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Navigating in a changing world:

Experiences of everyday life from the perspective of persons
with cognitive impairment or dementia

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ABSTRACT

The overall aim of this thesis was to enhance the knowledge of how people with cognitive impairment or dementia experience, approach, and manage the consequences of illness in the context of everyday occupations. Listening to the subjective experiences of people with cognitive impairment or dementia, who live in their own homes, can generate a deepened knowledge of their living conditions. This knowledge might support occupation-based interventions contributing to the well-being of people with dementia.

The thesis includes four studies. The participants were persons with cognitive impairment or dementia. **Study I** focused on nine persons' work situations and the attitudes of seven workplace respondents. In **Study II**, the motives and meaning of everyday occupations of six persons with Alzheimer's disease were explored. In **Studies III and IV**, awareness of dementia in the context of occupations was investigated from two perspectives. These were the use of a phenomenological approach to the lived experiences of six persons with AD, and measurement of the relationship between occupational performance and awareness of disability in 35 older adults with cognitive impairment, AD, and other dementias. **Studies I-III** used qualitative interviews and observations that were analyzed with a constant comparative method (**Studies I-II**), and a phenomenological method (**Study III**). In **Study IV**, data were collected with the AMPS and the AAD and analyzed with descriptive, nonparametric statistics.

The findings in **Study I** showed that the possibility of remaining at work seemed to depend on multiple factors, including the individuals' apprehended ability to work and the length of the sick leave. A great variety of personal motives and meanings of everyday occupations were found in **Study II**. Identifying and supporting these occupations might contribute to the well-being of persons with AD living at home. A structure of awareness of disability was described in **Study III** with two main characteristics. These were discovering and managing changes in occupational and social interactions, and reflecting on a changing life situation. The results of **Study IV** showed a positive relationship between occupational performance and awareness of disability, where participants with AD were less able and less aware than participants with MCI. However, there was a large variation in awareness of disability within the diagnostic groups.

In conclusion, the findings of these studies showed that everyday occupations held a variation of individual meaning for the participants, and provided them with an important arena for experiencing and expressing changes. Supporting persons to continue with occupations of individual meaning for as long as this is experienced as beneficial by the person with dementia was highlighted as an important task in care. Their perceptions of changes in everyday occupations were intertwined with their experiences of being ill, but their understanding of the illness was difficult to integrate with the changes they experienced. Furthermore, the findings showed that people with dementia may be sensitive to other peoples' perceptions of them. This might be of importance in their own views of their situation, and hence significant for how to approach persons with dementia in clinical practice. Finally, a multidimensional approach using both interviews and measures is suggested to capture awareness in people with cognitive impairment or dementia.

Key words: activity, dementia, occupation, occupational therapy, work, awareness of disability

LIST OF PUBLICATIONS

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

- I. **Öhman, A.**, Nygård, L. & Borell, L. (2001). The vocational situation in cases of memory deficits or younger-onset dementia. *Scandinavian Journal of Caring Sciences*, 15, 34-43.
- II. **Öhman, A.**, & Nygård, L. (2005). Meanings and motives for engagement in self-shosen daily life occupations among individuals with Alzheimer's disease. *OTJR: Occupation, Participation and Health*, 25 (3), 89-97.*
- III. **Öhman, A.**, Josephsson, S., & Nygård, L. Awareness through interaction in everyday occupations: experiences of people with Alzheimer's disease. Accepted for publication in *Scandinavian Journal of Occupational Therapy*.
- IV. **Öhman, A.**, Nygård, L. & Kottorp, A. The relationship between occupational performance and awareness of disability in older adults with cognitive impairment or dementia. Submitted.

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ABSTRACT

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INTRODUCTION

".....everyone grows old eventually, even if this is rather early. And I don't know, I would like to hear about,.... But how sick are you when you have this [talking about Alzheimer's disease]? It's so difficult to be healthy and still being sick."

["..... det är ju klart att alla åldras ju till slut, även om det är ganska tidigt. Och jag vet inte, jag skulle vilja höra,.... men hur sjuk är man när man har sånt här? Det är ju så väldigt svårt att vara frisk och ändå vara sjuk."]

This quote illustrates the point of departure for this thesis, which is an endeavor to shed light on some of the experiences of dementia from the perspective of those actually living with it. The quotation is from a research interview with a man in his 60s, who had been diagnosed with Alzheimer's disease a couple of years before. He lived at home with the support of his family, still maintaining his routines and interests in daily life but with limited possibilities to practice them due to the progression of the illness. He was well aware of his condition but had a hard time incorporating this knowledge with the way he depicted and perceived himself. In his mind, he was still the same man as he had always been, but now with a strange and intrusive illness that made the world sometimes appear to be changed, and he tried to navigate in this world where even the simple tasks of everyday occupations were a challenging to him.

This thesis explores the experiences of living with impaired cognition or dementia from the perspective of the person, and the consequences to everyday life occupations brought about by the illness with particular focus on the occupational dimension. The thesis incorporates different aspects of the persons' everyday life with this condition, such as everyday occupations, work, and social interactions. The studies aim to broaden the knowledge about persons with cognitive impairment or dementia by including their perspective in research, from the standpoint of occupational therapy. In the early 90s, Cotrell and Schultz (1993) suggested that the perspective of the person with dementia was a neglected field of dementia research. Since then, a growing body of literature has emphasized the importance of including the subjective experiences of persons with dementia in research (Hughes, Louw & Sabat, 2006; Kitwood, 1997a). Turning attention to the persons' own experiences is expected to

generate a deepened knowledge of the living conditions of people with dementia that might support the development of supportive interventions, particularly in the early phase while they still are living at home. By juxtaposing different perspectives and methodologies, this thesis has the ambition of contributing to this growing body of knowledge. Before turning our attention to the issue in focus – that is, how people with cognitive impairment or dementia experience, approach, and manage the consequences of their illness – some medical conditions need to be clarified.

COGNITIVE IMPAIRMENT AND DEMENTIA

The past two decades of extensive research have expanded the understanding of cognitive impairment and dementia and provided important knowledge on the origin and course of the diseases as well as advances in early detection and advances in medical treatments (Overshott & Burns, 2005; Yaffe, 2005). To get a comprehensive picture of cognitive impairment and dementia, a brief overview of the magnitude of occurrence and course of these is given in the following.

Dementia is known to increase disability and mortality in the older population with an expanding need for support and a shortened life expectancy (Agüero-Torres, Fratiglioni & Winblad, 1998; Ritchie & Lovestone, 2002). The number of people with dementia diseases is considered to be growing and dementia is one cause of economic strain in healthcare in western countries with aging populations (Wimo, Jonsson & Winblad, 2006). The worldwide occurrence of dementia was estimated at about 27.7 million persons in 2003 (Wimo et al., 2006). In Sweden in 2003, the estimated number of persons diagnosed with dementia was between 110 000 – 140 000 (Socialdepartementet, 2003).

Today there is a consensus favoring early diagnosis of dementia diseases (Waldemar et al., 2007). Establishing a diagnosis has been found to be crucial for early support as it provides the person and his or her family with the information needed to adjust and take necessary actions (Husband, 1999, Robinson, 2000). Sets of diagnostic criteria are used to establish

diagnoses; commonly used sets are DSM-IV-TR (American Psychiatric Association, 2000), ICD-10 (World Health Organization, 1993) and the NINCDS-ADRDA (McKhann et al., 1984). The most common form of dementia is Alzheimer's disease (AD) (Cummings & Cole, 2002) with about 60 -70 % of the cases of dementia in older adults. Old age is the most important risk factor for AD (Mohs, 2005). Other types of dementia are vascular dementia, dementia with Lewy bodies, and frontotemporal dementia (Grossman, Bergmann & Parker, 2006).

Alzheimer's disease

Alzheimer's disease (AD) is a progressive neurodegenerative disorder that leads to cortical and subcortical dysfunction, resulting in a complex cognitive decline (Ritchie & Lovestone, 2002). The hallmark of AD is a gradual onset of cognitive deficits including memory impairment, aphasia, apraxia, disturbances in visuospatial skills and disturbance in executive functioning (such as planning and judgment) (APA, 2000; Cummings & Cole, 2002). The cognitive deficits cause impairment in social or occupational functioning and represent a significant decline from the previous level of functioning (APA, 2000; McKhann et al, 1984). Symptoms such as apathy and agitation become increasingly common as the illness advance. Cummings (2003) showed that depression symptoms were present in approximately 50% of AD cases.

Mild Cognitive Impairment

Mild cognitive impairment (MCI) has been in focus in research on aging and dementia during the past few years and is described as a clinical condition between normal aging and AD, not yet meeting the currently accepted criteria for AD (Petersen et al., 2001). However, in this thesis, *cognitive impairment* is used to characterize persons with cognitive impairments but not dementia as established through a diagnostic evaluation, the reason being that the thesis also incorporates persons diagnosed with cognitive impairment before the concept of MCI was clinically established. At the international First Key Symposium on MCI, the following general criteria for MCI were recommended: cognitive complaint not normal for age and not demented, cognitive decline (self and/or informant report and impairment on objective cognitive tasks and/or evidence of decline over time on objective cognitive tasks) and preserved basic activities on daily living/minimal impairment in complex instrumental

functions (Winblad et al., 2004). However, the criteria have been challenged to incorporate the possibility of changes in complex everyday life activities (Artero, Petersen, Touchon & Ritchie, 2006; Nygård, 2003). For example, IADL activities, such as money management, have been found to be impaired in people with MCI (Griffith et al., 2003; Pérès et al., 2006; Perneczky et al., 2006a; Toukko, Morris & Ebert, 2005). The diagnosis of MCI is used both clinically and in research and is looked upon as a risk factor for the development of dementia, but could also be stable or even regress (Visser, Kester, Jolles, & Verhey, 2007; Winblad et al., 2004). In spite of the abundance of literature on MCI, very little is known about the experiences of people living with MCI.

In this thesis, both persons with dementia in a mild to moderate stage (WHO, 1993), and persons with cognitive impairment or MCI are included, as the research issue is the experiences of everyday life occupations in people with these conditions.

