome functional limitation does not automatically mean that you have reached your goals or can engage in your valued activities. According to the perspective of the thesis, it can instead be necessary to provide AT for which the prime aim is not to overcome the functional limitation, but instead, the difficulties that hinder the valued activities and in that way provide a positive change. From this perspective the definition ISO 9999, used by the International Organization for Standardization (ISO, 2011) is well suited. ISO 9999 has been revised to align with the ICF (WHO-Family of International Classifications, 2010) and is defined as follows:

*“An assistive product is any product (including devices, equipment, instruments and software) especially produced or generally available, used by or for persons with disability*

- *for participation*
- *to protect, support, train, measure or substitute for body functions/structures and activities, or*
- *to prevent impairments, activity limitations or participation restrictions”.*

In both of these definitions it is very clear that the definition of AT covers both products especially produced to compensate a disability and those commercially available products with the purpose of serving users in general, that is, mainstream technology. Whether a product should be viewed as AT or not, is defined by the purpose of use, that is, whether it meets a need related to a disability. Even if the term *assistive product* is used in the definition from ISO (2011) the term *assistive technology* (AT) will be used in this thesis, since it is more commonly used.

The purpose of providing AT as cognitive support has been described by Wey (2004) as to enable and empower the person and *“to help bring the world around them back*

*within their grasp*”( Wey 2004, p. 203) and further, to improve their sense of agency, their social confidence and self-esteem. According to Wey (2004), there is a risk however that AT could disable a person if the person’s desires, goals, life history, capabilities and social context are not taken into account. These apprehensions have been shared by other researchers in the field (e.g. Cash, 2003; Scherer, 2002; Sixsmith, Orpwood & Torrington, 2007). The need for the potential user to judge whether the activity, in which the AT would provide support, is worth doing and if the AT is worth using for that activity has also been emphasised (Efring, 1999; Krantz, 2012). These standpoints have guided the provision of AT in the studies included in the thesis. The AT in the present studies was both mainstream technology and technology designed for cognitive support either already on the market or more in a prototype state.

The electronic AT available on the market and/or used in research is proposed to assist in everyday life, both the persons with cognitive impairment and/or the caregiver. Support for the caregiver is for example, alarms ([www.abilia.se](http://www.abilia.se)) and videophone support (Magnusson, Hanson & Nolan, 2002). AT that supports the person with cognitive impairment is for example, support for being reminded, time orientation, making phone calls, taking notes and locating belongings ([www.hi.se](http://www.hi.se)). GPS technology has afforded the possibility to provide mobile safety alarms with positioning (Melander –Wikman, Jansson, Hallberg, Mörtberg & Gard, 2007; [www.posifon.se](http://www.posifon.se)) and support for outdoor orientation ([www.eadept.se](http://www.eadept.se)). When mainstream technology such as smartphones and computers has become so easy to modify to the individual user, they have become a very good support for people with cognitive impairments in e.g. structuring the day or being reminded (Lindén, Lexell & Larsson Lund, 2011). It has also become possible to combine standard smartphones and computers with software specially designed for persons with cognitive impairment, providing support in, e.g., surfing or e-mailing, paying in shops or having control of expenses and other payments (Hjälpmedelsinstitutet, n.d.).

When mainstream technology is designed to include a greater number of user groups e.g. by being more modifiable, it can be viewed as inclusive design (Coleman, 2006). The concept of inclusive design implies that people with more extreme impairments or people with multiple minor impairments should be included to as great an extent as is possible (Coleman, 2006) already from the beginning of the design process to thereby enable the inclusion of the greatest possible number of users (Keates, Clarkson, Harrison & Robinson, 2000) and this is a great challenge (Emiliani, 2006).

## 1.5 USABILITY AND USEFULNESS

The importance of usability issues when assessing the outcome of AT use has been emphasised, such as in all interaction between a person and a product (Arthanat, Bauer, Lenker, Nochajski & Wu, 2007) and the usability of the AT has a great impact on activity and participation for persons with disability (Arthanat et al., 2007).

The concepts of the usability and the usefulness of AT have been in focus especially in study 4 in the thesis. Both concepts are of crucial importance together with the utility of the AT in research connected to the use of the AT and also in the decision making and follow-up in clinical settings.

The most common definition of *usability* is the standard formulated by the International Organization for Standardization (ISO, 1998): “*The extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use*”. The intrinsic terms of usability - effectiveness, efficiency and satisfaction - are defined as follows: *Effectiveness* is defined as the accuracy and completeness with which users achieve specified goals. *Efficiency* is defined as the resources expended in relation to the accuracy and completeness with which users achieve goals. *Satisfaction* is defined as freedom from discomfort, and positive attitudes towards the use of the product (ISO, 1998).

Effectiveness has been considered as the most important component in usability for AT (Jutai, Fuhrer, Demers, Scherer & DeRuyter, 2005). Usability should be viewed as a relative concept and is dependent on users, goals and context of use under the particular set of circumstances (Petrie & Bevan, 2009) and for that reason: usability testing should as closely as possible resemble the circumstances in reality (Genov, Keavney & Zazelenchuk, 2009; Nielsen, 1993) .

The concept of usability has been discussed both in terms of whether the concept covers important usability issues, e.g. qualities related to the users’ experience (Petrie & Bevan, 2009) and, further, concerning the fact that the users’ high level of satisfaction with a product does not automatically have a positive effect on the usability of it ( Lindgaard & Dudek, 2002; Norman, 2005).

Nielsen (1993) described *usability* as included in the concept of *system acceptability* together with the two related concepts of *usefulness* and *utility*. According to Nielsen (1993), the issue of whether a product is accepted for use by a person, the acceptability of a product (in Nielsen’s case: the computer system), is divided into two types of

acceptability; the *social* and the *practical acceptability*. One of the subcategories in practical acceptability is usefulness, which is the “*issue of whether the system can be used to achieve some desired goal*” (Nielsen, 1993, p. 24). Usefulness is divided into the categories utility and usability. Utility is the issue of “*whether the functionality of the system in principle can do what is needed*” (Nielsen, 1993, p. 25) and usability is the issue of “*how well users can use that functionality*” (Nielsen, 1993, p. 25). This way of viewing practical acceptance forms a basis for the studies in the thesis.

It is important to add that social acceptability has a great influence on the acceptance of a system or product (Nielsen, 1993). A practical acceptable product risks not being used by specific users if they view the social acceptability as low (Nielsen, 1993) which has been taken into consideration in this thesis, even if it has not been its primary focus.

The *specific context of use*, which is also included in the definition of usability (ISO), is of great concern in occupational therapy, and the context “*can exert an all-important influence on occupation*” (Kielhofner, 2008, p. 86). Townsend and Polatajko state (2007) that, every person lives in a unique cultural, institutional, physical and social context and consequently responds to this unique context through engagement and participation in occupations. This means that the context has a great influence also on the use of the AT, since AT is a part of the context and can also affect and be affected by the context. The relationship between the person and the environment has been addressed in models and several theoretical constructs exist that all try to explain this relationship. Best known is the General Ecological Model of Aging (Lawton & Nahemow, 1973) that explains how decreased competence affects the ability to handle the demands from the environment. This model has influenced other models which have a more explicit focus on a person’s activity performance, e.g. the Person-Environment-Occupation (PEO) model (Law et al., 1996) which is related to the Canadian Model of Occupational Performance, CMOP (Canadian Association of Occupational Therapy [CAOT], 1997). In this model, the continuous interaction across time and space between the unique person in a variety of roles, the environment in a broad sense and the occupation in which the person engages to meet needs is described (Law et al., 1996). Lately a transactional perspective (Cutchin, 2004) has been applied in research on the use of technology (Rosenberg, 2009), the context (Brorsson et al., 2011) and people with cognitive impairments. Adopting a transactional perspective, the person and environment are viewed as interconnected and inseparable.

There are models that focus specifically on the person's interaction with AT in the context. Two examples are the Human Activity Assistive Technology (HAAT) model by Cook and Hussey (2000), which has complemented the PEO model with an extra factor; the AT, and the Matching Person and Technology (MPT) model, which focuses on the person, the technology and the context but does not in its three main areas include the activity (Scherer & Craddock, 2002). There are also instruments that explicitly assess the usability of AT and the usability of the home context. Those found are the Usability Scale for Assistive Technology, USAT, (Arthanat et al., 2007) which takes its conceptual framework from HAAT (Cook & Hussey, 2002) and MPT (Scherer & Craddock, 2002), and Usability in My Home, UIMH (Fänge & Iwarsson, 2003) which has the PEO model (Law et al., 1996) as its basis.

In the studies included in this thesis, the role of the environment derived from the Model of Human Occupation, MOHO (Kielhofner, 2008), with its strong focus on occupation, was used as a framework for how to view the usability of the AT. The MOHO (Kielhofner, 2008) explains how e.g. the physical (in terms of both the space and the items within it), social or cultural environment can influence motivation and performance of occupations, and how the environment provides resources but also constraints when someone chooses and does things. In what way the context affects the person's doings is also related to the person's values and motivation (personal causation), roles, habits and performance capacities (Kielhofner, 2008) which is also important to consider in research relating to usability.

## **1.6 ASSISTIVE TECHNOLOGY IN EVERYDAY LIFE**

A limited number of studies have explicitly examined the usability (e.g. Boman, Borell, Tham, Bartfai & Hemmingsson, 2010; Meiland et al., 2012) or the usefulness (Boman et al., 2010; Cahill, Begley, Faulkner & Hagen, 2007; Kim et al., 2000; Meiland et al., 2012) of AT as cognitive support in the home context. A larger number of studies which can be viewed as examining the usability and usefulness of AT as cognitive support in a more general sense have been conducted in the participants' homes. In a literature review, Topo (2009) found, however, that only a few of these studies focus on for example social inclusion or meaningful activities, and, further, that there are few studies in which the person with cognitive impairment actively uses the AT. In most studies, one specific product is distributed to all participants in the study, often as a



result of an observed or reported cognitive impairment. These types of studies assume that all the participants in the study share the same need or desire of the AT, which seldom would be the case in real life. This can be illustrated by how a person who has difficulties with time orientation is assumed to need an electronic calendar even if the person's goals and desires are not known or have not yet been identified. This limited attention in research to the person's own desires and goals has been acknowledged (Topo, 2009) and questioned previously, for example since the way of providing the AT is neither in line with current knowledge of brain injury rehabilitation research (Lindén et al., 2011), nor is it supported by the occupational therapy guidelines related to client centeredness (Lindén et al., 2011).

There are a number of studies that apply a perspective in which the persons with cognitive impairment are the active agents and these studies are conducted with the goal that specifically these persons should benefit from the use of the AT. For example, PDAs (Personal Digital Assistants) for reminders and structuring have been shown to be useful (Kim et al., 2000; Wilson, Evans, Emslie & Malinek, 1997; Wilson, Emslie, Quirk & Evans, 2001) for persons with e.g. stroke, by providing efficiency, increased confidence and independence to the user, also over time (Kim et al., 2000). Furthermore, the study demonstrated how it is possible to enable the user who had had a stroke to maintain already developed routines also after having stopped using the device (Wilson et al., 2001). To some extent an easy-to-use telephone, (e.g. equipped with photographs and speed dialling) can enable phone calls (Topo, Jylhä & Laine, 2002) and provide a sense of independence and reassurance (Cahill et al., 2007) and, further, an easy-to-use mobile phone with a Global Positioning System (GPS) can provide safety for both the user and the significant other (Rasquin, Willems, de Vlieger, Geers & Soede, 2007). The fact that support for time orientation can compensate for problems related to time has, to some extent, been demonstrated in a few studies (Nygård & Johansson, 2001; Topo et al., 2007) and also that support for time orientation provides independence and reassurance for the individual user (Cahill et al., 2007).

