Supporting persons with dementia and their spouses’ everyday occupations in the home environment

Sofia Vikström
"No man is an island, entire of itself ;
every man is a piece of the continent,
a part of the main".

John Donne
1572-1631
ABSTRACT

The overall aim of this thesis was to investigate how persons with dementia and their informal caregivers do every day activities together and to evaluate the result from an intervention designed to encourage mutual engagement. The sample in all four studies consisted of 30 cohabiting couples, where one part was a healthy spouse caring for a partner diagnosed with mild to moderate stage dementia. Study I had a twofold focus: to identify the supportive acts that caregivers spontaneously use in everyday occupations, as well as to describe the consequences of those acts on the person with dementia. Study II aimed at describing the individual participants’ perception of their own, their spouses and their mutual engagements in everyday occupations.

In Study III and IV a home-based collaborative intervention including training on a functional as well as activity level, was evaluated. In Study III the effects of the intervention was evaluated through assessing the individual and mutual episodic memory-functions in the persons with dementia and their caregivers. In Study IV the intervention effect on caregivers’ communication and interaction skills when performing an everyday occupation together with their spouses with dementia was evaluated.

The findings in Study I showed that the caregivers to the persons with dementia used a wide range of supports when working together with their partners. Most of these supports were shown to be beneficial to the occupational performance of the person with dementia, although some support that had negative impact on the performance of the latter was identified.

The findings in Study II showed that both spouses perceived a loss of social and activity engagements as a consequence of the changes due to one having dementia. The caregivers described dilemmas they faced, but they also had management approaches to handle the altered everyday life.

The results in Study III and IV showed that the collaborative intervention had a positive effect on the individual memory-performance of the persons with dementia. Also, Study III showed that the persons with dementia had a learning potential regarding individual episodic memory-functions when included in collaboration.

In conclusion, the findings of these studies showed that the persons’ with dementia and their spouses’ engagements in everyday occupations were perceived as altered by both of them. The caregivers and the persons with dementia demonstrated different resources in finding strategies to solve the consequences of dementia in their everyday life. The identification of how persons with dementia and their spouses can learn strategies to collaborate might be useful in designing future interventions.

Key words: Activity, dementia, occupation, home-based intervention.
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1 INTRODUCTION

“How we have always helped each other, been chitchatting if we were in the same room. We have grown together into one in a way during the years.”

This quotation, from an interview with a spousal caregiver to a person with dementia, illuminate one point of departure for this thesis, which is to take on a social approach on everyday occupation in dementia.

The subject for this thesis is how persons with mild to moderate dementia, and their informal caregivers do everyday occupations together. The focus on doing something together, as opposed to individual engagement, is needed because of the consequences of the disease for the person with dementia in everyday occupations. These consequences include difficulties for the persons with dementia in handling everyday demands such as e.g. cooking, dealing with one’s own economy or pursuing errands and lead to a need for engagement and support from others (American Psychiatric Association, 2004; Farran, Loukissa, Perraud & Paun, 2003). Hence the consequences are also social in nature: the occupational difficulties impact the everyday life of the people around the person with dementia who as a consequence are involved. When research have included persons with dementia and their caregivers in everyday life activities, the focus has commonly been on compensation for the functional losses of the person with dementia, in order to enable optimal individual functioning, or on the situation of caregivers such as how to reduce caregiver’s burden and stress or support their coping abilities (Dooley & Hinjosa, 2004; Gitlin, et al, 2003a; Haley et al, 2004). However, research has rarely focused on the engagement in, and performance of everyday occupations from a social perspective (see Schulz, 2000 for an overview). Because persons with dementia need support from others to function in everyday occupations, knowledge about how both parties perceive support and can be supported is needed (Bourgeois, Schulz, Burgio, & Beach, 2002; Heinrich, Neufeld & Harrisson, 2003; Redmann & Lynn, 2004; Quayhagen & Quayhagen, 2001).
In this thesis, the following key-concepts are used.

**Human Occupation.** Within this thesis, *human occupation* is understood as a dynamic system, as in the Model of Human Occupation (MoHO) (Kielhofner, 2007). According to MoHO (Kielhofner, 2007), several intrapersonal factors as well as interpersonal and external/environmental factors, dynamically interplay in occupational performance. In line with the American Occupational Therapy Association documentation (AOTA, 2002), occupations will be defined as activities of everyday life, named, organized and given *value and meaning*, by individuals in social interaction and by a culture. Activities, are here defined as a term that describes a class of human actions that are goal directed (AOTA, 2002). We here expand our definition of activities to include such actions we commonly make in everyday life without necessarily giving it a strong sense of meaning or viewing it a clear goal.

**Social environment.** Spousal, or informal caregivers can be viewed as part of the social environment. The social environment from an occupational therapy point of view is often defined in line with Kielhofner (2007) as the social and cultural form, patterns and processes that influence a person’s or a groups’ everyday occupations. In this thesis, the view of the social environment is narrowed to mainly incorporate the spousal caregiver and friends.