DEMENTIA AND EVERYDAY LIFE OCCUPATIONS

Everyday life encompasses a variation of occupations that become increasingly difficult when having a dementia disease (APA, 2000; Hartman, Fisher & Duran, 1999). Familiar occupations, also referred to as instrumental activities in daily life (IADL), such as using the telephone, shopping for groceries, driving, or taking care of finances become gradually more difficult (MacQuarrie, 2005; Nygård & Starkhammar, 2003; Wild & Cotrell, 2003). A variation of spontaneous and planned strategies to manage everyday occupations are used by the person with dementia while he or she eventually becomes more dependent on support from a spouse or other people in daily life occupations (Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001; Vikström, Josephsson, Stigsdotter-Neely, & Nygård, submitted). Eventually, the ability to perform personal activities of daily life (PADL) will also be influenced, e.g., grooming and dressing (Leifer, 2003). The influence of dementia on caregivers and other people close to the person with dementia, such as children and relatives, leading to a strained situation, are also well documented (Chappell & Reid, 2002; Corcoran et al., 2002; Tindall & Manthorpe, 1997).

It is not clear when in the illness progression the very first occupational difficulties occur or when they can be identified through clinical assessments, but several studies show that changes in complex everyday activities can be observed or experienced before a dementia diagnosis can be established (Artero et al., 2006; Perneczky et al., 2006b; Toukko, Morris & Ebert, 2005). Some studies indicate that more complex occupations, such as work tasks, are influenced as one of the first indications of cognitive impairment (Reed, Cantley, Clarke, & Stanley, 2002; Robinson, 2000; Seidler et al., 2004). Most persons with cognitive deficits or dementia are elderly (i.e., over the age of 65), but about 1 % of them are under the age of 65 (Socialstyrelsen, 2003; Wimo, et al., 2003). The course of dementia in younger people is described as different in comparison to older people with dementia (Reed et al., 2002; Tindall & Manthorpe, 1997). Younger adults are more likely to be working, having a parenting role and be more physically able (Beattie, Daker-White, Gilliard, & Means, 2002; Reed et al., 2002). The diagnosis of dementia in younger people is described as more unexpected and hence, it could be perceived as more stigmatizing by the person when compared to having dementia in old age (Tindall & Manthorpe, 1997). Separate and specially tailored services have been suggested for younger persons with dementia and their caregivers, based on their special needs (Reed et al., 2002; Robinson, 2000; Tindall & Manthorpe, 1997).

In general, it has been made very clear that dementia has a decisive influence on the afflicted persons' everyday life occupations. Persons with cognitive impairment or dementia continue to live in their homes in spite of their increasing difficulties after receiving diagnosis, with the support from family. Currently there is no cure for dementia, but medical treatment may temporarily improve the symptoms and the performance of ADL/IADL (Kawas, 2003; Overshott & Burns, 2005; Ritchie & Lovestone, 2002). Non-drug therapies for dementia, including approaches such as music therapy, reminiscence therapy, memory training, reality orientation, and validation therapy, have been suggested as possible interventions to delay illness progression, to influence the symptoms of dementia and improve abilities (Gori, Pientini, & Vespa, 2001; Gräsel, Wiltfang & Kornhuber, 2003; Kasl-Godley & Gatz, 2000). However, such benefits of these non-drug therapies have not yet been proved (Gräsel, et al., 2003).

Occupational therapy interventions are another type of non-drug treatment, used to facilitate and support everyday life occupations in these persons and their caregivers. In the following, the thesis' theoretical standpoint of departure concerning occupations will be presented, as well as occupational therapy interventions for people with dementia.

OCCUPATIONAL THERAPY

Occupational therapy enables the clients to achieve their goals by helping them to overcome problems that limit their occupations. By that, they make a unique contribution to healthcare through the focus on the occupations of everyday life (Law & Baum, 2005). Therapy has the challenge of being the bridge between what has come before and what is to come when functioning in occupations is challenged (Hasselkus, 2002; Kielhofner, 1995).

Everyday occupations have a central position in occupational therapy and are defined as *the ordinary and familiar things that people do every day* (Christiansen, Clark, Kielhofner, & Rogers, 1995). Law, Polatajkon, Baptiste, and Townsend (1997, p. 30) defined occupations as *activities of everyday life, named, organized, and given value and meaning by individuals and a culture. Occupation is everything people do to occupy themselves, including looking after themselves, enjoying life and contributing to the social and economic fabric of their communities*. The definitions refer to what people do, and incorporate words of action (Hasselkus, 2002).

Moreover, occupation is not only everything we do in life, in terms of actions, tasks, activities, but also involves thinking and being (Law & Baum, 2005). Christiansen and Townsend (2004) stated that the terms *activity* or *task* are not synonymous with occupation; occupation is broader than either one of them. Whereas *tasks* or *activities* may fulfill specific purposes, occupations bring meaning to life (Law et al., 1997). This thesis accedes to the wider definition of occupation, as stated above. However, while the term occupation is used throughout the thesis, activity is sometimes used as this term commonly is in use in much literature on activities of daily living.

As the definition of occupation implies, what people do is not just about performance. Rather, occupational performance is the product of the dynamic relationship among persons, their occupations and life roles, and the environment in which they live (Kielhofner, 2002; Law et al., 1997). Through their occupations persons express who they are and the values they embrace (Law et al., 1997). In occupational therapy occupation is described as a basic human need and a determinant of health and well-being that develops and changes over a lifetime (Law et al., 1997). When illness or disability interferes with a person's ability to do things that are important to him or her, well-being can be diminished (Christiansen & Baum, 1997).

Given that dementia intrudes so extensively on performance of everyday occupations, knowledge of the occupational dimension of life with this disease seems to be necessary. From the point of departure presented above, knowledge about the mere ability to perform occupations is not enough when developing interventions in occupational therapy for these people: other qualities of occupations need to be taken into consideration.

SUPPORTING EVERYDAY LIFE OCCUPATIONS

In 1994, AOTA stated that occupational therapy can make important contributions to the care of persons in all stages of dementia by interventions aiming to maintain, restore and improve abilities, promote participation in activities, and to ease caregiver burden (American Occupational Therapy Association, 1994). The specific aim of occupational therapy for older people with dementia living in their own homes is to enhance and maintain independence in daily activities, their social participation, and quality of life (Steultjens et al., 2004).

Several authors have suggested interventions in addressing community-dwelling persons with dementia. Recently, Graff et al. (2006a, 2006b) showed evidence that occupational therapy interventions, with education for the caregivers, setting realistic goals, using adaptations of the physical environment, training compensatory skills and educational skills, can improve the daily performance, communication, sense of competence and quality of life for both the

person with dementia and his or her caregiver. Environmental interventions of adaptations combined with education for caregivers are also suggested to be effective in enhancing independence and sense of competence in both parts (Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001; Graff et al., 2003; Josephsson, Bäckman, Borell, & Bernspång, 1995). It is suggested that individualized occupational therapy interventions can improve quality of life for the persons with dementia, but also the quality of life for their primary caregivers (Dooley & Hinojosa, 2004). Intervention programs to support everyday occupations in both parts have been presented (Baum & Edwards, 2003; Gitlin et al., 2002; Josephsson, Bäckman, Nygård, & Borell, 2000; Miller & Butin, 2000).

Assessments of occupational performance can be used to provide baseline data in planning interventions, but also to measure how people fulfill their roles in various dimensions of living, according to Ottenbacher and Christiansen (1997). As the functional capacity often determines whether or not a person with dementia can remain living at home, a thorough and detailed assessment of the persons' intellectual, behavioral and physical functioning is needed (Robinson & Fisher, 1999). However, conclusions based on tests on memory and cognition is not sufficient to predict functioning in everyday tasks, as shown in several studies (Reed, Jagust, & Seab, 1989; Robinson & Fisher, 1996, 1999). To gain a comprehensive picture of a person's abilities, it is important to evaluate the ability to perform activities of daily living (Hartman, Fisher & Duran, 1999).

In summary, the management of ADL/ IADL has received much attention in research. The desired outcomes of interventions in the home have received less attention by researchers. Bamford and Bruce (2000) identified the desired outcomes of community care for persons with dementia and their caregivers by interviewing service users at a research center. They found that the desired outcomes of community care were related to quality of life such as access to social contact, access to meaningful activities, maintaining a sense autonomy and personal identity, as well as to service process outcomes such as feeling valued and respected and having influence on the help provided. Based on these desired outcomes, occupational therapy has the potential to contribute to these people's well-being, given the perspective outlined in this thesis.

Epidemiological studies proposed that engaging in activities can decrease the risk of developing dementia (Karp et al., 2006; Scarmeas, Levy, Tang, Manly & Stern, 2001; Verghese et al., 2003). Since the results have received much public attention, they seem to have brought the significance of occupations among people who are diagnosed with dementia and their families to the fore. However, the significance of participation in activities *when diagnosed with dementia* is another issue, one that is less addressed in research. Participation in activities has been suggested by several authors as important in the care of persons with dementia to maintain abilities and enhance well-being (Brooker & Duce, 2000; Buettner & Kolanowski, 2003; Nolan, Grant & Nolan, 1995; Pulsford, 1997). Even if the benefits of activities are emphasized in research and in clinical practice, evidence is scarce and theoretical frameworks are often lacking (Marshall & Hutchinson, 2001).

In favor of choosing activities with a specific fit for persons with dementia, the point of departure of using occupations in therapeutic practice should be activities with an individual meaning to the person, Hasselkus and Rosa argued (1997). Moreover, they stated that because meaning represents an invisible dimension in occupations, the only way to learn about the meaning of our clients and to understand their situation is to ask them, to listen carefully, and to take the time necessary to do that. This, they said, might be a way to provide a therapeutic experience that fits into the larger context of the client's life, and hence can be the difference between success and failure in a therapy program (Hasselkus & Rosa, 1997).

All in all, this literature suggests that several aspects must be considered when providing support to people with dementia and their caregivers in the home. One aspect concerns the potential of everyday occupations to enhance the well-being of people with cognitive impairment or dementia through their experienced meanings, which has been studied here. Thus, the findings of the present thesis might be a valuable contribution to occupational therapy for persons with dementia.

THE PERSPECTIVE OF THE PERSON WITH DEMENTIA

The dominating paradigm in the research of persons with dementia has been biomedical and that has been very successful in exploring the diseases' causes and effects, developing medical treatments, and for examination of cognitive function (Sabat, 2001). In the discourse of dementia research, criticism has been raised, claiming that this view tends to neglect social factors involved in the attribution of behavior and in the experience of the illness (Lyman, 1989), as there is a tendency here to explain and treat all symptoms and behavior as medical problems (Bond & Corner, 2001; Cotrell & Schulz, 1993; Lyman, 1989). Such a view is not suitable when studying the variety of ways in which the disease may affect the experience of the person with dementia as he or she attempts to navigate through a world of dynamic social interaction (Sabat, 2001).