In one study, a variety of mainstream technology, such as for example, software calendars, mobile phones, PDAs and voice recorders has been shown to support persons with stroke in accomplishing their activity goals (Lindén et al., 2011). Even if a number of intervention studies have focused on the participants own goals in the design of the study, there is still a lack of studies applying the perspective of the users' desires and goals (Östlund & Topo, 2009).

There are few studies that focus on the process of becoming a user of AT for cognitive support concerning persons with AD or stroke. Rosenberg and Nygård (2012a) described how all actors involved in the process want to do what is right when a person who is diagnosed with dementia becomes a user of the AT, but that there is a risk that they all have different agendas. Someone else, other than the potential user, might have the power to decide regarding the AT (Rosenberg & Nygård, 2012a). Larsson Lund, Lövgren-Engström and Lexell (2011) illuminated how habits are developed by users who have acquired brain injury (e.g. stroke) in order to make use of the AT and how the significant others are often involved during the initial phase after the provision of the AT.

Some studies show features or stages of the process of becoming a user of AT in general (e.g. Kintsch & DePaula, 2002; Ripat & Strock, 2004). These studies report that, initially, a sense of desire for change is present (Kintsch & DePaula, 2002) or a stage of anticipation (Ripat & Strock, 2004). After that, people often experience some frustration connected to the adaptation to the AT (Kintsch & DePaula, 2002; Ripat & Strock, 2004) or a stage of exploration (Ripat & Strock, 2004). Later on feelings of competence could be identified (Kintsch & DePaula, 2002; Ripat & Strock, 2004) which was also reported when AT for cognitive support was used (Larsson Lund et al., 2011).

There are a number of studies that focus on the reasons for the abandonment of AT in general. These studies provide information about the prerequisites for becoming an AT user. The studies report that whether the AT supports the performance and/or accomplishment of the task better in comparison to another way of doing it is of importance for its continued use (Wielandt & Strong, 2000). It can also be related to whether anticipated goals can be achieved (Goodman, Tiene & Luft, 2002) or that important values are reinforced by the AT (Hocking, 1999). Unsafe and faulty AT increases the risk of the AT not being used according to Wielandt & Strong (2000) and Hocking (1998), as well as if it is difficult to use either by the user with cognitive impairment (Goodman et al., 2002; Hocking, 1999; Wielandt & Strong, 2000) or the family members in terms of configuring the AT (Dawe, 2005). Furthermore, the appearance of the AT affects the desire to use it (Rosenberg & Nygård, 2012a; Wessels, Dijcks, Soede, Gelderblom & De Witte, 2003). Other prerequisites to avoid abandonment of the AT are consideration of the environment, goals, values and daily routines when providing AT (Wessels et al., 2003; Wielandt & Strong, 2000) and also to include family members in the discussions about the AT intervention (Goodman et

al., 2002; Wessels et al., 2003; Wielandt & Strong, 2000). Wessels et al. (2003) state that the provision of instruction and training, the correct process and installation provision and the provision of follow-up services all affect the use of AT. There is also a chance that the AT is not needed any longer thanks to increased ability (Kintsch & DePaula, 2002; Wessels et al., 2003) which of course is a positive type of non-use.

**To conclude**, it is evident that people, due to cognitive impairments from a stroke or dementia, have difficulties in performing activities in their everyday life. Research has shown the potential in AT for cognitive support, to support the tasks that are related to some of these difficulties. Many of these studies have, however, not been conducted in the everyday context focusing on the persons' own goals and desires, and this makes it difficult to understand how the AT can support persons in achieving their anticipated goals in real life. There is a need to further investigate how persons become users of the AT when they want to achieve their own goals and to identify what the factors that influence the use of it. That is the intention of this thesis.

## 2 AIM

The overall aim of this thesis is to expand the knowledge base for a better understanding of how persons diagnosed with dementia or stroke become users of AT for cognitive support in everyday life.

The specific aims of each study were:

- 1) To identify in which everyday activities a specific type of computer-based and modifiable assistive technology could provide adequate support to persons who experienced difficulties related to cognition after a stroke.
- 2) To explore and examine in depth, how computer-based assistive technology for cognitive support influenced the everyday lives of both persons who had had a stroke and their significant others.
- 3) To describe how persons with early-stage Alzheimer's disease became users of AT in their everyday lives, and what the use of AT came to mean to the users and, when relevant, their significant others.
- 4) To examine the usability of different AT for cognitive support by identifying features that promoted and/or impeded cognitively impaired users' performance of tasks that were identified as hindering engagement in valued activities. An additional aim was to examine how the users could reach their activity goals and expected gains as a result of the support of the AT, that is, the usefulness of the AT.

### 3 METHOD

#### 3.1 STUDY CONTEXT AND DESIGN

The four studies in the thesis were conducted within two intervention projects. Intervention project no. 1 (P1) aimed at examining the possibilities for a specific type of AT for persons with cognitive impairments, and was conducted during 2007-2008 together with the Municipality of Huddinge and researchers from KTH, The Royal Institute of Technology. Intervention project no. 2 (P2) aimed at examining how individually selected AT was used and what the AT meant to persons with AD.

**Table 1: Overview of the four studies included in the thesis**

	<b>Study I</b>	<b>Study II</b>	<b>Study III</b>	<b>Study IV</b>
	Project 1 (P1)	Project 1 (P1)	Project 2 (P2)	Project 1, 2 (P1,P2)
Design	Descriptive	Explorative Qualitative	Explorative Longitudinal Qualitative	Descriptive
Partici- pants	6 persons with stroke 6 significant others	4 persons with stroke 4 significant others (from study I)	10 persons with AD <sup>o</sup> 10 significant others	4 persons with stroke (from study II) 10 persons with AD <sup>o</sup> (from study III) 14 significant others (from study II and III)
Data collection	- Semi-structured interviews before provision of AT based on assessment instruments: OMFAQ* CAPM** - Field notes	- Semi-structured interviews at 1, 3 and 6 months after provision of AT - Field notes	- Semi-structured interviews before provision of AT based on OMFAQ* and CAPM** - Discussions for provision of AT - Semi-structured interviews at 1, 3 and 6 months after provision of AT - Field notes	- Semi-structured interviews before provision of AT based on OMFAQ* and CAPM** - Discussions for provision of AT - Semi-structured interviews at 1, 3 and 6 months after provision of AT - Field notes
Data analysis	Content analysis (Graneheim & Lundman, 2004)	Constant comparative approach (Glaser & Strauss, 1967)	Constant comparative approach (Glaser & Strauss, 1967)	Content analysis (Graneheim & Lundman, 2004)

\*OARS Multidimensional Functional Assessment Questionnaire, OMFAQ, from instrument OARS, the Older Americans Resources and Services ( Fillenbaum, 1998)

\*\*Comprehensive Assessment of Prospective Memory, CAPM (Roche et al., 2002)

<sup>o</sup> Alzheimer's disease

P2 was conducted during 2008-2009 with support from the Swedish Brain Power network. Table 1 presents an overview of the four studies included in the thesis and how they were related to the two projects, P1 and P2.

### **3.2 ETHICS**

The participants and significant others were provided with written as well as oral information about the aim of the study and the intervention procedure. The participants and the significant others gave oral informed consent to participate in the study.

At every home visit, the participants were informed that they could withdraw from the study at any time without giving any reason and, further, that they could decline to answer any questions. Due to difficulties related to the cognitive impairments, such as memory and language difficulties, the issue of agreeing to participate in the studies continued during the whole intervention period, which has been previously recommended (Hubbard, Downs & Tester, 2003; Lloyd, Gatherer & Kalsy, 2006; Nygård, 2006).

It has been stressed in previous research, how there is a risk that the autonomy of participants with cognitive impairment included in research can become eroded (Hubbard et al., 2003). To promote the autonomy of the participants in the two projects, they were invited to choose whether the significant other should be present or not during the interviews. In order to avoid feelings of exclusion, the participants were present in all interviews conducted with their significant others. In those cases in which the significant others had to be interviewed by telephone, the participants were asked by the interviewer for permission to contact the significant other on every occasion.

During interviews when both the participant and the significant other were present, the research team intended to capture the experiences and opinions of both parties and the intention was not to view any of the two perspectives as more accurate or relevant than the other (Nygård, 2006; Pesonen, Remes & Isola, 2011). To avoid uneasiness, the researcher never questioned statements made as regards whether they were true or not.

For the same reason, questions about specific points in time, places and names were avoided when it was apparent that such questions were difficult for the participants to answer. Avoiding these types of questions has been shown to be of importance since when persons with cognitive impairment are continuously confronted with questions that cannot be answered by them, there is a risk that feelings of loss or fear are heightened (Hubbard et al., 2003).

In order to increase autonomy and safety, the participant and the significant other, in each case, received information about the potential AT and they were both included in the decision making about what product to use. This procedure was also based on the purpose of the research design. The perspective adopted in this step of the intervention was that the possible risk for the participants should not exceed the risks that they normally took in their everyday lives. This perspective has previously been recommended as a guideline in relation to intervention studies (The National Ethics Advisory Committee [NEAC], 2008). Information about whom to contact if technical problems occurred was provided and all participants were informed that the researcher was available on the telephone at all times.

When the products were provided in the home of the participants, the participants and the significant others were given oral and written information about the conditions for the specific product, and under what circumstances the products could be kept after the intervention, which differed between the products. Either the participant or the significant other confirmed in writing that they had received the information. After the intervention it was, in most cases, possible for the participants to keep the AT if they wanted and a contact with an occupational therapist was provided.

Ethical approval was obtained from the Regional Ethical Review Board in Stockholm, Dnr: 2006/1001-31/5, 2008/1612-32.

### **3.3 PARTICIPANTS**

The participants included in the studies for this thesis were persons who reported experienced difficulties in everyday life due to cognitive impairments. The persons who had suffered a stroke were included in the first intervention project, P1, which provided data for studies 1, 2 and 4. The persons who had been diagnosed with AD were included in the second intervention project, P2, which provided data for studies 3 and 4. They were recruited through healthcare professionals in a municipality (P1, P2), patient organisations (P1, P2), and a unit for memory investigation (P2). This means that the potential participants were approached either individually by healthcare professionals with previous knowledge about their diagnoses or that the potential participants themselves made contact with the researchers after having received general information about the projects. In either case, the researcher paid a visit to the potential participant to further inform him/her in person about the project and provide an opportunity to ask questions. After a couple of days, the researcher called the potential participant and

asked whether he or she wanted to participate in the study. The significant others were most often present during the home visits and if not, the researcher called them to inform them about the project, to answer questions and ask for their participation in the study. Both events also provided an opportunity for the researcher to check whether the inclusion criteria were fulfilled by the participant and significant other. Potential participants who stated that they experienced difficulties in everyday activities due to cognitive impairment were of interest for the studies. To be included 1) they had to be willing to discuss the perceived difficulties, 2) they should be interested in using AT as support in their everyday activities, and 3) they had to choose a significant other as an additional informer for the studies. Additionally, in P1, the participants should be over 65 years of age, and should have had a stroke at least one year ago and, in P2, the participants should have been diagnosed with AD by a specialist physician at a unit for memory investigation.