**Social interaction.** Social interaction is in this thesis defined as the ability to engage with others in casual and sustained relationships individually, and within the context of a variety of small groups (Mosey, 1986).

**Collaboration** is here used as an overall term for the engagements that co-habiting persons in different ways perform together in everyday life occupations towards a goal (Bourgeois, et al, 2002; Heinrich, Neufeld & Harrisson, 2003; Zarit, Femia, Watson, Rice-Oeschger, & Kakos, 2004).

**Caregivers** are in this thesis, persons who provide informal, unpaid assistance, care and support to a co-habiting person with dementia (Jansen et al., 2007).
The studies within this thesis have had several focuses. First, the focus has been on identifying ways spouses support their partners with dementia, when providing support on their own initiative. Moreover, identifying how persons with dementia and their spouses, who live together perceive their doing together in everyday occupations have been in focus. Finally, focus has been on creating and evaluating an intervention that addresses collaboration in everyday occupations in couples where one part has dementia.
2 BACKGROUND

The background in thesis will include the following: The starting point will be the dementia disease and its consequences in everyday occupations for persons with the disease and their informal caregivers. In addition, the consequences of dementia for caregivers and the effects dementia can have on the cognitive functions of the person with the disease are presented. Second, interventions, theoretical and philosophical resources for interventions, and the importance of the social environment for interventions will be presented. Thirdly, occupational perspectives on persons with dementia and their caregivers are presented including reflections on the idea of engagement together in occupations. Finally, the problem area for this thesis is identified.

2.1 DEMENTIA DISEASE AND ITS CONSEQUENCES

Dementia and its consequences in everyday occupations

Dementia diseases - such as Alzheimer’s disease, Vascular dementia and other subtypes of dementia - are progressive disease syndromes that lead to a gradual deterioration of cognitive functioning such as memory and visual perception, affecting abilities to perform everyday occupations (American Psychiatric Association, 2004). The two most common types of dementia are Alzheimer’s disease and Vascular Dementia. Both eventually lead to memory impairment as well as cognitive impairment included one of the following: Aphasia (language disturbance), Apraxia (impaired ability to carry out motor activities despite intact motor function), Agnosia (failure to recognize or identify objects despite intact sensory function), and disturbances in executive functions (planning, organizing, sequencing and abstracting).

The cognitive deficits usually cause significant consequences in social and occupational ability that lead to increasing dependency (American Psychiatric Association, 2004). Such consequences range from performing routine tasks and being aware of the surroundings, to communicating effectively and making good judgements (Alzheimer’s Association, 2007). Although there may be some differences in the very mild stage of Alzheimer’s dementia compared to vascular dementia, it has been suggested that, as the disease progresses, the neurological damage becomes so widespread that observable differences in the diseases are difficult to identify (Lenzi & Altieri, 2007). Therefore,
this thesis uses the more general term ‘dementia’ when referring to the participants in the included studies irrespective of the diagnosis - Alzheimer’s or Vascular dementia.

Memory related consequences in dementia are characterized by a decrease in episodic memory functions- i.e. memory for personally experienced events or material, but also in semantic memory (memory for general information) and prospective memory, including remembering that something needs to be done, and doing it in the appropriate time. In comparison, procedural memory (memory for motor skills needed to perform occupation) appears to be relatively spared in dementia (Kasl-Godley & Gatz, 2000).

It must be noted that there has been little support in the literature for an overall cause and effect relation between cognitive functions and consequences in occupational performance. Rather, empirical findings indicate that the consequences of dementia are complex, and that differences in performance in cognitive assessments (e.g. the Mini Mental State Examination (MMSE) (Folstein, Folstein & McHugh, 1975) are not necessarily mirrored in occupational performance in a familiar environment (Guralnik & Kaplan, 1989; Kielhofner, 2007; Nygård, Amberla, Bernspång, Almkvist & Winblad, 1998).

From a functional viewpoint, the symptoms of dementia disease are often described in three stages, mild, moderate or severe stage dementia (Wimo, Jönsson, Karlsson & Winblad, 1998). According to such stages the participants in the studies in this thesis are in a mild to moderate stage of the dementia disease. However, the focus in this thesis is on the everyday occupations of persons with dementia rather than the stages. In addition, the described stages are not always easily distinguishable in individuals. Hence, a description of the commonalities of occupational consequences in mild to moderate stage of dementia, taken together will be presented.