However, during the past decades there has been an increasing interest in the perspective of persons with dementia, challenging the notion of a fading personhood and dementia as a "loss of self" (Downs, 1997; Kitwood, 1997a; Sabat, 2001). Firsthand accounts of the experience of living with dementia have appeared supporting the view that the person with dementia is not simply a passive victim of impairment, but rather an active individual that tries to make sense of and deal with what is happening, actively seeking meaning, responding, and attempting to act on what they experience (Sabat & Harré, 1992; Woods, 2001). Research has been done including the persons' own experiences, as well as biographical descriptions of the persons' own experiences. Friel-McGowin (1993) described her own travel into the experience of Alzheimer's disease. In another autobiography Bryden (2005) described her struggle when meeting the challenges brought about by her illness together with her family and how she continues to lead an active life to remain as well as possible for as long as possible.

As a backlash to the biomedicalization of dementia, Kitwood (1997a) highlight the need to first of all see the person with dementia foremost in research, but above all in dementia care. The person-centered approach exemplified above emphasizes the importance of understanding the person's experience of living with and managing the difficulties so that healthcare services can build on their abilities and needs (Gillies, 2000, 2001; Woods, 2001). In a recent study, Langdon, Eagle & Warner (2006) concluded that persons with recently

diagnosed dementia were very sensitive to the responses of others and were well aware that other people adopted strategies to protect them. In addition, they also wanted to be treated as normally as possible. Studies also suggest that people with dementia might need support in their understanding of their own condition (Phinney, 2002; Robinson, 2000). Several studies have described how persons with dementia strive to cope with the onset of dementia (Clare, 2003; Pearce, Clare & Pistrang, 2002; Phinney, Wallhagen and Sands, 2002), indicating that this is a particularly important phase where support seem to be needed.

Research in the fields of caring science and psychology have targeted different aspects of living with dementia, such as subjective well-being and quality of life (Woods, 1999; Zank & Leipold, 2001), coping strategies (Pearce, Clare and Pistrang, 2002), and identity preservation (Beard, 2004; Smyth et al., 2002), whereas research in occupational therapy has paid attention to the experiences of everyday occupations. For example, Nygård, Borell and Gustavsson (1995) found that images of the occupational self in a changing occupational life could be demonstrated in different ways, and that these images provided a means for others to understand these persons' management of changes. Everyday occupations have also been found to offer a possibility to rest from the threat of dementia by engaging in individually chosen occupations (Nygård & Borell, 1998). Josephsson (1994) argued that everyday occupations could create an alternative meeting-place between the person with the dementia and the spouse, providing social interaction and meaningful communication in doing of things together. These findings raise the thought of other possible meanings of occupations that are individually self-chosen. As this may be important when using occupations therapeutically, further studies are needed.

Several authors have emphasized the importance of considering the perspective of the person with dementia in research and there is a growing body of knowledge of how dementia is experienced as expressed by the person with the illness (Downs, 1997; Marková, Clare, Wang, Romero, & Kenny, 2005). The specific problems of recollection and communication in persons with dementia might have contributed to the common exclusion of the persons themselves in dementia research (Bond & Corner, 2001; Hubbard, Downs & Tester, 2003). Qualitative research approaches have been suggested as a way to involve people with dementia. Kitwood (1997b) suggested several ways to get access to the subjective world of

dementia, through written accounts by people that have dementia, and through interviews, and listening to what people say in their everyday lives. Several authors point out that using a combination of interviews and observations with persons with dementia (Nygård, 2006, Hubbard et al., 2003; Sabat, 2003) provides a way to give voice to the subjective experiences of persons with dementia. However, when seeking ways to access the experiences of people with dementia, the issue of their awareness is highlighted. This is the issue discussed in the following section.

AWARENESS IN DEMENTIA

As discussed above, knowledge on the perspective of the person of dementia has developed during recent years, with the emphasis on bringing out the person's own perspective. However, as people with dementia generally are known to have increased awareness, this concept deserves some attention.

Commonly, unawareness of impairment or deficits is described as common in patients with Alzheimer's disease and dementia (Kazui et al., 2006; Mullen, Howard, David & Levy, 1996) and also in mild cognitive impairment (Onor, Trevisol, Negro & Aguglia, 2006; Vogel et al., 2004). An extensive field of literature concerning persons with dementia shows that the phenomenon of awareness is complex. Different terms and definitions are used in literature relating to *awareness*. Additionally, the terms are commonly used synonymously (Katz & Hartman-Maeir, 1997; Marková, et al., 2005). For example, Cotrell (1997) and Vogel et al. (2004) interchangeably use three terms: *unawareness of deficits*, *lack of insight*, and *anosognosia*. The terms all refer to impaired awareness of the consequences of the disease but with no unifying definition. The difficulty of finding a consensus of definitions could be a reflection of the complex construct of awareness and the underlying different perspectives (Marková et al., 2005). The literature argues that deficit awareness has an impact on caregiver burden, the occurrence of depression, increased risk of accidents and difficulties in daily functioning (Aalten, van Valen, Clare, Kenny, & Verhey, 2005; Feher, Mahurin & Inbody,

2006; Kazui et al., 2006) and some results show that the level of awareness decreases as dementia progresses (Aalten et al., 2006).

Awareness as a phenomenon could only be understood in relation to something; to be aware requires something to be aware of (Marková et al., 2005). Understanding the subjective experiences of developing dementia, the construction and expressions of how awareness is expressed has been explored in several studies (Clare, 2003; Langdon et al., 2007; Nygård & Borell, 1998; Phinney, 2002). For instance, it seems likely that a person needs to be aware of his or her difficulties at some level in order to consciously use strategies and consequently, also report their use of these strategies (Seiffer, Clare & Harvey, 2005). Marková et al. (2005) describes that there has been an increased interest in empirical studies on such awareness in several areas during the past decades, including stroke rehabilitation (Tham, Ginsburg, Fisher, & Tegnér, 2001), traumatic brain injury (Port, Willmott, & Charlton, 2002), and dementia (Clare et al., 2005).

However, as shown in the literature review and in the studies of this thesis, persons with cognitive impairment or dementia *could* elicit their perspective on having these conditions, indicating some awareness. As an approach to capturing and describing the experiences of persons with dementia, a life world perspective of phenomenology has been suggested (Clare et al., 2005), based on the phenomenological philosophy of Husserl (1970/1900-01). The life world represents the world that is experienced by us and from which we start to understand and describe our everyday world: it is the world we all live in and always taken for granted (Bengtsson, 2001; Karlsson, 1997). By examination of the lived experiences in the everyday life world we can gain access to the person's experienced reality. This may also open up for better understanding the issue of awareness in people with dementia.

When an illness fundamentally challenges a person's life world, such as in the case of dementia, the change in the life-world leads to the person starting to notice and reflect on the changes (Dahlberg, Drew, & Nyström, 2001). Phenomenological methods allow the researcher to enter into this experiential and changing world of the person with dementia, thereby offering a possibility to better understand the nature of his or her awareness and how it could be accessed. Marková and Berrios (2006) argued that awareness carries crucial

implications for the meaning of insight in different situations. Cotrell (1997) pointed out that awareness has clinical importance that calls for a more complete understanding of the effect it has on persons with dementia and their families. Consequently, if occupational therapy aims to increasing well-being for people with dementia, it is important to better understand in what ways they may be aware of their situations.

As previously mentioned, there has been some dispute on the traditional perspective of persons with dementia as being unaware of their difficulties. A growing body of literature points out awareness as taking place within a psychosocial context unequated with cognitive functioning alone (Clare et al., 2005; Downs, 2005). In all, the literature review on the perspective of the person demonstrates that everyday occupations need to be continuously explored, as this will guide our understanding of how these occupations could be apprehended, implied, and used therapeutically in interventions. This thesis has the ambition of expanding this knowledge by further enhancing the understanding of how persons experience and approach the consequences of their dementia in the context of everyday occupations.

RESEARCH AIMS

The overall aim of this thesis was to enhance the knowledge of how people with cognitive impairment or dementia experience, approach, and manage the consequences of illness in the context of everyday occupations.

The specific research aims were:

- To describe how persons with memory deficits or younger on-set dementia perceived and met their problems, with particular reference to their present and future vocational situation, including describing the parallel observations and attitudes of other significant persons in the vocational context (Study I).
- To uncover and describe the meanings and motives for engagement in self-chosen daily life occupations among community-dwelling individuals with Alzheimer's disease (Study II).
- To explore and describe the characteristics of the phenomenon awareness of the consequences of having Alzheimer's disease on everyday occupations (Study III).
- To examine the relationship between occupational performance and awareness of disability in older adults with cognitive impairment or dementia (Study IV).

METHODS

PARTICIPANTS AND CRITERIA FOR SELECTION

The participants in this thesis were primarily persons with cognitive impairment or dementia in the mild to moderate stage of illness progression, still living in their own homes. An overview of participants, data collection and analysis methods in the studies is presented in Table I.

	Study I	Study II	Study III	Study IV
Participants	<i>n</i> =16	<i>n</i> =6	<i>n</i> =6	<i>n</i> =35
Gender F/M	a) 3/6 b) 4/3 a) Participants with memory impairment or dementia (<i>n</i> =9) b) Workplace respondents (<i>n</i> =7)	3/3 Older adults with Alzheimer's disease	3/3 Older adults with Alzheimer's disease	27/8 Older adults with cognitive impairment or dementia
Age, years mean (range)	a) 55.6 (51-62)	72.7 (65-80)	72.7 (65-80)	77.9 (59-92)
Research approach	Qualitative approach	Qualitative approach	Phenomenological approach	Quantitative, descriptive approach
Methods of data collection and instruments	a) Interviews with the modified WRI and assessment of ADL performance with the AMPS b) Interviews with interview guide	Interviews with interview guide and observational field notes	Interviews with interview guide	Assessments of ADL performance with the AMPS, awareness of disability with the AAD, and cognitive screening with MMSE
Analysis	Constant comparative method	Constant comparative method Interpretation	Empirical, phenomenological, psychological method	Descriptive, non-parametric, statistical methods

Table 1: Overview of Study I –IV: participants (number, gender, age), research approach, methods of data collection, instruments, and analysis.