All together there were 16 participants included in the two intervention projects, nine males and seven females. They were between 54 and 87 years old and the average age was 70.4 years of age. There were ten female (eight partners, two daughters) and six male (six partners) significant others included in the two projects. The participants were all born and raised in Northern Europe and the four participants who were born abroad had lived in Sweden for at least forty years. The years of education differed between six and fifteen years. Approximately half of the participants had a university degree. Table 2 presents further information about the participants.

Two of the participants from study 1 did not participate in studies 2 and 4. The reasons why they had to decline their participation in the studies were in one case due to personal reasons and in the other case due to the fact that no support for his perceived difficulties could be provided.

The Mini Mental State Examination, MMSE, (Folstein, Folstein & McHugh, 1975) scores are included in Table 2 in order to describe the included participants' cognitive abilities in a general way. The MMSE is a screening instrument, the purpose of which is to identify dementia diseases (Folstein et al., 1975). It only shows a modest relation with the ability to perform everyday activities, such as cooking and driving (Strauss, Sherman & Spreen, 2006). Caution is therefore needed when relating the result in the MMSE to how the person is affected by the dementia disease in everyday life. It is also commonly used for people who have had a stroke, but the instrument has not been developed for that diagnosis group and its relevance in this group has been questioned (Blake, McKinney, Treece, Lee & Lincoln, 2002).



**Table 2: Background of participants in study 1 – 4**

Participant	Sex	Diagnosis	Age	Living conditions	MMSE** xx/30 p	Sign Other in study <i>W: working</i>	
Project 1: Study 1, 2, 4	1	F	Stroke*	76	With partner	27	Husband
	2	F	Stroke	69	With partner	27	Husband
	3	M	Stroke	87	Alone	25	Daughter
	4	M	Stroke	77	With partner	28	Wife
	5	M	Stroke	77	With partner	27	Wife
	6	M	Stroke*	76	With partner	26	Wife
Project 2: Study 3, 4	7	F	AD <sup>o</sup>	76	With partner	25	Husband
	8	F	AD	75	Alone	25	Daughter <i>W</i>
	9	F	AD	60	With partner	20	Husband <i>W</i>
	10	F	AD	56	With partner	28	Husband <i>W</i>
	11	F	AD	54	With partner and children	27	Husband <i>W</i>
	12	M	AD	79	With partner	24	Wife
	13	M	AD	74	With partner	28	Wife
	14	M	AD	64	With partner	15	Wife
	15	M	AD	63	With partner and children	27	Wife <i>W</i>
	16	M	AD	63	With partner	18	Wife

\*Only included in study 1

<sup>o</sup>Alzheimer's disease

### 3.4 PRODUCTS

Products used in the projects included both products specifically designed to support persons with cognitive impairments (P1, P2) and mainstream technology (P2) and are presented in Table 3. In line with the purpose of the studies, all products were to be equipped with some type of processor. The areas of support for the products were; home surveillance, time orientation, reminders related to time, reminders when leaving home or room, locating items, communication and orientation outside the home and note taking. In P1, only one specific product was used (Tentaculus, see Table 3 and studies 1 and 2). It was chosen since it had been reported to be modifiable in order to fit different users and needs, particularly in the area of reminders and warnings at home. The assumption was that with a modifiable support system it would be possible to cover a range of different needs and possible to provide more generic support.

**Table 3: Products used in intervention projects P1 and P2 (between 2007-2009)**

<b>Name of product</b> Field of application	<b>Purpose of product</b>	<b>Features of product</b>
<b>Abilia Reminder</b> Reminder	Give a spoken reminder when the door opens.	Pre-recorded message is played when two magnets are parted.
<b>C.STATUS</b> Home surveillance	Show status of appliances and doors at home /outside home.	Panel with lit-up text information when appliances are turned on or doors unlocked, key tag with same information.
<b>Doro Handleplus</b> Mobile phone	Enable simplified phone calls outside home.	Mobile phone with five buttons for pre-programmed phone numbers. No display.
<b>FOFA</b> Item locator	Locate lost items.	Key tags with buttons, attached to selected items. Every key tag is equipped with radio transmitters for locating each other.
<b>Forget-me-not</b> Electronic calendar	Inform about day and date.	Electronic calendar showing day and date on a display.
<b>Handi Hitta</b> Mobile phone with GPS	Enable simplified phone calls outside home. Guide the user to a specific location. Send text messages with GPS coordinates.	Mobile phone with touch screen, simplified dialing, GPS for orientation to a specified location. Pre-programmed text messages with GPS coordinates to a significant other.
<b>MEDOS</b> Alarm watch	Give regular reminders.	Wrist watch with alarms (sound or vibration).
<b>MEMO day-planner</b> Day planner	Give a sense of time visually and enable time estimation.	Whiteboard chart with a clock in the shape of a light bar. Light point descending every quarter of an hour.
<b>MEMO messenger</b> Talking clock	Give audio time information on request and give spoken reminders.	Portable device connected to a base station. Deliver spoken information about time in analogue form and spoken reminders at preset points in time.
<b>Olympus VN-3500pc</b> Note taker	Record audio.	Common digital voice recorder.
<b>Skeeper</b> Mobile phone with GPS	Enable simplified phone calls outside home, provide a position of user on map for significant other.	Wrist mobile phone with buttons for pre-programmed phone numbers, equipped with auto-answer and GPS. Configuration and localisation are made on a web-site by a significant other.
<b>Smart finder</b> Item locator	Locate lost items.	Remote control device with receivers attached to selected items.
<b>Tentaculus</b> Support system	Give (also repeated) reminders or warnings under preprogrammed terms.	Software program for computer, hardware for communication with e.g. sensors. Provides reminders and warnings regulated by time or sensors at home. The reminders/warnings /confirmations are configured and conditioned to suit the user.

### 3.5 INTERVENTION PROCEDURE

The steps included in both of the projects (see Table 4) were formed to resemble the general provision process of AT in a clinical context and are built on a model comprising nine steps that aims at supporting in the provision of AT for persons with dementia (Björneby, Topo & Holthe, 1999). The steps included are: 1) describe the

living situation for the participant, 2) analyse the individual needs of the participant, 3) identify the problem that needs to be solved, 4) identify appropriate technology and alternatives, 5) discuss ethical dilemmas and issues around potential technology, 6) assess and recommend technology, 7) choose solutions and decide, 8) implement the chosen solutions and, finally, 9) assess results.

**Table 4: Intervention procedure in P1 and P2**

<i>Step according to Björneby et al. (1999) with additional comments for P1 and P2.</i>	<b>Procedure</b>	<b>Persons involved</b>	<b>Home visit</b>
1. <i>Describe the living situation for the participant</i> , by mapping out his/her abilities, habits, contexts and use of everyday technology.	Semi-structured interview. Basis: OMFAQ*. Questions formed for the studies about habits and use of everyday technology.	Participant, Interviewer Optional: Significant other	No. 1
2. <i>Analyse the individual needs</i> by identifying self-perceived difficulties in the participant's everyday life, related to cognition.	Semi-structured interview. Basis: CAPM** with follow-up questions, questions about temporal and spatial orientation.	Participant, Interviewer Optional: Significant other	No. 2
3. <i>Identify the problems that need to be solved</i> by assessing importance, current performance and satisfaction with the performance of activities that were hindered by the identified difficulty.	Set questions inspired by COPM***. Answers both in own words and with visual analogue scale. Informal conversation about AT for support.	Participant, Interviewer Optional: Significant other	No. 2
4. <i>Identify appropriate technology and alternatives</i>	Discussions of analysed material from steps 1-3. Questions: What modifications (P1) or products (P2) can support the task? Is it feasible generally/in current situation?	Research group Optional: Technician	—
5. <i>Discuss ethical dilemmas and issues around potential technology</i>	Ethical discussions within the research group about potential risks related foremostly to safety, integrity or autonomy.	Research group Optional: Technician	—
6. <i>Assess and recommend technology</i> to enable an informed choice	Presentation of potential AT in accordance with described needs, desires and habits, in a way suitable to the participant.	Participant, Interviewer, Significant other	No 3
7. <i>Choose solutions and decide</i>	Discussion about possible AT solutions. The participant makes a decision with varying levels of support from others.	Participant, Interviewer, Significant other	No 3
8. <i>Implement the chosen solutions</i> and ensure a good introduction of the AT.	Provision of AT. Instruction of participant and significant other. Practicing on 1-5 occasions when needed. Follow-up phone call after one week.	Participant, Interviewer Optional: Significant other, Installation engineer	No 4 (+0-5 for practice)
9. <i>Assess results</i> and thereby ensure that the AT works as planned.	Check whether AT works as planned on three occasions (at the times for data collection). Home visits when AT fails.	Participant, Interviewer, Significant other	No 5-7

\* Older Americans Resources and Services Multidimensional Functional Assessment Questionnaire, OMFAQ (Fillenbaum, 1998)

\*\*Comprehensive Assessment of Prospective Memory, CAPM (Roche et al., 2002)

\*\*\*Canadian Occupational Performance Measure, COPM (Law et al., 1994)

The research group, referred to in steps 4 and 5 in table 4 included the researcher (EL) and a second interviewer (both registered occupational therapists, with long experience in geriatric rehabilitation), the supervisor (with 20 years of experience as a researcher in the field of the living situation for old people with a specific focus on persons with dementia) and a consultant researcher from the Royal Institute of Technology, KTH (with experience of research focusing on technology for older people).

In step 8 in Table 4, the numbers in brackets shows the number of times the author visited the participants in order to be present as support when the participant, and in some cases, the significant other practiced the use of the AT. Mostly, the introductory visit was enough, but especially the use of the mobile phones and orientation support demanded more practice, which resulted in two to five extra home visits.

Three assessments were used as a basis during the interviews conducted in the planning of the intervention, before the AT provision in both P1 and P2. These interviews aimed at identifying suitable AT solutions. The Older American Resources and Services Multidimensional Functional Assessment Questionnaire, OMFAQ (Fillenbaum, 1998) - a part of the Older American Resources and Services, OARS (Fillenbaum, 1998) - focuses on to what extent 24 everyday activities are performed independently. A Swedish version of the OMFAQ (Fillenbaum, 1998), translated by the research team, was used as the basis for an interview about the participant's everyday life (step 1, Table 4). Empirical evidence supports the internal construct validity and predictive validity of the OMFAQ (Haywood, Garratt & Fitzpatrick, 2005).

The Comprehensive Assessment of Prospective Memory, CAPM (Roche, Fleming & Shum, 2002) focuses on to what extent the participant perceives memory-problems in relation to the performance of 39 everyday tasks. The Swedish version of the assessment (Ehrenfors & Gudjonsdottir, 2005) was used as the basis for the interviews in P1 and P2. In this case, the interview aimed at focusing on what difficulties the participant experienced in the everyday life related to the cognitive impairments (step 2, Table 4). Two extra questions were added due to their relevance; to use the ATM (automated teller machine), and to turn off the coffee maker. In the interview about difficulties in everyday life, some questions about time orientation, spatial orientation and the use of everyday technology were added outside the frame of the assessments. Test-retest reliability and internal consistency for the CAPM are within acceptable ranges (Chau, Lee, Fleming, Roche & Shum, 2007).