In the very early, mild stage of the disease, difficulties in occupational and social functions are subtle. Differences in occupational performance might mainly be apparent to the persons with dementia themselves, co-habiting partners, close friends or workmates (Öhman, Nygård & Borell, 2001). Also, in the mild stage dementia the person with dementia may start to experience perceptual problems such as difficulties finding the ways at home, and even more commonly in the, well-known, outdoor neighbourhood. Placing items in their right place at home, as well as finding them, is
often becoming difficult. Furthermore, engagements in instrumental activities of daily living - such as managing finances, handling everyday technology and riding with public transportations (Fraker, 2007; Nygård & Starkhammar, 2007) - can be affected. Also, in the mild stage of the disease the person with dementia might experience difficulties in performing instrumental activities in daily life such as shopping groceries, cooking and managing medication, while in the moderate stage eventual difficulties in basic activities such as managing personal hygiene and dressing might also appear (Gitlin et al, 2003b).

Two aspects of change in the person with dementia are often apparent: changed ways of engaging in everyday activities including increased disengagement and lack of interest, and/or inconsistencies in emotional responses (Wimo et al., 1998). Such aspects are commonly explained with persons in early stage dementia perceiving a loss of confidence in their abilities to continually perform everyday occupations the way they are used to it (Pratt, Clare & Kirchner, 2006). However, although they might lose confidence in their occupational performances, persons in mild to moderate dementia have been identified as having a multitude of management strategies in everyday life (Nygård, 2004). For example, they can balance between accepting, or avoiding challenges in activities. More specifically they aimed at either activating themselves by adjusting occupational performance or habits, or choosing to avoid challenges and relinquishing. Examples of the latter being to avoid too taxing situations, like unfamiliar places and activities or situations, where their competence might be inadequate (Nygård & Öhman, 2002). Perhaps some of the avoidance of taxing situations might are a consequence of the thoughts of worrying over loss of occupational roles persons with early stage dementia describe (Öhman, Josephsson & Nygård, 2007) and experiencing depressiveness (Husband, 2000).

Another aspect adding to everyday consequences of dementia disease is the technological development in society. These have been shown to contribute to problems in the everyday life of the person with dementia (Nygård & Johansson, 2001; Nygård & Starkhammar, 2003; Nygård & Starkhammar, 2007). In these studies, the persons with dementia have shown problems in compensating for their difficulties in handling everyday technology arising not only concerning new technology, but also such technology that could be considered to be familiar. Typically, the difficulties were
perceived and/or shown in complex combinations, for example where the timing could be failing, although it was performed logically correct (Nygård & Starkhammar, 2007).

In time, memory-problems become more pronounced along with difficulties in conceptualizing, judging, planning, organizing, abstract thinking, and speaking. Furthermore, as the disease symptoms progresses the speech might become less fluent and might decrease. Thus, talking may become impulsive, and sometimes even inappropriate (Fraker, 2007). This in turn, can be hindering the withholding of social relations, including the closeness of the spousal caregiver (Garand, Dew, Urda, Lingler, Dekosky et al, 2007). A complicating factor in this moderate stage of dementia is that the early occupational performance problems often become more obvious and are usually compounded by loss of initiative and motivation (Wimo et al, 1998).

The above mentioned changes can increase the risk of the person with dementia becoming generally passive, resulting in deteriorating body-functions (Grossberg & Desai, 2003). Passivity has also been shown to increase the risk of depression that may cause further unnecessary disability in persons with dementia (Kitwood, 1997). In turn, depression in persons with dementia has been shown not only to be associated with poor health in them themselves, but also with poor health in their informal caregivers (Sewitch, McCusker, Dendukuri, & Yaffe, 2004).

In conclusion, persons with dementia experience profound consequences in their occupational life during the course of the dementia disease, affecting the way they live their lives. Hence, providing support in such a changing life-situation has been suggested to be an important avenue for interventions towards persons with dementia.

**Demographic data on persons with dementia and their families living at home**

Five to ten percent of persons over the age of 65 years in Sweden have a dementia disease, and this very large number is a result of that people live longer. In 2005, the number of persons with dementia disease in Sweden was estimated to be about 142,200 where a bit over half of them (76,700), still lived in their own homes. In addition around 25,000-30,000 people develop a dementia disease every year (Socialstyrelsen (SoS), 2007b). Alzheimer’s disease and vascular dementia represent 70-85% of all cases of dementia (Larsson & Thorslund, 2006; Ritchie & Lovestone, 2002). At present, there is no pharmacological therapy that can cure Alzheimer’s
disease. However, some pharmaceuticals can delay the cognitive functional impairment and symptoms (E.g., Rive, Vercelletto, Delamarre Damier & Cochran, 2004; Sörensen, Duberstein, Gill & Pinquart, 2006; Wimo, Winblad, Stöffer, Wirth & Möbius, 2003). A consequence of that delay is that persons with dementia might remain in a mild to moderate stage of dementia for a longer period of time, with related need for support or assistance from others (Winblad, Wimo, Möbius, Fox & Fratiglioni, 1999). In addition, pharmaceuticals do not affect everyone with dementia, a result that further underscores the need for non-pharmacological interventions (Wimo et al., 2003).