Study I

Study I had 16 participants; they included nine participants under the age of 65 with memory deficits or suspected dementia, and seven workplace respondents from the subjects' work places. Criteria for participation in the study were a) having a memory deficit or suspected dementia under investigation at an inpatient clinic, b) being under 65 years of age, c) being employed, d) being on sick leave part time or full time because of cognitive problems for no longer than 18 months, e) being able to participate in the data collection and f) agreeing to participate. All diagnoses were established by a physician based on the results of the investigation after the participants' stays at the clinic, and hence after the data were collected for this study. Within 11 months of consecutive inclusion procedure, 11 persons fulfilled the criteria above. Two of them declined participation, and finally nine participants were involved, here called *participants with memory deficits or dementia*.

During the inclusion period, 105 persons under 65 years of age were inpatients at the investigating unit. Of these, 96 did not fulfil the criteria because of: disability pension ($n=31$), not sick-listed ($n=20$), lack of employment ($n = 12$), too short admission time ($n=9$), sick-listed longer than 18 months ($n=7$), sick-listed for other reasons than cognitive problems ($n=6$), occupational pension ($n=6$), failing general health ($n=3$), and declining participation ($n=2$).

The nine participants with memory deficits or dementia were six men and three women between 51 and 62 years of age (mean=55.6) with diagnoses of memory deficits ($n=4$), cognitive deficits ($n=3$) and dementia ($n=2$). They had different professions and had been employed at their places of work between 2 and 45 years. Five of them were still working part time. Cognitive screening was conducted by using the MMSE (Folstein, Folstein & McHugh, 1975) ($range= 19-30$, $mean=25.7$).

Each participant was asked to suggest someone from work that could be contacted for an interview concerning attitudes and observations made at the workplace. Two participants felt that there was no person familiar with their situation at their workplaces, while seven of the participants gave permission to contact the work place and provided names and telephone numbers of possible respondents. The seven persons at the workplaces all agreed to

participate, and they are called here *workplace respondents*. They held different positions; three were the heads of department or supervisors, two were staff secretaries, one was a personnel manager, and one was a fellow worker. They all also had, to a certain extent, a personal relationship with the participant.

Study II and III

The participants in Studies II and III were the same six persons with Alzheimer's disease. The participants were selected as a convenience sample (Polit & Beck, 2004) at a memory investigation unit of a university hospital in an urban area. The primary inclusion criterion was having Alzheimer's disease (AD) in a mild to moderate stage according to DSM-IV (APA, 2000) and NINCDS-ADRDA (McKhann et al., 1984). Some variation concerning age, gender and marital status was sought to provide richness in the data, as recommended when using this approach (Patton, 1987). The participants were three men and three women, 65-80 years old (*mean*=72.6 years). They had had their dementia symptoms for four to eight years according to medical records. Their MMSE scores (Folstein et al., 1975) were 15 – 28 scores out of 30 (*mean*=21.7). They were all community-dwelling, three were living alone, and three were living with a spouse.

Study IV

Potential participants in Study IV were persons: a) with mild cognitive impairment (MCI) (Winblad et al., 2004) or b) with a suspected or diagnosed dementia according to diagnostic criteria, DSM-IV (APA, 2000) or NINCDS-ADRDA (McKhann et al., 1984), c) living in the community, d) having a decreased ability to perform everyday occupations in accordance with clinical observations by an occupational therapist or a physician, a case history or case records, e) intended to be assessed with the AMPS, f) with a given consent for participating in the study, and g) with verbal ability to understand information and instructions to participate in interviews.

The selection was based on convenience sampling procedures (Polit & Beck, 2004) of persons that were referred to occupational therapy by a geriatrician at two outpatient units for memory investigations in two geriatric clinics. Potential participants that fulfilled the criteria for inclusion were contacted by the occupational therapists during or immediately after their stays

at the clinic. Diagnoses were made by the physician based on the results of the investigation, after the outpatient period. Persons with other main diagnoses, such as depression or stroke, and persons that were estimated to be unable to participate in the assessments and interviews were excluded.

The study comprised 35 subjects (mean age was 77.9 years, range 59-92), women (n=27) and men (n=8). Of these, 24 (69%) were living alone and 11 (31%) were living with a spouse. Eight participants had MCI (23%), while 18 participants had AD (52%). Of the remaining participants five had vascular dementia, while four had unspecified dementia. The MMSE mean score (Folstein et al., 1975) was 21.6 out of 30 (range 12-29).

DATA COLLECTION

Interviews and observations

In Studies I-III, data were collected primarily using interviews that focused mainly on the perspective of the study participants, using a semi-structured interview guide. Field notes and participant and non-participant observations were also used in Studies I and II. All data were collected in a clinical setting or in the participants' homes during or soon after their memory investigations. The interviews were carried out in an informal and familiar atmosphere, allowing the participants to take their time and reflect on aspects of the interview themes.

In Study I the interviews focused on the participants' experiences and perceptions of their work situations. A semi-structured interview guide was used, based on a modified version of the Worker Role Interview (WRI) (Velozo, Kielhofner & Fisher, 1999). The WRI is an interview instrument used for identifying psychosocial and environmental factors influencing a person's return to work after injury or illness, e.g. expectations, values, and interests. The WRI was translated to Swedish and modified for use as an interview guide in this study with permission from the authors. The assessment form itself was not applied. All interviews were carried out during the participants' stays at the clinic, once for each participant. The interviews were audiotaped and lasted from 24 to 118 minutes, mean duration 60 minutes.

Secondarily in Study I, the workplace respondents were also interviewed using a semi-structured interview guide that was developed for this study. The main themes in the interview guide concerned the respondents' apprehension of the subjects' possibilities to work at present and in the future, together with a description of the former work situation, before onset. The workplace respondents' interviews lasted from 27 to 76 minutes with a mean length of 45 minutes, and were carried out once at each of the seven workplaces.

Studies II and III were based on the same data. Data were collected by means of repeated interviews; primarily in the participants' home environments, whereas some of the first interviews were conducted in a secluded area at the geriatric clinic. A semi-structured interview guide (Kvale, 1996; Patton, 1987) was used, aiming at concrete descriptions of the participants' daily occupations, their experiences and perceived significance of daily occupations, their motives for occupational engagement, and their perceptions of competence and changes. The participants were encouraged to provide concrete descriptions of their experiences of everyday life occupations and their experiences while engaged in these. All participants were interviewed on two to four occasions during a two-week period. The interviews were tape-recorded and lasted between 19 minutes and two hours. Tape recordings of conversational interviews that reflected the participants' experiences while performing the tasks were also included, as the intention was to obtain an understanding of the participants' engagement as expressed in everyday occupations. All interviews were transcribed verbatim and comprised in total about 650 pages.

In Study II, both participant and non-participant observations (Bogdan & Biklen, 1998) were obtained in addition to the interviews. The observations were conducted in everyday occupations, chosen by each of the participants as representing various ordinary everyday tasks that were familiar and meaningful to each participant. In the participant observations, the first author (AÖ) interacted with the participant during his/her performance of everyday occupations. The non-participant observations required that the second author (LN) made field notes during the course of events. The observations were documented as field notes immediately after each session and transcribed in text, in total 110 pages.

ASSESSMENTS

For Study I, no standardized assessment to estimate the work abilities was available. Hence, the Assessment of Motor and Process Skills (AMPS) was used to obtain a measure of the participants' ability to perform complex instrumental tasks (Fisher, 1997, 2006a). The AMPS assessments were carried out at the inpatient unit. Each participant performed two or three tasks that were relevant and familiar to him/her, such as making coffee or setting the table for lunch.

In Study IV, all participants were evaluated in two ADL tasks with the AMPS (Fisher, 2006b) and the Assessment of Awareness of Disability (AAD) (Kottorp, 2006). The assessments were conducted by four clinical occupational therapists, who made between six and nine assessments each. The data were collected either in a clinical setting in a kitchen at the clinic or in the participants' homes, depending on the ordinary team work procedures at each of the clinics. In addition, the MMSE (Folstein, et al., 1975) was used in all four studies to provide information on the participants' levels of cognitive ability.

The Assessment of Motor and Process Skills

The AMPS is a client-centered observation-based performance assessment used by occupational therapists. The AMPS is designed to measure a client's quality of performance of ADL tasks (Fisher, 2006a) and the direct influence on the ability to perform both personal activities of daily living (PADL) as well as instrumental activities of daily living (IADL). The client performs two or more ADL tasks that are relevant and familiar to him or her. The occupational therapist observes and evaluates the quality of performance in 16 motor skills (such as Walks and Calibrates) and 20 process skills (such as Chooses, Initiates and Uses) (Fisher, 2006b). The client's performance is scored for all skills using a scale of 1-4, where 4=competent performance and 1=markedly deficient performance.

All raters undergo a five-day course and are calibrated in order to ensure that their scores are consistent and reliable. The AMPS raw scores for each client are entered into the occupational therapists' individualized copies of the AMPS computer scoring software (Computer

Adaptive Technologies & Fisher, 1994-96), generating two measures of individual performance. One measure is of ADL motor ability and one measure is of ADL process ability. These ability measures can also be evaluated relative to two motor and process cut-off measures. The cut-off measure is 2.0 logits for the motor scale and 1.0 logit for the ADL process scale. Clients with measures below the cut-off measure on the ADL motor scale are likely to demonstrate increased effort when performing ADL tasks. Clients with ability measures below the cut-off measure on the ADL process scale are likely to demonstrate increased inefficiencies, safety risks, and a need of assistance when performing ADL tasks. In addition, clients below the cut-off measure on ADL process scale are likely to need assistance to function in the community (Fisher, 2006a).

The AMPS is found to be free of gender bias (Merritt & Fisher, 2003). The validity, reliability, and clinical utility of the assessment are well documented in a number of research studies on clients with dementia (Doble, Fisk & Rockwood, 1999; Nygård, Bernspång, Fisher & Winblad, 1994; Oakley & Sunderland, 1997; Oakley, Duran, Fisher & Merritt, 2003; Robinson & Fisher, 1999).