After the interview about perceived difficulties in everyday life that could be related to cognition, the specific AT support was to be chosen and decided upon. To identify

what tasks or activities in everyday life that could come in question for AT support, the participants were asked to judge how they valued the identified difficult tasks that hindered the activity goal (step 3, Table 4), inspired by the questions included in the Canadian Occupational Performance Measure, COPM (Law et al., 1994). They were asked to first describe in their own words how they assessed the importance, performance and satisfaction with the performance of the difficult task. Thereafter, when possible, the participant used the visual analogue scale for assessing the same factors. COPM has been shown to capture other information relevant for intervention than more standardised instruments (Dedding, Cardol, Eyssen & Beelen, 2004) and has also been shown to provide supportive evidence for convergent and divergent validity (Dedding et al., 2004).

### **3.6 DATA COLLECTION**

The procedures for data collection were conducted in the same way during the two projects. On all occasions in the intervention, field notes were written by the author or the second interviewer and the interviews were audio recorded. The interviews conducted before the provision of AT, based on assessments (see Table 4) and aimed to provide information for the selection of suitable AT solutions, were collected for analysis. The data were included to different extents in all the studies, foremostly in studies 1 and 3.

After the provision of AT, there were three semi-structured interviews at one, three and six months in both intervention projects, after the point in time at which the AT worked as planned. The interviews aimed at examining how the AT was used and experienced by the participants and the significant others. The collected data from after the provision of AT were used in studies 2, 3 and 4.

#### **3.6.1 Interviews**

The semi-structured interviews (Kvale, 1996) were conducted in the participant's home. In order to obtain a trustful climate, sufficient time for some small talk (Nygård, 2006) and a cup of coffee was set aside for the home visits. The questions in the interviews were developed to be as concrete as possible to enable the participants to provide rich answers (Lloyd et al., 2006; Nygård, 2006). Questions that were of a more abstract nature were sometimes changed slightly for participants who could not understand these most abstract questions (Nygård, 2006). In one case, one significant

other also helped the interviewer to rephrase questions in order to make them easier for the participant with aphasia to understand.

When the participants chose to let the significant other participate during the interview, the significant other could, in some cases, provide support; their presence indicated that everything was under control, which facilitated for the participants when answering the questions. This has been recognised in previous research related to persons with dementia (Pesonen et al., 2011). The design of the intervention that implied that the participant was present when the significant other was interviewed by the interviewer enabled the interviewer to capture how the participant viewed the opinions of the significant other by listen to the upcoming discussions. These discussions were judged by the research team as making an important contribution to the data. When differing views were identified the interviewers asked additional questions in order to better understand both views. The importance of capturing both views in the interviews has been emphasised previously (Nygård, 2006; Pesonen et al., 2011). In the cases in which the significant others had to be interviewed by phone, the responses to the interview were written down during the conversation.

The interviews conducted after the provision of the specific AT served as data in studies 2, 3 and 4 and included two parts. First, there was a discussion about how the AT had worked since last time. In this discussion both the participant and the significant other were asked to contribute. They were also encouraged to describe episodes, experience of using the AT, or other experiences related to the use of the AT. Their expectations before the provision of the AT were read to them, and they were asked whether the AT had met their expectations and they were also asked to exemplify in what way they felt that the expectations had or had not been met. They were also asked to explain how they used the AT during an ordinary day. In the second part of the session, a semi-structured interview was conducted. They were asked to describe whether they perceived changes in: activity performance outside or inside the home, social contacts, safety, independence, confidence and sense of control, which they could relate to the use of the AT. Irrespective of whether they did or did not perceive any changes, they were asked to describe their perceptions further. Open questions requiring a great deal of explanatory responses were avoided since they have been shown to be difficult to answer (Nygård, 2006).

### **3.6.2 Field notes**

Field notes (Polit & Hungler, 1995) were written after or during all contacts with the participant, the significant other and also in the contacts with the company that provided the AT. The field notes comprised mainly of observational notes, for example, reports of observations during home visits and reports from conversations had outside the interview with participants/significant others at home, during phone calls and e-mail conversations. The correspondence between the researcher team and the AT companies, when referring to a specific case, was also included in the field notes. The field notes could also include comments relating to observations or conversations or to methodological issues and the researcher's personal reflections were also written down. Since the phone interviews were not audio recorded, the field notes for these events were written in even more detail in order to capture the whole conversation.

## **3.7 DATA ANALYSIS**

In all of the four studies the data for analysis included transcribed audio-recorded semi-structured interviews and field notes. The audio-recorded material collected before the provision of the AT was thoroughly listened through and all data that were judged as relevant to the aims of the studies were transcribed verbatim. All audio recorded material after the provision of the AT was transcribed verbatim. Since the assessments were conducted within the audio-recorded interviews, the spoken answers to the questions included in the instruments formed part of the data analysis together with the filled-in assessment documentation.

### **3.7.1 Study 1 and 4**

In studies 1 and 4, content analysis was applied to the data as described by Graneheim and Lundman (2004). In the first step, the analyses of the data in studies 1 and 4 were very similar to each other. The data (transcribed interviews, field notes and e-mail conversations) were thoroughly read to find and identify all of the difficulties in the everyday life that could be judged as being related to the specific cognitive impairment of the individual (study 1) or to find features of the AT or the perception of the AT that influenced the use of the AT (study 4).

#### **3.7.1.1 Study 1**

In the next step in study 1, a matching procedure was conducted between the AT in focus (Tentaculus, see Table 3) and the difficult tasks identified. To perform this

procedure a tool was required that could support the analysis of which functionalities that were needed in the AT to support the difficult task. Since no tool designed to perform such analysis was found, it was designed within the study. To design this tool, a content analysis of material collected during the implementation of the AT was conducted. The data in this step consisted of field notes and e-mail communication between the research team and the AT company and within the research team. The analysis identified the functionalities needed for the AT to provide support in tasks reported as difficult by the participants. Thereafter, the identified functionalities were coded and sorted into content areas according to the features of the data. This process resulted in four steps included in a process of how this type of modifiable AT should react to support the specified task: 1) receive information, 2) deliver information, 3) confirm information, and 4) additional actions. The four steps comprised the *AT support process* which can be viewed as a generic process for support from modifiable computer-based AT of this type. With the collected material as a basis, questions, judged as requiring answers when matching the AT with a specific task, were designed for every step.

With the designed questions included in the *AT support process* the match was conducted focusing on whether the AT could support the targeted difficult task and to what extent.

To validate the findings in the above three steps, consensus was sought, influenced by the Delphi method (Murphy, Black & Lamping, 1998). Two assessors, experienced in working with this specific AT in research, answered questions concerning whether each of the identified difficult tasks or activities could be supported by the AT. The author discussed the responses individually with the assessors in a structured manner to achieve an understanding of the underlying reasoning.

In a last step the difficult tasks were sorted into one of two categories dependent on whether the AT could provide the desired support or not. Sub-categories showing tasks in which the AT could provide sufficient support were sorted in accordance with how the AT received the information to react upon. The sub-categories showing tasks in which the AT could not provide sufficient support were sorted according to why the support was judged as not being possible to provide.

#### 3.7.1.2 Study 4

To be able to analyse the collected data in terms of usability and usefulness, the first step was to operationalise those concepts into manageable definitions for the purpose of this study. Using Nielsen's (1993) term of usability as a basis, the definition of usability



for this study was: *how features of the AT promote and impede the performance of tasks that have been identified as hindering the achievement of his/her goals in daily living*. For the analysis in this study, usefulness was also defined using the terms of usefulness from Nielsen (1993) as a basis: *whether the user achieves his/her goals - that is, to perform one or more valued activities or activities in general – and his/her expected gains, when the use of the AT takes place in the relevant context of use in the performance of the task that has been identified as hindering the achievement of his/her goals in daily living*.

Goals related to valued activities and goals related to the task that hindered performance of the valued activities were separated, since it was judged as possible that even if a goal related to the task was achieved this did not automatically result in the goal of performing a valued activity being achieved. This perspective was influenced by Norman (2005) who stated that it is of importance to consider the *comprehensive activities and goals* and not only the small procedure or the task when designing for usability. Data about the users' desired goals, their expected gains and about the tasks identified as hindering were retrieved from data collected before the provision of AT. In the next step, with data about desired goals and expected gains as a basis, data collected after provision of the AT related to the use of the AT were analysed with support from predetermined codes, which for example were named "promoting feature", "impeding feature", "context" and "user experience". Meaning units with data related to the predetermined codes were extracted from interviews and field notes in order to identify experiences of features in each AT device. This procedure enabled an analysis of how features promoted or impeded tasks in the relevant context of use according to the experiences of the AT in both projects. The identified experiences were condensed to 100 features that were judged to either promote or impede the performance of tasks.

To examine the usefulness of the AT, analysis focused on whether the users' activity goals were reached, and whether their expected gains were achieved and how the features, judged as promoting and impeding the hindering tasks, influenced their goals and expected gains. At this point, eight themes were formed and named in relation to the content.

### **3.7.2 Study 2 and 3**

In studies 2 and 3, the focus was on how the participants and the significant others experienced the AT and what it meant to them in their everyday life and, in study 3,

over time. The transcribed data were analysed with a constant comparative approach as described in Grounded Theory (Glaser & Strauss, 1967).

In a first step, the interviews and the field notes were arranged chronologically. In study 3, there was a large amount of text, since the material included transcribed interviews and field notes from both before and after the provision. To reduce the material, and before the actual coding, the next step in the analysis for study 3, summaries were written very close to the data in which many long relevant quotes were included.

In the next step in both studies 2 and 3, coding of the data was performed and a first preliminary categorisation was conducted. In this next step, comparisons were made between cases and within the cases in relation to the aim, between the participant and the significant other (studies 2 and 3) and between different points in time (study 3) which is suggested by Glaser and Strauss (1967). Notes were written during this process with the purpose of capturing the author's thoughts at the time (Glaser & Strauss, 1967). New questions, inductively derived from the data, were raised and comparisons were made between the coded material and the raw data.

Derived from the comparisons, categories were elaborated and formed in a back and forth process, and the categories were preliminary named close to the data. All the authors participated in this process and discussed the finding and the properties of the categories. Before the categories were finalised the original data were read through and compared again with the emerged categories in order to check whether all relevant data had been captured within the categories, and that no contradictions between original data and the analysed material existed. The categories were then finally reduced and named. The findings were interpreted (Borell, Nygård, Asaba, Gustavsson & Hemmingsson, 2012) to enable a better understanding of the experiences perceived by the participants and their significant others.

## **4 FINDINGS**

The findings in the four studies included in this thesis will be presented here and will focus on the aim of the thesis, that is, to illuminate different aspects that influence whether persons with dementia or stroke become or do not become users of AT for cognitive support to achieve anticipated goals in everyday life. The first section presents primarily findings from study 1 and describes whether support that actually was needed and desired was available for the potential users. The second section presents findings from study 2 and, in particular, study 3, and it focuses on the significant junctures that were of importance for participants to become users of AT. The third section shows how the participants and the significant others could benefit from being users of the AT according to findings in studies 2 and 3. The fourth section describes, with support from findings in study 4, how the features in a number of AT promoted or impeded the performance of difficult tasks and the participants' goal achievement, that is, the usability and usefulness of the AT.