What is noteworthy is that there is a demographical trend in the western world, that the average recipients of informal care were both older and more disabled in 1999 than in 1989. Moreover, there is a striking increase in the proportion of informal caregivers working alone - without any professional caregiver involvement. These data underscore the importance of identifying viable strategies to support family caregivers (Wolff & Kasper, 2006). Although no figures have been found concerning the percentage of informal caregivers who care for persons with dementia in Sweden, Szebehely (2000) found that for people 75 years and older approximately 20% of spouses provide care, 20% of care was performed by another close individual, and only 15% received assistance from social programs. The rest of the individuals (45%) lived at home without any announced need for assistance (Szebehely, 2000). The facts demonstrate how informal care for persons with dementia is very common.

In conclusion, the literature review shows that persons with dementia are an increasingly growing part of the population, a population that might become an increasing concern for Swedish healthcare. In addition, informal caregivers provide much care for people with early to moderate stage dementia.

**The tradition on viewing the individual as the client**

As can be seen in the chapter on demographics, the social environment of persons with dementia takes a large responsibility to care. However, the legislation as well as the ethical guidelines in healthcare and for occupational therapists (FSA, 2005), have a focus on the individual rather than on persons in their social setting. For example, The Swedish Health and Medical Services Act (In Swedish: Hälso- och Sjukvårdslagen (HSL, 1982)) entitles people access to healthcare professionals on
issues that concern their health. Furthermore, healthcare professionals are obliged to pay attention and to protect the interests of those who need support to claim their own rights (HSL, 1982). In accordance, Jansson & Norberg (1992) concluded that formal caregivers such as practicing nurses, tend to rate the persons with dementias’ autonomy very high.

Although there are several studies, including some of the mentioned, that has identified the challenging work that informal caregivers do, often at the expense of their own health (Covinsky et al, 2003; Ory, Hoffman, Yee, Tennstedt & Schulz, 1999), Swedish municipalities tend to rely on informal caregivers to provide care (Almberg, Grafström & Winblad, 1997; Johansson, 2007; Hjulström, 2007; Larsson & Thorslund, 2006). This trend can also be found in Great Britain (MacDonald & Cooper, 2007). And although health, and health promotion are important focuses of care, the code of ethics for occupational therapists (FSA, 2005) and legislations (HSL, 1982) continuously advocate for the importance to view those individuals who have a diagnosis, as their primary client. Hence, although knowledge on informal caregivers’ burden are extensive, their need for assistance might not be adhered.

Interestingly, occupational therapy theory and practice encourages a client-centred approach, a strategy that encourages a patient to help decide about the focus and nature of occupational intervention (Townsend, 1997). However, in most definitions of client centeredness the extended client – i.e., with inclusion of the closest family members – are in focus. It should be noted, however, that when the importance of family is included, the individual client is often the primary care recipient (Law, 1998). Furthermore, the World Federation of Occupational Therapists (WFOT) emphasizes that the personal preferences of the individual must be taken into account in the planning of service provision (WFOT, 2005). This relates to a common ethical principle in health-care, a principle that focuses on beneficence, doing good (and doing no harm) and striving to act in the patient’s best interest (Woods & Pratt, 2005). Harming people with dementia could be the result of viewing the patient as a ‘non-person’, where a caregiver believes the patient is incapable of making or contributing to decisions about their own lives (Woods & Pratt, 2005). However, healthcare professionals has been suggested to be aware of the risk that to ‘do good’ and create beneficence for people with dementia might lead to ‘doing harm’ as far as informal caregivers are concerned (Woods & Pratt, 2005). In this thesis, the ambition
has been to take into account both the interest and perceptions of the people with dementia as well as that of their spouses.

Consequences of dementia for informal caregivers

This chapter presents some demographics on caregivers as well as empirical findings on the consequences of dementia on informal caregivers.

The economic burden of dementia on society is high. The expense of healthcare raises a need to identify best practices for people with dementia and their caregivers (SoS, 2007b). However, recent Swedish statistics (SoS, 2007a) show that informal caregivers to persons with dementia generally provide care to an extent of 8.5 times the care the family is offered by the municipality. This means that informal caregivers perform a mere part of the provision of care for persons with dementia living in their homes. In accordance recent studies have identified that informal caregivers, to some extent, already possess resources to support their spouses with dementia in everyday occupations. For example, caregivers have described the need to reduce demands, guide and accompany their spouses (Phinney, 2007) and find ways to preserve strengths, maintain meaningful activities and aim for an appropriate level of assistance (Farran et al, 2003).

In addition, ethnographical observations and focus group interviews of informal caregivers identified that, besides being in charge of housekeeping and meal preparations, a large extent of more or less invisible care, aiming for the person with dementia to be able to function safely and securely is performed by the informal caregivers (Jansson, Nordberg & Grafström, 2001; Lach & Chang, 2007). Such safety-focused care has also been expected of caregivers to persons with dementia (Johansson, 2007; Runesson & Eliasson-Lappakainen, 2000).