The Assessment of Awareness of Disability

The Assessment of Awareness of Disability, (AAD) (Kottorp, 2006; Tham, Bernspång & Fisher, 1999) is a client-centered occupation-based assessment of a client's awareness of limitations in ADL performance that has been developed to be used in conjunction with the AMPS (Fisher, 2006a). The AAD is based on a standardized semi-structured interview comprised of eleven questions asked immediately after the performance of an ADL task. The purpose of using the AAD is to systematically examine if the client has a limited awareness of disability by assessing the discrepancy between the observed task limitations (as evaluated in the scoring of the AMPS motor and process skill items) and the limitations experienced and described by the client after the performance of a specific ADL task (Kottorp, 2006). The rater scores the magnitude of the discrepancy using a four-point rating scale (4= no discrepancy, 1 = major discrepancy).

AAD is a recently developed instrument that has not previously been used in clients with dementia. However, the AAD has been used both in stroke rehabilitation and in people with mental retardation, providing evidence of validity, reliability and sensitivity of the computer-generated measures (Hällgren & Kottorp, 2005; Kottorp et al., 2003; Tham et al., 2001). The awareness of disability measures have demonstrated sensitivity to change over time, and sensitivity in relation to occupational therapy interventions (Hällgren & Kottorp, 2005; Kottorp et al., 2003; Tham et al., 2001).

In clinical practice, the information obtained from the AAD could be used to identify clients with limited awareness of the problems they demonstrate in occupational performance, to provide adequate support and in planning interventions together with the client and his or her family, taking both the perspective of the client and the observable limitations into consideration, as well as the discrepancy between these.

The Mini Mental State Examination

The Mini Mental State Examination (MMSE) (Folstein, Folstein & McHugh, 1975) is a widely used clinical instrument for screening the cognitive level in elderly subjects with cognitive impairment or dementia (Crum, Anthony, Bassett & Folstein, 1993). In Studies I-III, the MMSE was used as one feature describing the background characteristics of the participants. In Study IV, the MMSE was used as a screening measure of overall cognitive functioning. In Studies I and IV, the MMSE was conducted by the geriatrician during the ordinary memory investigating procedure and excerpted from the participants' case records. In Studies II and III, the MMSE was administered within the research study and conducted by the interviewer in connection with the first interview. The maximum score is 30 indicating normal cognitive functioning (Folstein et al., 1975). In clinical practice and research, cut-off scores of >10 indicate severe cognitive impairment, 10-14 moderate impairment, 15-19, mild to moderate impairment, and 20-24 mild impairment (Włodarczyk, Brodaty & Hawthorne, 2004).

DATA ANALYSIS

Studies I-II

The interviews in Studies I and II and the field notes in Study II were analyzed using a qualitative comparative method (Bogdan & Biklen, 1998). This analysis method implies an inductive approach to the data. First, all transcribed interviews and the field notes were read to get an understanding of the content as a whole. In Study I the focus was on participants' experiences of the work situation and the conditions influencing each participant's possibilities to work. In Study II, the focus was on the participants' descriptions of motives and meaning of everyday occupations.

The process of analyzing interviews and field notes continued in parallel with a line-by-line coding, searching for references relevant to the aim of the studies. The analysis continued by shifting between re-reading of data and comparing participants' statements with preliminary categories that could further add to the development of themes. This process was conducted with the data for each participant, resulting in a set of categories. Then the categories for all participants were compared to identify differences and similarities, resulting in the final themes and categories. In **Study II**, a hermeneutical approach (Gustavsson, 1996) was used in the final step of analysis to formulate possible interpretations of the meanings of daily occupations supported by data and pertinent to all parts of the data.

Study III

During the process of analyzing data for Study II, the contradicting expressions in data of how the participants described and thought about on their illness and its consequences generated an increasing interest in their experiences in terms of awareness of their predicament. To understand more of how awareness of the consequences of Alzheimer's disease was expressed in the participants' descriptions of everyday life occupations, a phenomenological method was applied in analyzing the interview data. The Empirical, Phenomenological, Psychological (EPP) method (Karlsson, 1995) was used. This method is based on the phenomenology of Husserl (1970/1900-01) and aims to describe the meaning structure of a life-world phenomenon based on the research participants' accounts of their lived experiences. The psychological focus of this method was replaced with the perspective of

occupational therapy, on the experience and meaning of everyday occupations. The phenomenon in this study was formulated as *the awareness of the consequences of Alzheimer's disease in everyday life*.

First, all data was read through to get a good understanding of the content and to identify all parts of the text indicating expressions of the lived experiences of awareness. Data that were not relevant to the aim of the study were excluded from further analysis. Next, a new open reading of all selected data took place, with the intention of obtaining an empathic understanding of the whole content, without imposing any theoretical model or theory. The text was then divided into meaning units each time there was a shift in meaning in the data. Thereafter, the meaning units were analyzed in the light of the whole, and the units were transformed from their particular facts to their explicit and implicit meaning, applying a language close to data. Preliminary themes were created in a search for the main characteristics of the phenomena. Subsequently, the analysis included synthesizing the transformed meaning units and preliminary themes into "situated structures of meanings", presented as a synopsis for each participant. Finally, the situated structures from all participants were compared and synthesized into a "general structure" that incorporated all the characteristics of the phenomenon based on all situated structures.

During the analysis procedure, the horizontal consistency of all characteristics was examined by scrutinizing conflicting interpretations to ensure that the final interpretation was the most plausible (Karlsson, 1995). The interpretations were also continuously discussed in peer reviews with other researchers who were familiar with the phenomenological approach to research.

Studies I and IV

Initially in both Studies I and IV, each occupational therapist who collected data entered the individual raw AMPS scores into their individualized copies of the AMPS computer scoring software (Computer Adaptive Technologies & Fisher, 1994-96). The raw scores were then analyzed using applications of many-faceted Rasch analysis to generate two individual measures of ADL motor ability and ADL process ability (Bond & Fox, 2001; Fisher, 2006a). The application of many-faceted Rasch analysis included in the AMPS computer scoring

software adjusts for item difficulty, task challenge and rater severity so that all ADL motor and ADL process ability measures of the participants could be compared. In Studies I and Study IV, this analysis was used to compare the participants' ability to perform complex, chosen ADL tasks with each other.

The analysis in Study IV then continued. The raw scores for each client's AAD evaluation were analyzed by the researchers using many-faceted Rasch analysis to generate individual measures of awareness of disability. Similar to the AMPS, the application of many-faceted Rasch analysis with the AAD also adjusts for rater severity, task challenge, and item difficulty, so that all clients' measures of awareness could also be compared directly, despite the differences in tasks and raters. This analysis used a computer application of a many-faceted Rasch analysis, FACETS (Linacre, 2005).

Descriptive statistics were used to describe the characteristics of the participants. In order to examine the correlations between the measures generated from the AMPS and the AAD, Spearman's rank correlational statistics were used. In order to analyze the magnitude of any differences between participants with MCI and AD, *Mann-Whitney U-tests* were used.

ETHICAL CONSIDERATIONS

Persons with cognitive impairment or dementia could be described as particularly exposed and vulnerable in comparison to other people in health care research (Alzheimer's Association, 2004; Kim, Karlawish & Caine, 2002). For example, they might feel obliged to consent to participation when approached in a medical care setting from which they need care, and they might have a limited possibility to make a well grounded decision due to their cognitive limitations (Kim et al., 2002). In all four studies of this thesis this was carefully considered. However, developing a client-centred approach in interventions for persons with cognitive impairment or dementia also means involving the person in research (Norberg, 2004; Dewing, 2002). The participants were recruited at a point in time when they were in contact with medical care due to their condition and they comprehended our reasons to include them in the research and were made aware of the aims of our studies as requested in ethical guidelines (Alzheimer's Association, 2004).

Permission to carry out the studies was obtained from the local ethical committee. All data were coded to prevent identification of participants. All participants in **Study I-IV** received both written and verbal information about the study. After considering the information, all participants included gave their informed written consent to participate.

In **Study I**, the participants were contacted and informed by the researchers during their stay at the clinic. The included participants voluntarily provided names and telephone numbers to persons at their work places that could be contacted for an interview. The workplace respondents were informed verbally about the study at the first contact and they received written information and gave written consent to participate in conjunction with their interview session. In **Study II-III**, some of the participants were contacted and informed of the study during their admission period as outpatients at the clinic, and some of the participants were contacted a short time after their stay. All of the six participants' closest relatives were also contacted and informed, both verbally and written, about the study. In **Study IV**, all participants were informed about the study by the occupational therapist at the clinic in connection to the ordinary occupational therapy intervention. Six of the participants were asked by their ordinary occupational therapist at the clinic if they agreed to be contacted for

participation in the study by the researchers. The participants were then contacted by the researcher and informed about the study both verbally and written, and the participants gave their informed written consent.

In all studies, the researchers set great store of an ethical and heedful approach towards potential and included participants. Repeated information was emphasized and was adjusted to the individual participant and situation to underscore that participation was voluntary and that their decision would not affect their ordinary care. For instance, before each interview session the interviewer repeated the purpose of the interview and the aim of the research in a conversation with the participant. Additionally, the interviewer answered all question posed during the interviews about the usefulness of his or her contribution that at several occasions were asked by participants. The researchers and occupational therapists strove to be as attentive and sensitive as possible to any signs of discomfort or reluctance to participate in the participants to avoid constrained participation. For example, if a planned data collection occasion seemed to be inconvenient to a participant, the researcher adjusted and schedules were changed to fit the participant. None of the participants expressed a wish to disrupt their participation after inclusion in **studies I-IV**.

FINDINGS

In **Study I**, the aim was to describe how persons with memory deficits or younger on-set dementia perceived and met their problems at work including the attitudes of their co-workers. In conclusion, the possibility to remain at work seemed to depend on multiple factors, including the individuals' apprehended ability to work and the length of the sick-leave.

The findings reveal that the participants were the first to experience vague and gradual changes at work that also interfered with their general life situation, leading for instance to decreased self-confidence, sleep disturbances and worries about the work situation. The participants developed various strategies to compensate for their difficulties, rather than disclosing their problems. As time progressed, the strained situation led to the necessity to seek help. Only later, the workplace respondents attended to diffuse problems, such as that the participants' personality being changed, or that their achievements at work having deteriorated.

The workplace respondents expressed a will to support the person to remain at work for as long as possible. However, the situation also was perceived to affect the workplace negatively, in that the co-workers had to support the participants in their daily work and in problems finding more simple and adapted tasks due to a strained economy and demands for more effective working methods. All participants as well as the workplace respondents emphasised the importance of doing occupations that were experienced as meaningful. Those who were still working wanted to stay at work as long as they made valuable contributions. For participants who had been on sick leave for a considerable time returning to work was no option. They emphasized the importance of finding meaningful and satisfactory occupations to fill their time with and to being of importance to others even if they were no longer able to work.