### **4.1 POSSIBLE SUPPORT AND DESIRED SUPPORT**

In study 1, the features in a specific AT product (Tentaculus, see Table 3) were assessed as to whether they had the potential to support the performance of tasks, identified as difficult by the participants. According to the findings in study 1, the specific AT was judged as being able to provide support to a varying degree in 29 of the 65 tasks that were identified as difficult in everyday life by the persons who had experienced a stroke.

It was judged that the AT, with support from the calendar, could inform about day and date and provide prospective reminders (in terms of voice, text or light) customised to a varying degree to the user. The support was found to be most efficient when the reminder was to be used regularly, for example, for taking medicine.

By using sensors in the AT, the support was judged to be most appropriate when the AT provided support for the completion of an already initiated task, like reminding to turn off the cooker. It was, however, also judged as being very feasible to make use of reminders associated with a specific place or action, for example; a reminder to take along one's wallet when the installed sensors registered movements close to the entrance and it was assumed that the user was about to leave the home.

Among those 65 difficult tasks that had been identified by the participants, the specific AT was judged as supportive in tasks mainly related to warnings and reminders connected to household tasks (e.g. a reminder to turn off the cooker) or to health-related activities (e.g. reminders about exercising). In addition, the AT was also judged as able to provide support in some tasks related to keeping social contacts.

In study 1, approximately half (36/65) of the activities and tasks that had been identified as difficult were judged as not possible to support by the specific AT. These tasks were related to communicating, tracking items, handling technology and complex activities that included many decisions by the individuals in relation to the situation, for example, making dinner or playing cards.

When the participants in studies 1 and 2 who all had experienced a stroke, chose tasks for AT support among the 29 possible tasks, only 11 tasks were chosen, that is, only a third of the tasks were judged as highly prioritised in relation to personal goals and therefore suitable to attend to according to the participants. The chosen support was related to safety, health and social contacts. The goals related to the chosen support often had a social dimension, for example; a desire to decrease other persons' worries about safety issues, or to reduce other persons' burden of caring. Interestingly, tasks related to keeping things in order at home, such as remembering to turn off water taps or to flush the toilet were not chosen for intervention.

For the participants in study 3, who were more mobile and also had the possibility to choose an AT for support more freely than the participants in studies 1 and 2, the desired AT support also included services related to activities outside the home, such as being safe when outdoors, and being confident enough to leave home in a safe and efficient manner. The social dimensions identified in the participants' goals in study 3 mainly related to the possibility to come into contact with family members.

## **4.2 BECOMING A USER OF ASSISTIVE TECHNOLOGY**

On the participants' way towards becoming users of AT, four junctures were identified in study 3 that were of significance regarding whether the participants came to use the AT regularly in their everyday life or not. These junctures were also identified in study 2. The junctures were chronologically ordered, that is, they appeared in the same order for the participants. The space of time between the junctures differed, however.

The first juncture was identified in study 3 as *to make the decision to use AT as support*, which occurred when the participants were in the situation in which they had

to make a conscious decision as to whether they wanted to use a specific AT as support for a difficult task related to cognition. Two conditions for the decision were identified which, if they were met, increased the possibility for the participants to use the AT regularly. The first condition was that the task which was intended to be supported by the AT was experienced as difficult by the participant him/herself and not imposed on them by another person. In the case when AT was chosen in order to support a task viewed as difficult for the participant only by, for example, the significant other, the findings showed that the AT was less used, or not used at all by the participant. These findings were supported by findings in study 2.

The second condition which increased the possibility to use the AT regularly and shown in study 3 was that the task, or the goals connected to it, should be viewed as important and highly valued by the participants. When the task or the anticipated goals were not valued highly enough it was less likely that the use of the AT became a regular occurrence.

Both studies 3 and 4 showed that when an AT that the significant others could also gain from was chosen, for example decreased worries, the likeliness that it would be used regularly by the participant increased, since the significant others were seen to be more involved and active in the use of the AT.

The next significant juncture was identified in the findings of study 3 some time after the decision to try the AT had been made. At this juncture, the participants had *to make adjustments in their routines to include the AT* in their everyday life. How these adjustments were made influenced whether the participants started using the AT or not. Both in studies 2 and 3, the findings showed that the participants and in some cases also the significant others, were seen to have developed strong determination to make these adjustments.

Even if some participants felt confused at times at the beginning of their interaction with the AT, the findings in both studies 2 and 3 showed that, in most cases, they continued to try to understand and learn more about the AT. After a while the sense of confusion disappeared and the features that were perceived as a strain to begin with became understood and accepted. After a varying length of time for each person, the routines had become part of their everyday life. Findings in both studies 2 and 3 showed how routines were developed by the participants and the significant others, which enabled the participants to perform the tasks more efficiently and with a higher degree of control than before. The development of new routines was described by some participants as a prerequisite for being able to perform the chosen activities.

At the third significant juncture the question of whether *to trust the AT* or not, and to what extent, was in focus according to findings in study 3. Initially, when the participants developed routines for including the AT and became familiarised with it, at the same time they learned to predict its actions. After a period of use, the participants in study 3 expressed whether they trusted the AT or not, and the findings showed how this trust was related to the predictability of the AT. If they did not trust the AT, this matter overshadowed all other concerns and there was a significant risk that the participant stopped using the AT. The participants who had experienced unpredictable AT expressed how it was crucial for them to be able to trust the support. Some participants explained that due to their cognitive impairments it was even more crucial that the AT worked as intended, since they perceived that the impairments made them more vulnerable to unpredictability. The most significant reason for not trusting the AT was faulty AT. The importance of trust in the AT was not as evident in the findings of study 2.

At the fourth and last significant juncture the question of whether the participant perceived *a feeling of having enhanced capacity when using the AT* was in focus. According to the findings in study 3, there was a strong relationship between whether this point was reached and how the previous significant junctures had been overcome, that is, on what grounds the decision to use the AT was made, how the participants' routines were adjusted and to what extent the participants trusted the AT. The feeling of enhanced capacity was related to the participants' experience of themselves as being in control and being confident that they could handle the tasks in focus for the AT support. This enhanced capacity was illustrated, both in studies 2 and 3, by strategies, developed by the participants in order to allow the performance of the task. This also resulted in some of the participants even using their AT less frequently at the end of the project compared to at the beginning. When the routines had become manifest, some participants reported that they even thought that they would be able to do without the AT. They were, however, at the same time aware of their dependence on the AT to perform the tasks and of the vulnerability of their newly achieved feeling of capacity. The findings in study 3 show that the feelings of enhanced capacity could be absent, even if the task was performed as planned. It was indicated that this lack of feeling of capacity was related to the fact that the AT was connected to either the expected goal having decreased in value over time, which made the fact that the tasks was now performed more efficiently somewhat less meaningful, or to the fact that the task was performed well enough without the support. Another reason for an absence of feeling

of capacity even if the tasks were performed as planned was shown in study 2, when the significant other had taken on a more leading role in the use of the AT and still had the responsibility of reminding and encouraging the participant when the reminder was heard.

### **4.3 INFLUENCES OF ASSISTIVE TECHNOLOGY IN EVERYDAY LIFE**

Both studies 2 and 3 aimed at examining how AT could influence the everyday lives of both persons with stroke or AD and their significant others and what this influence meant to them. The changes in everyday life could not be observed from the outside in all cases, some of the changes were more related to how the participants perceived the quality of the performance of their valued activities.

The findings in study 3 clearly showed how time and effort was saved, how worries and stress had decreased, and how their feeling of safety had increased. How they benefitted from these new perceptions in their activities was not the same for all of the participants.

The mobile phones for instance, could infuse courage into both the participant and the significant other in enabling the participant to perform activities that were otherwise viewed as too risky, for example to go for a walk or run in the woods. For one person, this activity meant peace of mind, an opportunity to gather strength for the challenges in everyday life. For another person, running in the woods meant that he could feel independent for a couple of hours a day, instead of, as in every other activity, being guided by his wife. In some cases, in both studies 2 and 3, it was evident how the AT reminders encouraged the participants to take their medicine or to perform their planned exercise. For example, the exercise became more frequent and in study 2 it was shown that the significant others felt alleviated when the AT, as the significant others put it, backed them up and helped them to encourage the participant to exercise.

Also the AT for home surveillance could support physical health (study 3). When the participants knew that everything was under control at home, their worries decreased and they could go out for a healthy walk in a relaxed way instead of having a constant stressful feeling that he or she should go home to check that the appliances were turned off. For the same reason, visits to friends were less stressful, when the AT for home surveillance was used.

AT for reminders could also support social activities, but in a different way; by encouraging the participants to call friends and relatives, which also positively

influenced their social contacts. In one case from study 2, when the participant felt insecure due to speech difficulties connected to a stroke, the encouragements provided by the AT were the starting point for reshaping the participant's network of friends and acquaintances.

The use of item locators enabled the participants to make both the searching for the items and the leaving home more efficient which reduced stress to a great extent. It also made it easier to plan their time e.g. when catching the bus.

Findings in studies 2 and 3 showed that the fact that the participants gained confidence in the task enabled them, to a variable extent, to recover responsibilities in these tasks, for example related to medication or home surveillance. When strong routines for e.g. medication were formed and the participants thereby gained control of the task, the participants took over the responsible for the task from the significant others. Although it had become an extra responsibility, the participants' worries and stress decreased and they felt satisfied that they could alleviate the burden from the significant other in some tasks. There were also findings in study 2 demonstrating how a couple became collaborators in the mission to use the AT to be encouraged to call relatives instead of having arguments about it. This transfer of responsibilities showed that the participants were able to take charge of the tasks and this was expressed for example as creating a feeling of pride (study 2). There were also examples in study 2 when the significant other could not trust the participant to initiate a task, but instead, it was possible to transfer the responsibility from the significant other to the AT, and this was described by them as a relief.

Even if the shaping of routines was mostly a means to be able to perform a valued activity, the routines themselves could also be perceived as valuable. It was explained in study 2 how a couple had lost the rhythm of the days and weeks when the participant experienced the stroke. In their case the regular daily reminders provided a structure that they could form their other everyday activities around.

#### **4.4 USABILITY AND USEFULNESS OF ASSISTIVE TECHNOLOGY**

Study 4 focused on aspects of usability and usefulness of the AT used in the previous studies, that is, how the features in the AT promoted or impeded the accomplishment of the difficult tasks (usability) and how the users could reach their goals with support from the AT (usefulness). The goals identified before the provision of AT for both groups together were defined either as the actual performance of a valued activity or as



expected gains in terms of achieving increased safety, saved time and effort, enhanced control/assurance, increased independence, reduced stress and embarrassment connected to the task performance.

In study 4, eight themes were formed according to what usability aspects the features of the AT were experienced as either promoting or impeding with regard to the performance of the task. Three of the themes were connected to the use of the AT during the performance of the difficult task. Two themes that identified promoting features were related to the possibility to receive *constant access to information*, which increased the assurance and enabled the user to use the information provided to perform valued activities, and to the possibility to receive *recurrent reminders*, which supported developments of routines and thereby enabled the participants to perform valued activities more frequently and punctually and with decreased amount of worry. The third theme related to how *inappropriate design of buttons* could impede the performance of the task and, due to the perceived difficulties, it could convey a sense of worry, which in turn impeded the performance of the task.