As identified in the chapter of dementia disease and its consequences in everyday occupations, dementia causes may have a major impact on informal caregivers, even in its early stages. For example, caregivers to persons with dementia take responsibility for more household chores than do their spouses with dementia (Colling, 2004). Such indications of decreased occupational engagements of persons with dementia has also been showed and described by persons in early stage dementia (Öhman, Nygård & Borell, 2001).
Given the consequences of the disease and the progressive nature of the disease, informal caregivers might experience a sense of mourning due to the changing relationship and successive loss of a loved one (i.e. anticipatory grief) (Malaquin-Pavan & Pierrot, 2007; Moyle, Edwards & Clinton, 2002). The situation has been identified as complex given that caregivers need to accept the course of the disease while taking on the role of caregiver (Schulz, 2000). Informal caregivers typically provide support that range from assistance with activities of daily living to answer repetitive questions (Garand et al, 2007; Gitlin, Winter, 2003b). Furthermore, in contact with healthcare, informal caregivers have the challenge of communicating with healthcare providers meet, a challenge that requires observational and interaction skills with in-home helpers and physicians to describe their family member’s limitations and needs (Baum & Edwards, 2003).

Spouses living together for a long time develop extensive knowledge and insight into how their partners function. In line with this, close informal caregivers have shown to judge functional abilities in their partners with dementia very accurately (Loewenstein et al, 2001) and have deep knowledge of them (Perry, 2002). Hence, informal carers can be a valuable source for healthcare professionals. Studies on informal caregivers in Sweden have suggested (Johansson, 2007) and shown (Hellström, Nolan & Lundh, 2005) that caregivers have high ambitions regarding the occupational engagements in everyday life of their spouses with dementia. In accordance, the importance for health and social care to offer engaging activities for persons with dementia has been emphasized (Borell, Sandman,& Winblad, 1991; Johansson, 2007). Similar findings have also been found in international studies (e.g., Politis et al, 2004).

Although informal caregivers to persons with dementia have shown to respond differently to the increasing support their partner with dementia need, indications are that most informal caregivers perceive a need for a continued support from others during those changes (Andrieu et al., 2005). Studies taking a social perspective on the impact of caregiver strain in dementia have shown that informal caregivers needs might vary depending on how close the family is. For example, in a study by Lieberman & Fisher (1999) the researchers not only focused on the impact of the consequences of dementia on the primary caregiver, but on entire families as a unit, where they found that members in close families experience less stress than did less organised, busy family-members.
However, regardless of characteristics of the family, their routines are commonly disrupted, a situation that threatens isolating the closest caregivers from other family members and friends. Such isolation is suggested to risk resulting in a sense of loneliness (Beeson, 2003; Betts Adams, 2007). Also, when comparing informal caregivers to persons with dementia to caregivers to other persons with chronic conditions (Covinsky et al., 2003; Sewitch et al. 2004), studies show that levels of strain were significantly higher for caregivers of persons with dementia.

On the other hand, the caregiving experience may provide emotional benefits to the caregiver: they may manage to find meaning in caregiving (Andrén & Elmståhl, 2005; Farran, Miller, Kaufman, Donner & Fogg, 1999; Lee Roff et al, 2004). For example, Josephsson, Bäckman, Nygård & Borell (2000) demonstrated how informal caregivers were able to appreciate the potential of everyday activities as meeting-places for the caregivers and the persons with dementia when performed together. These caregivers related feelings of connectedness despite the fading dialogue and poor occupational performance of the person with dementia (Josephsson et al., 2000). Similarly, Jansson et al. (2001) also found that caregivers did not only practically care for their spouses, but they also showed in their daily actions that they emotionally, cared about their partner with dementia.

As can be seen by the review above, informal caregivers face a complex situation. A conclusion is that informal caregivers to persons with dementia handle their everyday caring situation in diverse ways and that the caregiver role also is complex. Caregivers are faced with physical and emotional challenges, but they also have opportunities for emotionally beneficial care situations.

2.2 POINTS OF DEPARTURE IN PLANNING FOR THE COLLABORATIVE INTERVENTION IN THIS THESIS

In this chapter the point for departure in planning for the interventions are presented and reflected upon. Occupation, here used to mean activities of everyday life, named, organized and given value and meaning, by individuals in social interaction and by a culture (AOTA, 2002) are often suggested to be fundamental to human existence.
According to Wilcock (1998) such an argument is underscored by two fundamental philosophical assumptions saying that: a) humans have a natural drive to be active and occupied, b) performance of occupations can contribute to fulfilling those needs (Wilcock, 1998).

A person with a disease or a dysfunction might experience that the consequences of the disease provide a hinder to perform the occupations that fulfil the need to be active. Building on this, there is a need to identify aspects that influence the possibilities for humans to be active. Within the The Model of Human Occupation (MoHO), Kielhofner (2007) draws on the systems theory to present circumstances within and around a person that affects occupational performance. In this thesis, the Model of Human Occupation will be used as a theoretical tool for us to better understand the way people occupy themselves.