In **Study II**, the aim was to describe the meanings and motives for engagement in self-chosen daily life occupations among people with Alzheimer's disease. The rich variety of motives and meanings, and the significance of occupations suggested that therapists and caregivers

might contribute to the well-being of persons with Alzheimer's disease living in their own homes by identifying and supporting daily life occupations of personal meaning and significance.

First, everyday occupations supported the participants to maintain their ordinary pattern of everyday life and provided content and structure to each day. The everyday occupations offered them an opportunity to be a part of a coherent context and were also important for maintaining a sense of normality and the experience of contributing to the social context and the significant experience of "being someone" to others. By being engaged in occupations the participants maintained their experience of being autonomous and in command of their lives, even though they sought help when needed.

The occupations also allowed them to experience and demonstrate certain characteristics of their identity that reflected the person they used to be. The participants described a "private sphere", i.e. a personal place, which seemed to provide a sense of freedom, enjoyment, inner peace, and an opportunity to follow their minds. The private sphere varied from being a physical place to an intrapersonal place. In addition, two categories were indirectly influencing motives for engagement in occupations, i.e. double-edged keys crucial to occupation and two modes of making sense of the cessation of occupations.

The aim of **Study III** was to explore and describe awareness of the consequences of Alzheimer's disease on everyday occupations among persons with Alzheimer's disease. In conclusion, the findings showed how awareness of the consequences of having AD was expressed through their reflections and in narratives of their experiences. The structure of the investigated phenomenon was presented as two main characteristics; *discovering and managing changes in occupational and social interactions* and *reflecting on a changing life situation*.

The findings showed that the participants gradually attended to and considered changes in their interactions with everyday occupations and socially with other people. They noticed the presence of changes as compared to before, and explored the changes by sometimes exposing themselves to challenging situations. Awareness was spontaneously expressed in situations

where the participants experienced forgetfulness. The participants used adaptive approaches that were developed to handle the changing abilities or to facilitate social interaction. This was understood to reflect the participants' awareness of the need that adaptive approaches were required to continuously manage everyday occupations. They tried to make sense of what was happening to them by connecting it to a normal course of aging, a previous accident or as being hereditary.

The experience of change was described as an elusive perception of change, being difficult to grasp and incorporate as a part of one self. They tried to relate to having Alzheimer's disease as a situation that seemed impossible to influence and they emphasized their option to still go on with life. The participants reflected on the impact their condition had on other people near them, concluding that their condition could imply an obstacle for other peoples' life styles.

The purpose of **Study IV** was to examine the relationship between occupational performance and awareness of disability in older adults with cognitive impairment or dementia. In conclusion, the results showed a positive relationship between occupational performance and awareness of disability. Participants with AD had lower ADL ability measures and significantly lower measures of awareness of disability compared to participants with MCI. However, there were also large variations within the diagnostic groups, implying that limitations in occupational performance are not equal with decreased awareness of disability. The results suggest that ADL performance ability and awareness of disability should be assessed on an individual basis.

The results further showed that the total sample had decreased ability to perform ADL tasks indicating a need of assistance to function in the community. The ability measures for the MCI sample ($n=8$) showed that all of these participants were above the cut-off measure on the ADL process scale, while the measures of ADL motor ability was below the cut-off for ADL motor ability for three of the participants. The ability measures for the AD sample ($n=18$) showed that most of these participants were below the cut-off measure on both the ADL process ability and ADL motor ability.

The MCI sample ($n=8$) showed an overall higher awareness of disability than for the participants in the AD sample ($n=18$) ($p<0.05$). There was a positive and moderate relationship between awareness of disability and occupational performance for the whole sample, suggesting a slightly stronger relationship between ADL motor ability and awareness of disability ($r=0.67$; $p<0.01$) compared to ADL process ability and awareness of disability ($r=0.44$; $p<0.01$). An evaluation of the raw scores for each participant in each task showed that 43% of the participants with cognitive impairment or dementia in this study were not aware of some of their limitations in occupational performance that resulted in unacceptable outcomes in everyday occupations.

The measures of cognitive functioning, screened by the MMSE showed a positive relationship with ADL process ability. There was no significant correlation between the participants' MMSE scores and ADL motor ability or MMSE scores and awareness of disability.

GENERAL DISCUSSION

MAIN FINDINGS

The purpose of this thesis was to shed light on the experiences of everyday life occupations and enhance the knowledge about having cognitive impairment or dementia, through exploration of the research participants' own accounts. To illuminate the subjective experiences of dementia in research, a varying set of research strategies has been suggested to generate understanding and practical knowledge (Hubbard et al., 2003). Interviews, observations and assessments were used in this thesis with the intention of capturing and illustrating the participants' experiences from different perspectives. When considering the transferability (Patton, 2002), it should be noted that the participants in these studies were persons in the early or moderate stages of the illness progression, living in their homes, with or without daily support. Consequently, they were still actively engaged in daily life occupations and participating in social life, although their living conditions were challenged by their progressing illness.

In this section, a discussion of the main themes generated from the empirical findings will be presented, focusing on different aspects of everyday occupations, the participants' experiences of being ill, and the significance to them of other people. Awareness as explored in these studies will also be discussed, followed by reflections on limitations in the research approaches that were used. Suggestions for further research are made, and finally, clinical implications based on the findings and results are presented.

EXPERIENCES OF EVERYDAY OCCUPATIONS

The point of departure in all four studies was occupations in everyday life and the findings exhibit and exemplifies the potential meaning and significance of everyday occupations. Therefore, occupations as an important arena for experiencing and expressing changes are further discussed below.

Meaning and significance of occupations

One of the major findings of these studies was how the meaning and significance of everyday occupations came to the fore in the participant's views, both concerning the performance and the underlying significance of certain occupations to the person. To be able to carry on with occupations that held individual meanings was indisputably important and the participants strove to continue with the occupations they wanted and needed to do in spite of an illness that is known to have a disabling impact on performing occupations.

In the findings, occupations were apprehended as meaningful in a wide variety of aspects. Particularly crucial aspects were that occupations could make the participants feel that they contributed something to the social context (Studies I-III), for example making useful contributions at work (Study I), doing something for another person (Studies II-III) and doing things that were satisfying to them in the sense of providing joy, amusement, or relaxation (Study II). In Studies I-III, the importance of everyday occupations was emphasized as contributing to the sense of competence in the participants. In the participants' life world of increasing difficulties that lead to fatigue and feelings of distress, these findings seemed particularly important and encouraging as they suggest everyday occupations as a possible arena for maintaining aspects of competence. This indicates that providing people with dementia with possibilities to continue doing those occupations that they find most significant, for as long as they experience this as meaningful, might contribute to their maintenance of experienced competence.

The meaning of occupations and of the "doing" of them has been investigated in occupational therapy in different ways (Hasselkus, 2002). The experience of meaningfulness in occupations has been found to be related to motivation, interests, and habits (Kielhofner, 2002). For example, Piskur, Kinebanian and Josephsson (2002) found in a study among well persons that occupations were related to well-being and were a way to create a feeling of balance in life. In occupational therapy's dementia research, certain individually chosen occupations have been shown to be used as a resting place by participants (Nygård & Borell, 1998), providing them with a possibility to rest from the threats of dementia.

Placing importance on the experienced meaning of occupations also influences the way in which occupational therapists carry out their practice (Hasselkus & Rosa, 1997). Josephsson (1994) suggested that occupations of everyday life with individual meaning could be used as a “meeting place” between a person with dementia at his/her caregiver when conversations had become impoverished. However, findings indicate that the significance of occupations might change during the course of illness (Nygård & Borell, 1998). The progressive nature of the disease and the resulting continuous changes are important considerations to keep in mind when implementing support and encouragement for people with dementia to continue their engagement in occupations. Eventually, the person may need support in letting go of occupations that are too challenging.

The wide array of experienced meanings of occupations presented in this thesis suggests that we have no reason to assume that the meanings and significance of everyday life occupations in people with dementia would be much different from the meanings other people impose on occupations. However, as the meaning of occupations is influenced by many factors, such as culture, environment and personal values (Hasselkus, 2002; Kielhofner, 2002), it is likely that illness is another influencing factor. An occupation might become more or less important to perform after the onset of dementia, or the inherent meaning of an occupation might be altered for a person. This was, for instance, shown in Study II, where some participants expressed that they had started to perform certain occupations as a way to maintain cognitive abilities or demonstrate that they were still independent. For some participants, the daily walks also meant being in a private sphere, aside from being a way to get physical exercise. This finding indicates that it is not enough in occupational therapy practice to consider that occupations are given individual meanings. It is important to be sensitive to the present also; occupations might have changed or lost their significance during the illness progression or just with the passage of time.

One of the findings in Study I was that the persons with cognitive impairment wanted to work for as long as it was meaningful to them and to their employers. What could be characterized as *meaningful work* must be regarded as highly individual and dependent on multiple factors (Gard & Sandberg, 1998). Johansson and Tham (2006) showed that younger persons with acquired brain injury experienced that the social dimension of work had taken on an expanded

meaning, for instance the contact with colleagues, but that work also had taken on a new and less important place in life. As in Study I, they concluded that it is important to pay attention to the individuals' work experience for designing individualized intervention programs. No studies were found about the work situation for persons with dementia, but a study on the retirement process among well elderly persons (Jonsson, Josephsson & Kielhofner, 2001) is in concordance with this, stressing both internal motivation and external demands as important to meaning and motivation for engaging occupations concerning both work and occupations after retirement.

The studies of this thesis identify individual significance and a variety of experienced meanings from being engaged in occupations when having cognitive impairment or dementia. Therefore, supporting these persons to continue with occupations meaningful to them in their present everyday lives must be one of the most important tasks for their families, as well as for occupational therapists and other health care professionals.

Everyday occupations as an arena for experiencing changes

In all four studies, everyday occupations seemed to serve as an important arena to the participants for acting on and experiencing the consequences brought about by cognitive impairment or dementia. These findings indicate that engagement in occupations might be more complex than merely a question of ability or independence. From the perspective of the person, being engaged in occupations also involves exploring, experiencing, engaging, and practicing occupations, as for healthy adults (Christiansen & Baum, 1997). It is worth noting that the participants in these studies stand out as agents with the intention and ability to act and interact, as opposed to being passive victims of their diseases. The view of the person with dementia as taking active part in everyday life occupations is central in the findings of the present thesis and contradicts the picture of the "demented" person as passive and lost; a view which earlier has been common (Sabat & Harré, 1994; Hughes, Louw & Sabat, 2006).