Five themes were connected to how the AT and the context were prepared and maintained by the participant, the significant other or the AT professionals in order to become supportive and in a next step, whether the goals were achieved. The themes were related to the *significant others' determination and ability to handle technology*, whether *the AT was charged*, and *how the AT was customised* for its intended use. One theme was connected to whether *the AT was accessible in the right situation*, which demanded different features in stationary and mobile AT. The last theme was also connected to the utility of the AT and showed how *faulty AT* increased worries and distrust and impeded the performance of a task.

There were aspects identified within these themes that influenced the usefulness of the AT. For example, even if a difficult task was performed with the support of the AT, there were cases when the support was perceived as stressful or irritating. This meant that even if the AT was usable, the expected gain defined as decreased stress was not achieved and it could be viewed as less useful. This could also result in the task not being performed at all or being delayed.

When the AT had an inappropriate design to promote the full performance of a task, the participant could sometimes make concessions regarding his/her desires and decide that the AT was supportive enough, that is, the AT could be judged as having impeding features but nevertheless be perceived as useful. This can be exemplified by when the

participant preferred to remove a difficult key lock on a mobile phone to enable phone calls even if it resulted in more inadvertent calls.

An adequate individualised support, e.g. in the form of a reminder for a specific appointment, could more easily become a more non-supportive reminder than a more general support when circumstances were changed. This inaccuracy risked decreasing the usefulness of the AT, and, in some cases, also decreasing its level of safety.

When the AT did not work as expected it did not always affect the performance of the task, but could have other consequences. For example, when an AT for home surveillance did not work it provided the same information to the user as if it worked and all appliances were turned off, and the participant could go on using the AT without knowing it was faulty. However, it clearly decreased safety and usefulness. The AT could also have less capacity than anticipated in comparison with similar products, for example limited coverage for some mobile phones. Even if it was not faulty, such a feature was very impeding, and jeopardised the usefulness and the safety of the AT. Even if these examples were connected to the utility of the AT, they also affected the usability and the usefulness of the AT.

## **5 GENERAL DISCUSSION**

### **5.1 DISCUSSIONS OF FINDINGS**

The overall aim of this thesis is to expand the knowledge base for a better understanding of how persons diagnosed with dementia or stroke become users of AT for cognitive support in everyday life. A number of aspects were identified that contributed to whether the participant became a user of the AT and three of these aspects will be further discussed in this section. In the last part of this section, the future for AT as cognitive support will be discussed.

#### **5.1.1 The achievement of anticipated goals**

The first aspect that contributed to whether the participants became users of the AT was shown in study 3. This was two-fold, firstly it concerned the fact that the activity in which the participant wanted support, was highly valued and needed by the participant, and secondly, it was related to the task which hindered the person from performing the activity – and which the AT intended to support - being experienced as difficult by the participant.

These findings are in accordance with previous research which suggests that individual desires and needs are crucial for whether to use the AT or not (e.g. Goodman et al., 2002; Krantz, 2012; Rosenberg, Kottorp & Nygård, 2012b; Scherer, 2002; Wey, 2004). The extent to which the individual's own desire to perform a specific activity highly influenced the willingness to make use of the AT was illustrated by findings from study 4. There were participants who chose to use the AT despite the fact that it did not work as anticipated which resulted in e.g. inadvertent calls or unnecessary reminders. These findings show that a task can have such a high priority that the AT support is accepted and used even if it only supports the person to a limited extent, which has been described previously (Eftring, 1999; Krantz, 2012). In those cases when the task was highly valued, the findings in study 3 showed how participants made efforts to learn to use the AT, which supports previous research (Larsson Lund, Lövgren Engström & Lexell, 2012).

It has been proposed that AT for persons with cognitive impairment should be designed to be intuitive and not to require new routines to be developed (Boman et al. 2009,

Rosenberg, 2009 et al, 2012b), which of course is beneficial and to be preferred. However, the findings in studies 2, 3 and 4 show that there are situations in which the user both wants and is able to adjust to the AT, in order to be able to use it even though he/she has cognitive impairments, and even if it demands an effort in terms of learning and developing new routines, on their part. These findings cannot be seen as representative of a large population or possible to generalise, still the preference of designing AT which needs no learning should not be taken as an absolute prerequisite, since such a perspective could hinder the development of useful AT.

The findings in both studies 2 and 3 showed how the participants paid close attention to people around them when they made their decisions about what task to support, even if the goal itself was not explicitly targeting the social context, for example, being able to estimate time was a way of avoiding people having to wait for you and, further, knowing day and date was a prerequisite for not being viewed as stupid. Findings in studies 2 and 3 imply that the AT was and can be used purposefully to reduce stigma that derive from cognitive impairments and provide examples of how the participants were enabled to act more “normally” with the AT than without it in a social context. These findings are of great importance since previous research has shown that AT risks being perceived as stigmatising for the user (Cahill et al., 2007; Karlsson, Axelsson, Zingmark & Sävenstedt, 2011; Larsson Lund & Nygård, 2003; Robinson, Brittain, Lindsay, Jacksson & Olivier, 2009; Rosenberg, 2009). The experiences from the interventions, which showed that most participants viewed the AT as relatively discrete and modern and that they reported how friends and relatives saw the AT as possibly useful for themselves, can be seen as examples of the AT not being stigmatising.

Previous research related to use and non-use of AT in general has acknowledged how people, not only the closest family, influence the goal setting related to AT (Karlsson et al. 2011; Louise-Bender Pape, Kim & Weiner, 2002; Wessels et al. 2003). The fact that people around them were considered to such a great extent during goal-setting indicates that behaving in a socially acceptable way and staying connected to other people are important factors for becoming users of AT and they are important considerations influencing the intervention.

The findings in studies 2 and 3 showed that set anticipated goals related to social gains such as maintaining social contacts and even enabling the social network to expand could be supported by the AT and this is of great value, since both stroke and

AD has a negative influence on social contacts (Carlsson et al., 2004; Holst & Hallberg, 2003). Other anticipated goals met by the AT were related to increased control, efficiency and safety and the AT could also reduce stress and worries in the tasks that enabled the performance of valued activities. These findings support previous findings from other intervention studies that AT can support increased safety and control (Cahill et al., 2007; Rasquin, et al., 2007). Further, the findings from studies 2 and 3 showed that the AT could enable the participant to regain former responsibilities and also convey courage to the participants to go to places and perform activities viewed as hazardous. These findings suggest that AT might have the potential to make a positive change to, for example, feelings of control, security and autonomy, which all are aspects acknowledged as commonly affected in early stages of dementia according to a review by Steeman et al. (2005) as well as in the event of stroke (Mukherjee, Levin & Heller, 2006). Also persons who experienced fear of being a burden (Clare et al., 2005) could be positively affected to some extent according to findings in studies 2 and 3. The new feelings of being capable, proud and courageous which were reported by some participants indicate that AT also has the potential to empower its users. One experience from the interventions in the present studies was that a number of participants were hesitant to try the AT due to their belief that they were not capable of using it and that they were sometimes encouraged to try the AT when they heard how other persons had benefited from their use of it. These findings might possibly be of use by clinicians in encouraging clients to try AT. There might be a positive value in this if the potential user is knowledgeable that other people in a similar situation have used it and benefited from it.

### **5.1.2 The engagement of family members**

The second aspect of importance that contributed to becoming a user of AT in the present studies was the engagement of family members. Their importance has been acknowledged in previous studies focusing on AT provision (Dawe, 2005; Kintsch & DePaula, 2002; Larsson Lund et al., 2011; Louise-Bender Pape, et al., 2002; Nochajski, Tomita & Mann, 1996; Rosenberg & Nygård 2011; Wessels et al., 2003; Wielandt & Strong, 2000).

Family members, in studies 2 and 3 as well as in previous research (Kintsch & DePaula, 2002; Nochajski et al., 1996; Rosenberg & Nygård, 2011; Wessels et al., 2003; Wielandt & Strong, 2000), were often involved, to some extent, in the decisions

made concerning choosing the AT solution. They were even more actively involved by encouraging the participant to use the AT and also in customising the AT. This type of involvement has also been acknowledged in previous research (deJoode et al., 2010; Kintsch & DePaula, 2002; Larsson Lund et al., 2011; Wessels et al., 2003; Wielandt & Strong, 2000). Less acknowledged, however, has been how significant others can take a very active part in the development of the family's routines for enabling the use of AT, which was demonstrated in studies 2 and 3. Their deep involvement made a very crucial contribution at this important juncture for the participants to become AT users and should be highlighted since routines can be viewed as “...*a necessary pathway, through which persons find their way back to the participation in everyday activities...*” (Kielhofner, 2008, p. 59). Since routines are of great importance in getting back to participation in everyday activities it would be very beneficial if clinicians could support significant others who want to take part in this process, by advising and discussing with them, together with the potential user of the AT (the person with cognitive impairment), how these routines could be formed, given that the potential users of the AT see their family's involvement as positive.

In the present studies, the significant others were actively involved, in terms of discussing solutions and taking action, in all eight themes presented in study 4 as being important for the use of the AT. The findings showed clearly, for example, that the significant others' part in enabling the use of AT connected to the Internet or the mobile network cannot be overestimated. It was evident that AT connected to the Internet or the mobile network increased the necessity for the significant others to be a link to the world outside due to the complex tasks that arose in terms of e.g. checking the AT signal or filling up the mobile phone account with money. It is of great importance that clinicians consider this need for extra support and extra efforts from the significant others when planning for provision of support.

As findings in study 4 showed, the significant others' involvement can be both considerable and can be related to many areas that influence the AT use, even areas which the primary user - the person with cognitive impairment - does not come in contact with to any significant extent. These findings imply that the AT should not only suit the user who has a cognitive impairment. It is important to consider that a prerequisite for the primary user to achieve set goals is that issues of usability for the significant others are also considered in the design and implementation of the AT, for example enabling them to customise the AT. It is not unlikely that the significant other is relatively old and thereby has limited eyesight, hearing and dexterity and might also

have limited experience of using new technology, and these aspects have to be accounted for when designing and customising products for this user group.

### **5.1.3 The influence of trust**

The third aspect of importance that contributes to becoming a user of AT was elicited particularly in studies 3 and 4, and is related to trust and safety. In the eight themes in study 4 that represented different areas of importance for the use of the AT, there were a significant number of features that could impede the task performance such as, inappropriate design of buttons or limited mobile phone signal. The findings clearly showed that the influence of these impediments affected the users' trust in the AT which in a next step could jeopardise the use of the AT. For example, when the AT on occasion did not deliver the anticipated support, there was a risk that the user was hesitant in trusting it, and, in a next step, stopped using it. The distrust in a specific feature of the AT could result in restricted use of it which made it less useful.

The importance of trust was emphasised by some participants in study 3 who described how their dementia disease increased the need to be able to trust in the AT working as planned. This need to trust the AT might be related to how other participants, both in studies 2 and 3, described that they had become dependent on their AT. It might be possible to explain their views as it being necessary to be able to rely on the item you have become dependent on to feel safe and in control.

Their experiences might be connected to how Lawton and Nahemow (1973) described how people with impaired competencies have been acknowledged as especially sensitive to their environment, and in this case, the AT is both a part of the environment and a tool with which to handle the environment.