In systems theory, a system is a set of interrelated factors that interplay with the environment and also changes over time. Applying system theory to explain occupational engagements for persons with dementia gives a wider focus than merely identifying functional capacities or occupational performance solely in the individual person. Instead, the dynamics that takes place between a person and the environment are in the fore (Kielhofner, 2007; Letts, Rigby & Stewart, 2003).

Occupational therapy also assumes the importance of the relationship between performance of occupation and experiencing oneself as competent (Christiansen, 1999). According to Christiansen (1999), maintaining the view of one’s self as a performer of, and a contributor in everyday occupations in the household, have positive effects on a person’s sense of competence. This way of reasoning highlights the importance of engagements in occupations for upholding a person’s practical competence and his or hers sense of competence. Furthermore, Nygård (1996) has shown that in the early stages of dementia, everyday occupations seem to have the potential of providing time for escaping from feelings of incompetence and anxiety. This may especially be the case when occupations are individually chosen and based on the specific meaning they provide for the person with dementia.

Another way of avoiding feelings of incompetence, and promoting occupation is to engage with people, socialization that has been suggested to be one factor that influence a person’s sense of competence (Christiansen, 1999, Borell, Asaba, Rosenberg, Schult & Townsend, 2006). For example, Gillies & Johnston (2004) found that a decreased
sense of competence derived from internal recognition (e.g. subjective experiences of failure in practical situations), as well as from external reactions, such as positive or negative caregivers approaches. Recognition from people in the social environment as well as provision of opportunities to engage in occupations seems to have importance influences on a person’s possibility to experience sense of competence. In line with the above reasoning, the present studies focus on social relationships and the participants’ engagements in everyday occupations.

Further, the present thesis bases the included intervention programme on three different resources. First, we build on the philosophical assumption for provision of support to a person suggested by Yerxa (1998). Yerxa proposed persons with difficulties performing occupations would benefit if “the just right challenge” is established in their everyday occupations. Here, the ‘right challenge’ is achieved when the demands of engagement in everyday activities matches individual skills. Yerxa (1998) suggests that provision of such well-adjusted support will increase the person’s ability to participate on her/his own terms without losing the sense of competence or finding participation to be boring. Further, by implementing and evaluating the notion of providing “The just right challenge”, in the present thesis we acknowledge and evaluate the effect of a notion that is often referred to not only by Yerxa (1998) but also other occupational therapy theorists (E.g. Nelson, 1995), but that to our knowledge, has not been tested empirically. In doing so, one issue that occupational research has been criticized for: the lack of evaluations of non-pharmacological interventions and theories are adhered to (Gräsel, Wiltfang & Kronhuber, 2003; Winblad et al., 1999).

Secondly, the idea of grading cues from cognitive psychology on supporting everyday memory is used (Bird & Luszcz, 1993). In line with the reasoning behind “the just right challenge”, support is provided with increasing grade of difficulty. The grading starts from the most difficult cue, from a support recipients viewpoint, and if needed, moving towards a gradually increased (more specified and helpful) support, and, if needed ending with hands-on support.

Thirdly, from educational theory on teaching skills teaching and learning strategy of role-modelling has been used (Minton, 2005). Role modelling traditionally means that one (often more knowledgeable) person attempts to transfer his/her knowledge to a learner by practically acting and illustrating the pedagogic ideas. The strategy of role-modelling was chosen for its opportunity to support learning by
intuition, such as how to handle delicate social interactions, rather than learning facts. Informal caregivers might identify how support could be delivered when viewing the support provided by a role-model rather than being told how it should be delivered (Minton, 2005).

In conclusion, the theoretical and philosophical resources for the intervention in this thesis are, Systems theory-based Model of Human Occupations and Christiansen’s (1999) reasoning on the relationship between occupational performance and sense of competence. Further, three specific pedagogic strategies have influenced the studies: the notion of support provisions according to ‘The just right challenge’. The hierarchic memory-support technique called ‘Graded cues’ and the pedagogic learning-teaching strategy of role-modelling.

2.3 THE INFLUENCE OF THE SOCIAL ENVIRONMENT

In this thesis, the informal caregivers and their interactions in occupations with persons who have a dementia disease are central. This shift of viewing people has gradually become more present in occupational therapy theory and practice. McColl (2003) describe that it was not until in the early 1940’s that the social feature in occupational engagements of people was recognized in occupational therapy literature. For example, it was noted that a person’s occupational performance benefited from social contacts such as working in groups (McColl, 2003). Hence, it was concluded that the support from the social environment concerning performance of everyday occupations can make a difference. This idea is also central in the Model of Human Occupation (Kielhofner, 2007) where the social environment is one of the environmental factors that is suggested to influence the occupational performance of a person.