In Studies I-III, the findings identified everyday occupations as arenas in which the participants could discover that something had changed or was changing. Their perceptions of changes resulted in painful experiences of failure and feelings of anxiety. However, although

occupations implied difficulties, they also brought about contradicting experiences of joy and appreciation of being able to continue with everyday life. This appreciation seemed to include a continuous checking of their competence, and allowed the participants to demonstrate to other people that they could still manage, though watching out for changes. For example, the findings of Studies I-III showed that the participants became more watchful about all presentations of change.

In Study I this came to the fore in the work situation, where the demands of work could be characterized as more strained than in the familiar life at home. This may be understood as meaning that work tasks are more complex and demanding on efficiency and flexibility. Therefore, it seemed likely that these tasks would be more sensitive to experiences of changes such as increasing insufficiency and signs of failing cognition. This was expected, as we know that dementia first affects the most complex activities of daily life. More remarkable was the fact that in Study I the changes were experienced by the participant long before they were noticeable by the workplace respondents. This indicates that changes in the beginning of the illness progression are more appreciable to the person than to others, as was also concluded by Robinson et al. (1997). This finding is contradictory to the general view on dementia symptoms as first noticed by others but not by the person with the illness.

This has implications for how to approach the experiences of people being under medical investigation for suspected dementia. It suggests that their subjective accounts of experiencing changes should be taken seriously, considering this as possible manifestations of cognitive impairment, as also been suggested by Robinson (2002) and others (Husband, 2000; Katsuno, 2005). Recent studies have also found that persons with MCI do experience disability in everyday occupations (Artero, Touchon & Ritchie, 2001; Perneczky et al., 2006; Toukko, Morris & Ebert, 2005), which supports this recommendation.

Taken together, these findings support the notion that the occupational arena is important for persons with cognitive impairment or dementia, in spite of their difficulties in performing everyday occupations. The findings of this thesis have particularly identified occupations as an arena in which they can explore and comprehend perceived changes.

THE EXPERIENCE OF BEING ILL

The findings revealed the participants' experiences of being ill to be intertwined with their experiences of everyday occupations. Most of the participants in Studies I-III could describe aspects of being ill as a consequence of the perceived changes. They suspected or knew about having, for example, Alzheimer's disease and all of the participants in Studies II-III understood why they took dementia medication. Yet this knowledge seemed to be incompatible with the views they had of themselves; they knew about the change and about the features of dementia but they could not imagine what they should experience with this disease. Hence, the knowledge about having Alzheimer's disease seemed difficult to integrate and incorporate with the perceptions they had of themselves.

The views they communicated of themselves as being ill seemed to be in contrast and disagreement with the views they had of what having Alzheimer's disease meant. Bond and Corner (2001) described that the commonly shared view on people with dementia in society as "victims" or "sufferers" emanates from the biomedical perspective on dementia as a degenerative brain disease that leads to loss of self. Consequently, this common view in society could explain some of the difficulties the participants in this work experienced; they could not integrate their own perceptions with the commonly shared societal view on people with dementia. This was also found in a qualitative study on the social effects of a diagnosis of dementia by Langdon, Eagle, and Warner (2007). In their study, the word "dementia" awoke aversion among participants diagnosed with dementia and they feared that other people would change their behavior towards them as a result of their diagnosis. Hence, being part of the commonly shared understanding meant that the participants in Studies I-III had difficulties in integrating their understanding of dementia with the changes they experienced.

On the other hand, the findings in Studies I-III demonstrate that the participants felt physically fit and capable, and enjoyed being physically well. This indicated that they did not view their difficulties as a physical illness, a notion that also was expressed by some of the participants. Most of them emphasized the importance of keeping up their physical ability in general terms, i.e. taking daily walks and doing as much as they could. Early stage dementia

involves uncertainty and vague symptoms that the participants described as difficult to grasp. These experiences could be easy for them to attribute to other conditions, such as stress and fatigue (Study I), or traumatic events (Studies II-III) than to the new disease.

Moreover, a recurring expression in all data was that memory failure is “normal” in old age. This could be related to their trying to make sense of dementia, and attributing it to “normality” in old age, as found in both Studies II and III and in other studies (Langdon et al., 2007; McQuarrie, 2005). It could also be understood as attempts to fit in the world of “normality”, which is an explanatory model in social psychology of how chronically ill adjust to illness in social relationships (Radley, 1994). To further understand this ambiguity of both knowing about dementia and trying to incorporate this illness with the view of how persons with dementia should perceive themselves needs further studies that would benefit from incorporating a societal perspective.

SIGNIFICANCE OF OTHER PEOPLE AND SOCIAL INTERACTION

Even though these studies focus on the perspective of the person with cognitive impairment or dementia, other people close to them were also seen from their perspective. Some of the participants lived with a spouse or close to other relatives, and some lived alone. Whatever their social situation, it was clear that other people and social interaction were important to them in different aspects.

Firstly, the findings in Studies I-III showed how participants viewed themselves within the social interplay; they pondered on how they were perceived by people around them, and it was apparent that what other people thought of them mattered to them. For instance, the participants in Study I concealed their increasing problems from their colleagues even though they trusted them. In Studies II and III, the participants described how they reflected on other persons’ reactions to them, when they told about their diagnoses. They also reflected on whether their disabilities were obvious to people in their environment. This is remarkable as the general view on people with dementia is that they are not aware of their problems (Marková et al, 2005). However, findings in Study III reveal that they are aware of having

difficulties and, moreover, that they hence reflect that others might notice their difficulties or that others might even notice difficulties that they themselves are unable to perceive. This aspect has also been found in other qualitative studies from the perspective of the person with dementia (Clare, 2003; Langdon, et al., 2007).

One particular aspect of this came to the fore in Study III, where the participants went beyond their own experience and reflected on how their illness must have consequences for other people close to them. Consequently, their awareness did not only concern themselves but also persons in their environment, e.g. when they were elaborating on how their illness had to affect their spouses' everyday life. Similar findings have been presented in a few studies previously (Clare, Goater & Woods, 2006; Pearce, Clare & Pistrang, 2002). Taken together, these studies indicate that people with dementia may be very sensitive to what other people around them express concerning perceived influence of the illness on the others' lives. Consequently, other people might have a significant impact on how persons with dementia apprehend the consequences of their situation, which is important to consider in support and caregiving.

Secondly, studies have focused on the interaction in couples where one of them has dementia (Vikström et al., 2005; Vikström et al., submitted; Hellström et al., 2005), focusing on the supportive social environment. In Studies I-III, this was also pointed out by the participants as being important. It has been argued that other peoples' expectations of people with dementia influence their behavior (Bond & Corner, 2001; Lyman, 1989). Hence, this might have an impact on how the participants viewed themselves and experienced their situation. The findings in Study I revealed that the social fellowship and support the participants experienced from colleagues at work were of vital importance to their attitude towards continued work. The wish to continue to "be something to another person" in spite of the disabling illness was expressed in Studies I-III, indicating for example that the perception of others could be experienced as a confirmation of maintained ability. Hence, the findings raise the importance of carefully considering how to approach persons with dementia in clinical practice. While it is not possible to influence the disease, it might be of outmost importance to consider that how they are approached by others in social interactions might either facilitate or worsen their perceived situations.

AWARENESS IN PEOPLE WITH DEMENTIA

Awareness of disability was in focus in Studies III and IV, using different research approaches to capture the participants' awareness of disabilities in everyday occupations. Through lived experiences, Study III showed the participants' awareness in various ways. The abundance of findings in Study III indicates a concordance with results from studies of Clare (2003) and MacQuarrie (2005) who conclude that the way in which people with AD understand and mediate their experiences is more complex than previously indicated. Set against the traditional view of persons with dementia as being unaware of their disability, this supports the argument that awareness is a complex concept (Marková et al., 2005).

Using a phenomenological approach in Study III allowed us to enter into the experiential world of the person with AD that presented one view on the awareness of the consequences of AD. In Study IV, we used a clinical method to measure awareness of disability, using the AAD (Kottorp, 2006). The results of this study, in contrast to those of Study III, clearly showed that persons with cognitive impairment or dementia have a limited awareness of disability compared to their results on the ADL assessment made by the occupational therapist. Yet limited awareness as measured in this traditional sense does not mean lack of reflections and adaptive efforts. It is well documented in research that people with dementia or cognitive impairment have decreased awareness of their cognitive deficits as compared to the estimations of their family members, or as found in studies comparing well older adults with persons with AD (Arkin & Mahendra, 2001; Derouesné et al., 1999; Graham, Kunik, Doody & Snow, 2005).

Based on such results, it could be argued that there is no point in paying attention to the awareness of persons with cognitive impairment or dementia since it is reasonable to assume that all persons with dementia have impaired awareness. On the other hand, as an increasing body of research has shown that people with dementia do experience and reflect on their disabilities, such presumptions need to be challenged: this was also shown in Study III. Moreover, the level of awareness might impact on the wellbeing in persons with dementia and their carer and influence the outcome on rehabilitation interventions (Clare, Wilson, Carter,

Roth & Hodges, 2004). This has also been found in persons with stroke (Tham et al, 2001) and persons with intellectual disabilities (Kottorp, et al., 2003). Thus, it could be argued that the findings of this thesis expand on earlier findings concerning awareness in people with dementia.

Taken together, the results of Studies III and IV showed that using just one approach might not capture the full picture of awareness, as the participants in Study III appeared to have good insight into their problems, while the participants in Study IV, on the other hand, were found to have limited awareness of their disability. Consequently, this suggests that a multidimensional approach (Howorth & Saper, 2003, Clare et al., 2005) using both measures and interviews would reflect different aspects of awareness providing a more comprehensive, albeit not a complete, understanding of what the person experiences (Prigatano, 1997). This could better support both clinicians and families in interventions that will facilitate the persons' adjustment process, and hence, their well-being as suggested in cognitive rehabilitation (Prigatano, 1997). It might also help the person with dementia to better understand their personal reactions to the consequences of their disability.