Previous studies found concerning the process of becoming users of AT in general do not address the issue of trust (Kintsch & DePaula, 2002; Ripat & Stroock, 2004). It could possibly be the case that persons with cognitive impairment fear that they cannot solve problems that might occur when the AT does not work as planned, both when it comes to accomplishing the task it should have been used for, and to arranging for the AT to be repaired. The findings support previous research which viewed reliance on the AT, e.g. related to the risks of faulty or unsafe AT or that it did not function as predicted, as reasons for non-use, according to a review by Wielandt and Strong (2000).

Some of the AT was intended for the provision of safety to the user. There were two situations identified in the findings in study 4 that were of importance when estimating how the AT could provide safety and thereby prove its usefulness.

One situation identified, showed how the lack of indication from the AT that it was faulty or less able than anticipated (such as having a low signal for the mobile phone), enhanced the risk that the participants thought they were safe but in fact they were not. This scenario can be explained as a person having a high sense of safety in that he /she thinks that everything is under control, but the actual degree of safety can be low since the AT displaying information related to safety is faulty. This hazardous false sense of safety has been described previously in relation to AT provision (Boman, 2009; Starkhammar & Nygård, 2008).

It was also evident that a contrary situation could occur as well, that the participants' actual degree of safety was high, since e.g. the cooker was turned off, but their sense of safety was low since the AT that reminded about turning the cooker off, did not provide information concerning home surveillance on a mobile display and therefore they could not retrieve information about the cooker when they were out. This situation can lead to stress and worries.

In both these situations it is likely that people behave in a way that is logical to their perceived and not to their actual degree of safety, as provided by the AT.

These findings stress the need to take both the *actual safety* and the *sense of safety* into consideration. Even if actual safety and sense of safety can both be achieved separately this is often less beneficial in terms of either increased worries or increased danger, which decreases its usefulness. If both actual safety and sense of safety are accounted for when designing and providing AT, which has been the case in some AT solutions, this would decrease both worries and danger. To accomplish this it is crucial that AT proposed to increase safety is designed to provide the information asked for in relevant contexts of use, that faults or decreased capacity should be indicated to the users and of course, that it is reliable.

#### **5.1.4 Assistive technology in a future perspective**

Findings from the four studies included in the thesis and findings from other studies show that technology can support persons diagnosed with AD or stroke in the future both when the support comes from products specially designed for persons with cognitive impairment (e.g. Boman et al., 2010) or from mainstream technology (e.g.



Lindén et al., 2011). Irrespective of what type of support product it is of value to identify the prerequisites when considering the future provision of AT, as has been elicited in the present studies.

Firstly, the product itself of course plays a crucial role in whether the AT solution can support the user to achieve the anticipated goals. However, according to findings in study 4, other components in the solution, such as how the AT is introduced, installed, customised and maintained are also of a very high significance in order to make the AT solution work. The quality of those components is directly influenced by how professionals or other people involved are able to prepare for the use of the AT in the person's context. Since the quality of the support provided by the AT is very reliant on those components and, in some cases, they are even a prerequisite for the use of the AT, it might be fruitful for companies that focus on cognitive support, to view the product itself as a part of a package that should include solutions not only for installation and modification, but also for how to introduce the AT to a user with limited cognitive capacity both in relation to the use of its services and in relation to customising it. It might also include an introduction to persons with limited technological knowledge (as a user with cognitive impairment or an elderly significant other). For example, manuals for the target group were asked for in study 4 and also previously (Lundberg, Sandström & Keijer, 2006; Mallenius, Rossi & Tuunainen, 2007).

The extra service of related support, prepared by the product companies and administered by, for example, occupational therapists might be the one factor that distinguishes solutions of AT for cognitive support. Focusing on the variety of potential users in the process in this way, that is, having a user-centred approach not only in terms of the design of the actual product but also for the surrounding support, would probably increase the usefulness of the AT and include more user groups, which is in line with the concept of inclusive design (Coleman, 2000; Keates et al., 2006).

One way of applying a user-centred approach in the design process is to involve the users in e.g. identifying unsatisfied needs in the technology, as suggested by Essén and Östlund (2011), in this case, perhaps also in the surrounding support.

When mainstream technology is provided, the experiences from the two interventions imply that there is an increased risk that the surrounding support is not taken into consideration by the production company, which might increase the need for a greater effort during the implementation by the user, the significant others and the professionals, e.g. the occupational therapists. If the future brings a greater focus on

inclusive design for mainstream technology in general, it might be possible to reduce the effort for those involved.

The second prerequisite elicited in the present studies that influences whether the AT will be used or not is related to the person's values, goals, underlying capacity and the social and physical environment, which are of importance in guiding all occupational choices (Kielhofner, 2008). This can be illustrated in studies 2 and 3, in which both the AT itself and the context of use made demands on the participants. The participants were motivated to make an effort to adjust to the AT and the context in order to make use of the AT, often together with a significant other.

Further, most of the participants in the studies included in the thesis were able to perform their valued activities. Their need of AT was instead related to initiating the activities or feeling safe enough to perform them. The AT appeared to become a type of facilitator, which has been described by Öhman and Nygård (2005) as a key, that is, a crucial factor in the context that creates opportunities for and facilitates the performance of valued activities.

Related to those findings and to previous research, (e.g. Scherer, 2012; Wessels et al., 2003); there are reasons to suggest that having the cognitive abilities needed, being motivated and being surrounded by supportive persons is paramount in the use of the AT, and further, that the usefulness of the support is highly dependent on e.g. how the individual's goals, desires and abilities are taken into consideration in the AT provision process and during the continued use of the AT at follow-ups. How these significant, promoting aspects are possible to combine with the expectations from society of increased safety, decreased costs and increased effectiveness might be an important issue for future research.

It is also important to consider that according to study 1 and to previous research (van den Heuvel, Jowitt & McIntyre, 2012; Lauriks et al., 2007), there are important tasks or activities that cannot be supported by any AT today. There is continuous technological development and many of those longed for AT solutions exist now or in the near future. There are, however, still tasks or activities that seem difficult to support due to their more complex structure, as for example, activities connected to maintaining a social life or connected to running a household, which were identified in study 1. There have been attempts in the research of a more experimental design (Lancioini et al., 2010; LoPresti, Simpson, Kirsch, Schreckenghost & Hayashi, 2008) to support e.g. activities which

include many tasks or steps, such as preparing food. No studies have been found, however, that show whether that type of support has been useful to a user in the everyday life. However, we did not earlier foresee all the AT solutions we have today, and what solutions there will be in the future are as hard to predict. Hopefully, this thesis has provided some new knowledge within the field and thereby increased the possibility for future AT to become more usable and useful for the users with cognitive impairment and their families.

## **5.2 DISCUSSION OF METHODOLOGY**

The studies all adopted an explorative approach to contribute new knowledge for a better understanding of how a person becomes a user of AT. The most important findings from the studies can serve as ideas for further testing and refinement in new intervention studies focusing on the use of AT in everyday life, and in the practice field of AT provision to persons who experience cognitive impairments. For example, it was shown that to become a user of the AT it was of great importance that the task intended to be supported by the AT is not solely identified as difficult, but is also connected to a valued goal that the potential user has a desire to achieve. That is, the AT should enable the person to achieve the goal, not only to perform the task. The importance of considering the social and physical context from the perspective of the user in a wide sense when making decisions about the AT was also illuminated. Two crucial factors were identified: the significant others' efforts to enable the use of the AT (in terms of either preparing the AT use or supporting routines connected to it) and the matter of trust in the AT (in terms of predictability and reliability). The questions for the "Assistive Technology Process" in study 1 might be supportive when modifiable, context-aware AT is provided and the eight themes identified in study 4 might be useful in avoiding obstacles during the implementation of AT for cognitive support in general. During the first period of time after the provision of AT it might be helpful to consider how to support the users as purposefully as possible at the significant junctures identified in study 3. There is, however, a need to look further into the transferability of the findings, considering the small sample.

In the studies included in the thesis it was seen as crucial to capture the experiences of the actual users, both regarding the participants who had cognitive impairment and their significant others. To allow especially the participants to describe their thoughts in a conversational way (Nygård, 2006; Hubbard et al., 2003), the interviewer asked as

concrete questions as possible during the interviews and more abstract questions were followed up by pragmatic questions. In some cases, the questions were reshaped by the interviewer or the significant other to suit the specific participant during the interview. This way to reshape questions during the interview was however not optimal. There was a risk that the questions unintentionally captured another aspect than planned. Since e.g. the participants who had aphasia provided important information with gestures and face expressions, thorough field notes which included information retrieved from gestures and facial expressions were written directly after the home visits. The discussed AT was always present during the interviews to facilitate the conversation and to remain focused on the subject (Nygård, 2006).

Other difficulties related to the interviews, which could reduce the amount of data or jeopardise its quality were for example, the participants' difficulties in recalling important information. It was sometimes possible to discuss the subject later on and at that time capture the information, or, the participant could turn to the significant other for memory support.

There were occasions when a participant could respond in a way that the interviewer perceived as somewhat arbitrary or impromptu, and the interviewer became uncertain whether the answer was actually grounded in the participant's opinions and experiences. To overcome this uncertainty, the interviewer asked probing questions in order to further investigate the opinions and experiences. When it was difficult to grasp how the participant had retrieved the opinion, the answer was treated as less valid until the participant provided richer information, perhaps in another interview.

To collect data by interviewing persons with cognitive impairments has become more common since the 1990s (Beard, 2004) and the previously described risk of acquiring less valid data has been modified. Today, research has shown that experiences related to the person's own state of well-being or regarding quality of life can be viewed as valid (Sands, Ferreira, Stewart, Brod & Yaffe, 2004). Interviews with persons with dementia, alone or with a significant other, have, for example, been conducted in a study examining technology use in everyday life (Rosenberg, Kottorp, Winblad & Nygård, 2009).

In the present studies, there were a number of interviews conducted with both the participant and the significant other present at the same time. This way of interviewing has been discussed as diminishing the possibility to let both persons speak freely (Pesonen et al., 2011). The presence of a significant other has on the other hand been

viewed as a way to provide a safe climate which promotes an open and sincere interview (Pesonen et al., 2011) and provide the most valid data (Rosenberg, 2009). The general experience from present studies is that the significant other lets the participant speak freely about his/her experiences, and the significant other could provide his/her view as well. The discussion between the two often enriched the data expressing experienced needs and use of the AT and the usability and usefulness of it. It was also a natural possibility for them both to comment on the other person's opinion (Pesonen et al., 2011). Some significant others and participants informed the interviewers after the interview if there was something specific they wanted to add in private to the interviewer. There were cases, when it was not suitable to have joint interviews, for example when the interviewees started arguing and both parties became very upset. A few interviews during the present studies were held separately for this reason.

The studies in the thesis are based on the idea that semi-structured interviews, in parts based on well-acknowledged assessments and additional questions designed for the studies would ensure that difficulties in everyday life would be possible to identify, and that the design would be the most suitable way to retrieve information for that purpose. The intention was to invite the participants to talk about activities and tasks that were experienced as problematic and still of great importance to them. Based on the aims of the research, difficulties that could have been identified in observations, but not judged as problematic by the participant or the significant other, would not have been of importance to address in an intervention. Nevertheless, informal observations were made and included in the field notes that were kept in the studies, for example, when the AT was to be introduced and customised.