One of the foundations for the idea that the social environment play a part in engagement of everyday occupations springs from traditional sociology theories, such as that of symbolic interactionism introduced by Dewey (1922). Within that tradition, an individual is viewed as a socially changeable human being that finds and understands herself through interactions with others. Mead (1967) another theorist in the field of symbolic interactionism, claims that a person’s social acts are perceived as meaningful only when they are performed in interaction with others. He explains that
all individuals are partaking in an ongoing adjustment and change of behavior, mainly as a response to how other people react and act. If linked to engagement in everyday occupation, this reasoning suggests that interactions with others assist to withhold our understanding of ourselves and in terms of the meaning we pose on what we do. In this thesis, it is argued that this reasoning is useful in working with persons with dementia and their caregivers. Berger and Luckman (1966), adding to the idea of interactionism, identify our daily perceptions and our knowledge of the reality as social constructions where the development or withholding of an identity can be viewed as a social construction appearing in an interaction process between people. Berger and Luckman (1966) argue that, although we are all part of creating our reality, interactions such as conversations, talks, or doing things together can be characterized by power structures between people, rather than equality. Similarly, in the social interactions between persons with dementia and their close informal caregivers, the consequences of the disease threatens to influence the power-structure between the two interacting persons. If such reasoning is applied to persons with dementia and their caregivers, it could be argued that the lack of equality between the two, or between the person with dementia and other people, bear the consequence that those people have to develop an understanding of what it is like to live with a dementia disease, in order to be supportive. In addition, how we understand the disease and its consequences is not only constituted by the disease and it’s symptoms itself. Rather, the view on dementia is also constituted by perceptions, values and discourses in society.

From a social interaction viewpoint, the communication between humans, such as between persons with dementia and spousal caregivers, could be viewed from a social responsiveness perspective (Asplund, 1987). In that view our elementary need to give, and call for responses in other human beings through dialogue is emphasized. Hence, Asplund (1987) points out that peoples’ acts often are performed within a framework or setting with others.

From an empirical standpoint, - e.g., studies of elderly residents in institutional care - it has been suggested that a lot of what residents do are likely to be results of caregiver acts and communication (Asplund, 1987; McCallion, Toseland, Lacey & Banks, 1999; Norberg, Melin & Asplund, 2003; Normann, Asplund, Karlsson, Sandman & Norberg, 2006). Asplund (1987) claims that what caregivers say or do (often with good
intentions) does not reveal itself as anything before the person who receive the message answer. Not until then is the actual comprehensive meaning of the act or saying is presented. He argues that our urge to pose questions and to be able to get a conversation going where one can contribute with answers is a complex behavior that amongst others explains how group norms develop. In the empirical findings mentioned above, it is discussed whether some lack of responsiveness from persons in advanced dementia might be attributed to the caregivers’ failure to engage properly (Norberg et al, 2003; Normann, Asplund & Norberg, 2002).

It has also been stressed that the emotional climate of care giving is also influenced by the caregiver-recipient’s perceptions. More explicitly, as in the social constructivist view and the theory of social responsiveness, the emotional climate is constructed in a process between the parties, depending on their response to each other. Hence, persons with dementia might influence the care-giving interaction (Olsson & Ingvad, 2001). Although the above reasoning has been developed in research in institutional settings, it can be argued that it is applicable also for persons with dementia and their caregivers outside institutions.

Both Mead’s (1967) symbolic interactionism-reasoning that personal meanings of acts depends on interaction and Asplund’s (1987) social-responsiveness view that stresses the importance of dialogue in social interaction can be further related to The Model of Human Occupation. As alluded to earlier, the MoHO underscores how the social environment influences the intrapersonal factors, such as the individual’s perception of their personal causation, roles, and continued habits as well as interpersonal ones (Kielhofner, 2007).

So far, the social environment has been addressed regarding individual functioning, as well as a resource for human. However, the tradition of the social environment is complex. In 1973, Lawton and Nahemow (Lawton, 1999) introduced a model of adaptation that predicts outcomes associated with the interaction between a person, characterized in terms of competence, and an environment of a given level of demands (press). In the model they describe the linear correlation between grade of environmental press on the competence grade in the individual. They concluded that, the less competent the individual the greater the influence of the environment on the
outcome of the occupational performance. In a similar vein, Lawton and Nahemow (Lawton, 1999) suggest that the environmental press, if relieved (e.g. by another individual) would transfer the individuals with occupational performance problems from a ‘zone of negative affect and maladaptive behaviour’, to a ‘zone of maximum comfort’.

Furthermore, if receiving care with aspects of training in it, such as by using ‘the just right challenge’ support idea, a zone of maximum performance potential might be reached. This suggests that the social environment could be helpful in decreasing the gap between the percipient’s ability/or competence and the environmental demands. Hence, there might be a value in having a person support or guide individual’s with limitations in their process of learning new or regaining ‘lost’ achievements. It has been suggested that Lawton & Nahemow’s ideas could be used in research on persons with dementia and their caregivers because the notion of such a performance potential could enhance caregivers’ ability to support more consciously the persons with dementia (Gitlin et al, 2003b). Lawton’s and Nahemow’s model can be critizised for being linear in its reasoning, while other contemporary models identify a more complex, dynamic understanding. Nevertheless, the potential Lawton & Nahemow (Lawton, 1999) suggest for a supportive person is something that might be a fruitful avenue for intervention.