METHODOLOGICAL CONSIDERATIONS

Conducting research including perspectives from persons with dementia, using for instance interviews, has been described as particularly challenging, as persons with dementia have difficulties with recollection and communication skills (Bond & Corner, 2001; Downs, 1997; Hubbard et al., 2003). Consequently, such research needs particular considerations. The emphasis in the studies for this thesis was to get access to the perspective of the person, in order to get an enhanced and deepened knowledge complementing previous research, where the occupational aspects of everyday life have been described or assessed mainly in terms of disability in ADL. The methodology used in these present studies took on a complementary approach, comprising interviews, observations, and assessments as suggested by several authors (Hubbard et al., 2003; Kitwood, 1997b; Nygård, 2006) when the aim is to capture the experiences of everyday occupations from the perspective of the persons themselves. Conducting these studies, methodological challenges had to be managed, ranging from comprehensive issues such as considering ethical dilemmas, to details such as formulating adequate interview guides with questions that were comprehensible and possible for the respondents to answer.

In the following, some of the methodological challenges in the present studies will be discussed, starting with the selection of participants. The criteria for inclusion could have affected the findings in these studies in different ways. In Study I, one of the inclusion criteria was having employment; hence all those who had left their employment were excluded. It could be assumed that some of them had left their positions to take early retirements or be on sick leave or disability pension for other reasons than memory problems. Moreover, the participants in Study I felt a strong involvement in their workplaces and this may have contributed to their still being employed. As a consequence of the inclusion criteria, the sample in Study I may have comprised a few persons who had stable employment, and therefore the findings should be interpreted in consideration of these conditions.

In Studies II-VI, a convenience sampling procedure was applied (Polit & Beck, 2002). The reasons for this were twofold. The data collection approach in Studies II-III included several interviews in the participants' homes. Consequently, participants had to accept home visits on

more than one occasion and be prepared to share their experiences. However, they were not included on grounds of being especially occupied with everyday occupations (Study II) or being particularly aware of their disabilities (Study III). Yet, as a result of the stipulated criteria, the findings in Studies II-III may reflect the experiences of persons with open minds and good adaptive skills that were prepared to welcome a researcher into their homes for repeated interviews concerning their disabilities. In Study IV, the selection was made by clinical occupational therapists in a convenience sampling procedure (Polit & Beck, 2002). Work conditions affecting the data sampling procedure beyond the therapist's control might have influenced the selection, such as heavy work load or lack of time. However, when the study sample was compared to samples in other studies, it was revealed to be comparable to community-living persons with dementia concerning ADL performance ability measured by AMPS, and cognitive screening measured by MMSE (Hartman, Fisher & Duran, 1999; Robinson & Fisher, 1996, 1999).

The basic inclusion criteria for all four studies were that potential participants should experience changes in performing everyday life occupations, i.e. it was not based primarily on a specific diagnosis. The issue of diagnosis therefore needs further comments. In order to find participants who had difficulties in everyday life occupations, who lived in their own homes and were in the early stages of dementia, all participants (Studies I-IV) were recruited from geriatric clinics, including an inpatient memory investigation unit (Study I), an outpatient investigation unit (Studies II and III) and two geriatric outpatient units (Study IV). Consequently, the participants were in an early or moderate stage of their illness progression. Since the intention was to capture the experiences at an early stage of dementia, this meant that not all participants had an established diagnosis at inclusion and that their diagnoses had to be obtained retrospectively after data collection. In Studies II-III, the probability of obtaining a dementia diagnosis guided inclusion, based on consultation with the medical team during the memory investigation. Eventually, all six participants in Studies II-III received the diagnosis of Alzheimer's disease. For the past ten years there has been an ongoing debate on the diagnosis of Mild Cognitive Impairment (Petersen et al., 2001; Winblad et al., 2004). At the time of Study I, this diagnosis was not used in practice and consequently, those participants who did not fulfill the criteria of dementia according to APA (1994) received the diagnoses of cognitive impairment or memory impairment in Study I. As the research in this

thesis focused on the experiences of cognitive impairment or dementia in daily occupations, which is an important issue for occupational therapists, an established diagnosis of dementia in participants was not prioritized. Even if receiving a diagnosis is of the utmost importance to the person who is experiencing the symptoms (Robinson, 2000), the consequences in everyday occupations of cognitive impairment or dementia still need to be approached and managed, the latter being of particular interest in these studies.

It is well known that dementia leads to changes in daily life occupations (APA, 2000; Nygård & Winblad, 2006). Hence, the studies set out to investigate how changes brought about by cognitive impairment or dementia were experienced from the perspective of those living with the changes. That was considered to be a fruitful way to capture the nature of these experiences. The method of repeated interviews in Studies II-III required participants who were able to share their experiences to some extent. However, it is not easy to judge the extent to which participants are willing or able to share their experiences in research interviews, particularly when they are afflicted with cognitive limitations (Hubbard et al., 2003). The participants in the studies for this thesis did share a surprising array of experiences. The fact that they were selected from investigation units where their difficulties were recognized could have contributed to this. As their perceived changes and symptoms had received attention during the investigation and they had been encouraged to talk about them, they understood why they were asked to participate in interviews and were responsive to the purpose of the studies. This circumstance may have assisted them in providing rich descriptions of their experiences.

In Studies II and III, the participants and interview data used were the same, while the analysis methods were based upon different approaches. This raises two questions. Firstly, to re-use the same set of data with another research question and another method of analysis could imply bias and an intrusive pre-understanding that could be difficult to bracket and disregard, which is considered important in phenomenological analysis (Karlsson, 1995). Certainly, this issue attracted attention and the pre-understanding was reflected on during all steps of the analysis process of Study III to prevent the findings from being influenced by the knowledge of former findings based on the data presented in Study II. On the other hand, without pre-understanding, there can be no new understanding (Ödman, 1994). In this case,

the analysis in Study II had evoked the interest in the participants' expressions of awareness, as this aspect showed in data. This led to the continued analysis in study III. Furthermore, time was an advantage in that the analyses in Studies II and III were carried out with a two-year interval, and the analysis of Study III was in fact conducted as a detached study.

The small number of participants in all of the studies may also be regarded as a limitation. However, Studies I-III used qualitative research methods on the basis of the research questions and scope. In qualitative research the aim is to increase the depth of understanding of what is studied by means of interviews, observations, and documents (Patton, 2002). In this research approach the unit of analysis is not the participants per se; but rather all pieces of data that show their experiences, opinions, feelings, and knowledge. Qualitative methods do not search for generalizations on statistical grounds. Rather, analytical generalization can be used, i.e. reflective judgments about the extent to which the findings in one study can be used as a guide to what might occur in other situations (Kvale, 1996). Consequently, the findings in Studies I-III can not be generalized to include all persons with cognitive impairment or dementia. Rather, the findings suggest a possible understanding of how everyday life occupations could be experienced, approached, and managed among these persons. The research approaches adopted in Studies I-III are in accordance with the recommendations made for this type of research (Kvale, 1996), as rich and reflective descriptions were obtained as required for validation of findings according to Bogdan and Biklen (1998), Kvale (1996), and Patton (1987, 2002).

Because of the small sample size in Study IV, especially concerning the different diagnostic groups, we used a nonparametric statistical method and the study should be regarded as a pilot study. However, this study provided important insight into the relationship between occupational performance and awareness of disability that could be applied in a larger sample size in forthcoming studies. In studies III and IV, the approach was to examine awareness from two different perspectives; by means of lived experiences and by assessment with commonly accepted method of measuring the discrepancy between the client's apprehended ability and the ratings from another respondent (Clare et al, 2005; Seiffer, Clare & Harvey, 2005). However, there are some questions about whether the latter approach captures a person's awareness of disability or if it measures his or hers perception of performance. To

clarify this, further research is needed. The results from Studies III and IV suggest that the information received through these different approaches may capture some of the complexity of awareness that may complement each other.

CLINICAL IMPLICATIONS

The findings of this thesis have clinical implications, primarily concerning people with cognitive impairment or dementia in the early to moderate stage of the disease, who are still living in their homes after having received a diagnosis. They often receive their diagnosis and occasionally medications, but are left without professional specialists to turn to with their questions, as indicated by the participants during the data collection in these studies. Everyday life with dementia almost always involves other significant persons. Therefore it will be important to address the possible implementation of the findings of Studies I-IV in interventions including the caregivers, such as spouses and health care professionals in future studies.

Although special support may be lacking, the findings of this thesis have implications for how caregivers, occupational therapists and other professionals can contribute to the well-being and the maintenance of the everyday occupational life of these persons. The need for home interventions to support persons with dementia to continue to live at home for as long as this is meaningful to the person has been acknowledged in research (Gitlin et al; 2001; Vikström et al., submitted). The findings of the studies in this thesis can hopefully contribute to the development of such intervention programs by providing enhanced knowledge of issues such as the meaning of occupations and the characteristics of awareness as it may be expressed in daily life. In conclusion, some of the clinical implications of this thesis are:

- As shown in Study I, cognitive impairments and dementia in people who still work influence the person, the co-workers and the family. In accordance with the finding of this thesis, several aspects have to be considered in planning future support for the individual, including the person's ability to work and his or her own experiences of the situation and wishes to continue, the possibilities of the workplace and employer to adapt and the length of the sick-leave.

- The findings from Studies I-II suggest that interventions supporting everyday occupations that have significant meaning to the individual might contribute to maintaining and fortifying the person's apprehensions of being a contributing person and reach beyond the traditional view of the person with dementia as a passive and receiving person.
- The findings from Studies I-III indicate that supporting everyday occupations that build on the resources of the person is suggested to improve the well-being of the person with dementia, including allowing and encouraging the person to give up occupations that are too demanding or that have lost their individual inherent meanings for the person.
- The findings from Study II particularly indicate that occupations with individual meaning have the potential to be used therapeutically in interventions as a means to provide opportunities to the person with dementia to experience competence, contentment, and enjoyment, and thus contribute to his or her well-being.
- Taken together, Studies III and IV showed that using both interviews of the persons' own accounts and assessments in examining awareness of disability might provide a broader base for interventions and provide a more comprehensive understanding of the nature and implications of awareness of disability in everyday life occupations.
- Overall, the findings from all four studies suggest that persons with dementia, although in a continuous process of change where their capabilities are constantly challenged, also have resources that are co-dependent on the environment as well as on the occupation they are engaged in. Their experiences are in part also dependent on the interaction established in these occupations. Caregivers, healthcare professionals and spouses have an important role in guiding and supporting the persons in this process by approaching them with an open mind to their resources and providing them with opportunities to express their evasive situation and to build interventions on individual assets.

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