The design of the study required that the researcher was involved in all stages of the interventions in nearly all of the cases, first of all, in the identification of difficulties, and secondly, in the judgments about the match between the identified difficulties and the AT. Further involvement was also needed in the implementation and the follow-up interviews. There is always a risk that this design, where the researcher is engaged in the intervention will affect the findings (DePoy & Gitlin, 1999). For example, the participants might have felt that they should be grateful for the AT and therefore only wanted to express positive opinions about it. In order to reduce that risk, the researcher was extra cautious about asking the participants to explain, in detail, when they recounted something positive about the AT or the intervention, and through those

questions identify grounds for the opinion. Negative experiences were also explicitly asked for, explained to the participants as being an important part of the research. The fact that the author had previous knowledge of the intervention and the AT also had some advantages. For example, the author knew about previous technical problems with the AT and could ask initiated questions about the difficult situations, which enriched the data.

It is difficult to assess to what extent the involvement of the researcher had an impact on the use of the AT but, according to theory, it is very likely that it had a beneficial effect. The personality of the researcher as well as the overall communication between the researcher and the participants are also examples of aspects that might have influenced the studies according to Kvale and Brinkman (2009).

In one of the projects (P2), there was a second interviewer involved. The second interviewer could not be as initiated as the person who had been involved in the implementation of the AT. That situation turned out to be advantageous in one respect; the participants often explained more thoroughly how the AT worked and how it was used, since they knew that the second interviewer was less initiated. These descriptions showed how the AT was understood by the participant and made important contributions to data.

From the experiences of the studies included in the thesis it is evident that choices are influenced by a number of people at different stages. There is a need to further examine how the decision making should be performed in order to assure that the person's own desires, needs, goals and abilities in relation to their physical and social context are fully taken into consideration. To entirely leave the person with cognitive impairment to make their own choices about future AT seems neither constructive nor ethical. To decrease stress and confusion, there is a need to provide processed information about for example AT solutions for the person to consider. How this information should be processed and presented to enable the most informed decision must however be further examined.

The specific products chosen for AT support had a great impact on some findings in the present studies. Even if the intention was that the participants were to be the ones that chose the AT, there were a number of aspects and persons that influenced their choice. It is therefore of importance to further discuss how the decisions related to the choices of AT might have influenced the findings.

First of all, the research team - including two registered occupational therapists (one of whom was EL), a senior researcher in the field of occupational therapy, and a consultant researcher from the Royal Institute of Technology KTH - assessed whether the tasks identified as difficult were possible to support either with the specific AT in focus (for P1, AT included in studies 1, 2 and 4) or with any AT available on the market (for P2, AT included in studies 3 and 4). The research team strived to find suitable AT solutions for the difficulties identified but it is still possible that another AT solution, which might have been useful in the situation, was unknown to the research team. There is also a risk that the AT in question was falsely judged as possible or not possible to support the task in target. This could have affected the data, since a less adequate match between the AT and the user might influence e.g. whether the AT is used or not (Wessels et al, 2003, Scherer & Craddock, 2002).

To enable an informed choice the research team assessed the participant's abilities in relation to the skills needed for a specific AT. The assessments were based on observations and conversations with the participants, on experiences of and general knowledge about cognitive impairments in stroke and dementia and, finally, on the functionalities of available AT, and they were conducted by one researcher (EL) with at least 15 years of experience as an occupational therapist with support from the rest of the team. AT solutions that were judged as possible for the participant to use were then introduced to the participant.

Still, there is always a risk that the judgments made by the research team were based on inaccurate or deficient information or that the research team made the wrong judgments. However, there were very few alternatives for each task and the reason for one choice instead of the other was often evident, as for example, when a participant could not read a clock but could understand if the time was presented vocally.

The participants made their choices with more or less support, advice and encouragement from the significant others and the research team. Reluctance related to whether the participants found it worth trying AT, whether they needed the AT or if they were able to make use of the AT available. In those cases the researcher tried to convey the feeling that the participant deserved this opportunity and that the participant was capable enough to give it a try. The possibility to try the AT for some time and thereafter make a decision to not use it was repeatedly explained. To a certain extent, this approach can have influenced some participants who would not have tried the AT otherwise but hence did so. When the participants wanted support in choosing one of two AT solution alternatives, the research team or the significant other could

recommend the participant what to choose in relation to previously discussed desires and abilities or have a new discussion to illuminate information that was of importance for the choice. The modifications were made in the same way: either decided by the participant alone or with support from their significant other and the research team.

The intention was to have a heterogenic group of participants, and this intention could be attained in terms of sex and age among the participants. The proportion of highly educated persons in the participant group was, however, high. Even if it was not directly shown in the findings, a participant's high level of education might have affected his or her greater motivation to use the AT and that he or she could make use of the AT, despite severe cognitive impairments (Roe, Xiong, Miller, John & Morris, 2007). The fact that all participants were born and raised in Northern Europe limited the studies, since it was not possible to capture opinions or experiences derived from other cultural backgrounds.

### **5.3 ETHICAL CONSIDERATIONS**

The ethical considerations in these studies were mostly related to the risk of violating the safety, the integrity, the autonomy and the self-esteem of the participants.

The most delicate aspect of safety in the studies was the conflict between the participants' wish to be safe and their wish to become more independent and free when using AT as support. In some cases, the participant's expectation of the AT was that activities that were judged by him/herself or the significant other as too risky to perform without any support should be possible to perform with support from the AT, as for example, activities related to outdoor orientation. The wish to use the AT to allow a freer everyday life and the risk associated with instable AT has been reported previously (Melander-Wikman, Fältholm & Gard, 2008; Robinson et al., 2007). To avoid increasing the risks, the perspective of the researchers before the intervention was that the risk when using the AT should not exceed the risk the participant normally took, which has previously been suggested as a guideline (NEAC, 2008). However, when the AT had been shown to be a support for the participant for a period of time, both the participant and the significant other started trusting the AT, which made them take greater risks than before, for example, when one couple knew that they would be able to get in contact with each other, the participant could go out on his own. To avoid



violating the safety of the participant, regular discussions about the risks were held within the research group and between the researcher and the participants/significant others. When the products were too unreliable they were removed or exchanged for a more reliable alternative. To withdraw the AT when it worked as planned to decrease the risk of e.g. getting lost was not seen as an option, since the AT had become a necessity in some participants' lives. The fact that withdrawing products used in interventions can be ethically inappropriate has been acknowledged in previous intervention studies (Magnusson & Hansson, 2003).

This situation illustrates one reason why it is important to have an ongoing discussion between the users (the person with cognitive impairment and the significant others) in order that they are aware of the risks they take when they extend the use of the AT and, further, that the pair have a plan to ensure safety if something goes wrong. Above all, it is important to avoid threats to safety and therefore it is necessary to assess the match between the users and the AT recurrently. The AT should also be very reliable at all times in the relevant contexts of use (Boman, 2010; Brebner, Brebner & Ruddick-Bracken, 2005; Lansley, 2001;).

The risk of violating the integrity of the participants has been acknowledged in previous research (Zwijssen, Niemeijer & Hertogh, 2011). In the studies included in this thesis there were some aspects that could have an impact on the integrity. One example in study 3 shows how a significant other could be informed about the participant's location without asking, with the support of a GPS position retrieved from the AT. The participant in this specific case was highly aware of this functionality and positive towards it. He felt safe when he knew that his wife could get the information. The opinion that the need of support overrules the risk of violated integrity or privacy has been reported in previous research (Melander-Wikman et al., 2008; Robinson et al., 2007). The tracking devices have also been suggested as increasing autonomy, since the user can move around more freely outdoors (Melander-Wikman et al, 2008; Robinson et al., 2007).

Another example from the studies that could have violated the participant's integrity was in the case when the AT, via the mobile network, conveyed information from sensors that monitored motions in specific areas, which can be referred to as violating "informational privacy" (Hensel et al., 2006). This information was not inspected by the researchers since it had no bearing on the aim of the study, but nevertheless, this information could reveal whether the participant was home or not. By using any type of

network for sending information, there is a minimal but nonetheless real risk that the information can get into the wrong hands, and can be used for criminal actions, like burglary. In this case, the AT company had taken precautions to reduce the risks by limiting the access to the computers in the participants' homes to a few administrators, using a login solution with high security.

The risk for a person with cognitive impairment to experience that their autonomy is violated in the everyday life is not unusual (Hägström & Larsson Lund, 2007; Steeman et al., 2005) and the risk for that to happen during research has also been acknowledged (Hubbard, 2003). The design of the studies included in this thesis required the participants' active involvement in e.g. the decisions regarding what AT to use and how to modify it, which could be viewed as influencing the autonomy positively. The more complex the AT, however, the more delicate was the task of involving the participants in parts of the decisions. The researcher tried to be responsive and to capture to what extent the participants wanted to be involved or managed to be involved in terms of stress and fatigue. There were occasions when the participants explicitly said that they did not want to be involved in parts of the process since they were perceived as stressful. This standpoint was of course respected and, in those cases, the significant others took a greater responsibility for the solution and the participants were informed on a need-to-know basis. The same approach was used when the research team gave instructions of how to use the AT; the participant was asked how much information he or she wanted to receive and to what extent he or she wanted the significant other to step in instead. With this approach, the research team intended to decrease stress but nevertheless promote autonomy for the participants.

The last issue for ethical consideration is related to the risk of violating the participants' self-esteem. It was most evident during the execution of the MMSE (Folstein et al., 1975) and this situation has been recognised in previous research (Hellström, Nolan, Nordenfelt & Lundh, 2007; Pesonen et al., 2011). Some of the participants and their significant others had very negative perceptions of the MMSE and became sad during or after the examination. It can be viewed as very stressful to be exposed to the MMSE and once again have to be confronted with one's short-comings, especially in one's own home. To reduce the necessity to perform a MMSE in the home, the participant was asked whether they permitted that their MMSE results were retrieved, when possible, from the memory investigation clinic instead,.

## 5.4 CONCLUSION AND IMPLICATIONS

The findings in the thesis provide new knowledge about how a person, who experiences cognitive impairments due to a stroke or a dementia disease in the early stage, becomes a user of AT. This knowledge can be of use in the provision of AT for cognitive support and for future research.

The findings showed the importance of having a user-centred perspective, also in terms of the social and physical context when planning for the provision of AT to the potential user. The findings suggest that the focus of the intervention should be on desired, highly valued, activities, both at the decision-making and as an outcome measure.

In the findings, the significant others were identified as a crucial factor for some persons to become users of AT. Their involvement can mean the difference between a useful or useless AT in terms of goal-achievement. Since they can have such a crucial role, and since according to the findings both the user and the significant others can benefit from the use, it is suggested that they should be invited to be active agents in the intervention together with the user.

The usefulness was also shown to be closely related to the matter of trust and sense of safety. To enhance the possibility to provide trustworthy and consequently useful AT, it is of importance to identify and solve problems related to impeding features in the AT that jeopardise the senses of trust and safety.

To conclude, the way towards becoming a user of AT was not always straightforward. In some cases, considerable effort was involved and in other cases, there were obstacles connected to the interaction with the AT in its context that had to be solved. However, when considering the findings that show how the AT could empower the users, enable them to perform valued activities, and increase their sense of control and safety, it is obvious that the cost of not trying can be much higher than that related to giving the AT a chance. Only the potential user and his/her family can make that judgment.

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