I would like to argue that there are implications from the social perspectives that address the engagement in occupations for persons with dementia. Dementia, for example, gradually increase a couples’ need to make use of people around them in order to function. Furthermore, in studies focusing on collaboration or interaction with others for persons with dementia, it has been recommended that communication is not only created by talking, but also by actions and doing things together (Josephsson et al, 2000; Norberg et al., 2003; Normann et al.,2002; Normann et al., 2006). The social interactions that people use, according to Mead (1967), to understand themselves through the reactions of others as well as the social responsiveness view (Asplund, 1987), where one is suggested to show meaning through acts and engagements , both indicate that communication and performance of activities are socially constructed.
2.4 INTERVENTIONS IN DEMENTIA

Interventions towards caregivers to persons with dementia

When evaluating studies focusing on informal caregivers to persons with dementia, a main focus has been on sense of burden, and experienced role-change for the caregiver (Haley, et al, 2004; Lee Roff et al., 2004; Sällström, 1994). Typically, psychosocial or psycho-educational caregiver interventions focus on decreasing the sense of burden and increasing sense of wellbeing and mood. For example, such interventions have offered caregivers participation in support groups, including information about the disease and information about environmental support strategies (see Schulz, 2000 or Sörensen, Duberstein, Gill & Pinquart, 2006 for an overview), or provided meeting centres (Dröes, Breebart, Meiland, van Tilburg & Mellenbergh, 2004). However for persons with dementia or their caregivers, most interventions only have modest effects on improving wellbeing and mood, and reducing caregiver burden (Mittelman, Roth, Haley & Zarit, 2004; Schulz, O’Brian, Czaja, Ory, Norris, Martire, et al., 2002). There are some exceptions: individual therapy sessions that address, so called behavioural management, focused on adhering to the care recipients behaviour (Farran et al, 2007; Gerdner, Buckwalter & Reed, 2002; Selwood et al. 2007). However, Gerdner et al. (2002) showed that a psychosocial intervention could have a beneficial impact on the frequency and quality of response to problem behaviours among spousal caregivers. This study did not show a decrease in performance of everyday occupations among care recipients. Similarly, Mariott, Donaldson, Tarrier, and Burns (2000) showed inconsistent results over time with respect to disturbing dementia behaviour, such as wandering and aggressive outbursts, decreased significantly at post-test, and they found no difference in comparison to controls at follow-up. In contrast, in assessments of activities of daily living for the persons with dementia, the same study showed that there was no difference between the groups at post-test, but there was a difference at follow-up. These results indicate that interventions to support activities of daily living among persons with dementia may need a longer time of training before potential changes show in assessments or that the assessments used were not sensible to change.

Another focus of caregiver interventions have been to reduce caregiver stress and improve their strategies for coping with the caregiving situation (Lévesque et al, 2002; Lavoie et al, 2005; Selwood et al, 2007). The above suggested outcome measures
focusing on the caregiver’s perceptions of their situation, are commonly used for informal caregivers (Brodaty, Thomson, Thimpson & Fine, 2005). Note that few studies target the practical acts of the caregivers in the performance of everyday occupations. However, one solution to caregiver burden presented in the literature, that aim to relieve the practical everyday life of informal caregivers, is provision of respite, meaning a planned, temporary time relief. Traditionally, respite comes in the form of day-care service, occasional in-home care, or a limited period of institutional short-time care (Messecar, 2000).

The need for respite might be even more important for caregivers, if they have adhered to findings from recent research focusing on the wellbeing of the persons with dementia, recommending that informal caregivers should support the person with dementia to remain actively engaged in everyday occupations as long as possible (Graff et al, 2007; Selwood et al, 2007). One of the reasons for such engagement being postponing decline of, or enhancing, cognitive abilities in the person with dementia (Bates, Boote & Beverly, 2004; Bäckman, 1996) or performance of daily activites (Graff et al, 2006) despite the disease. Another reason has been to enhance the quality of caregivers’ assistance and sense of competence (Graff et al, 2007; Winblad, Wimo, Mőbius, Fox & Fratiglioni, 1999).

In addition to these findings, other arguments for continued engagement in occupations for persons with dementia and their caregivers have been that persons with dementia might view everyday occupations they can still handle, as ‘resting places’ (Nygård & Borell, 1998). Further, caregivers have described an interest in their spouses with dementia receiving motivational occupations in their everyday lives (Johansson, 2007; Sällström, 1994) and an ambition for the care to be of high quality (Almberg, 1999), and for the two of them to ‘meet’, or have a social connectedness in occupations (Josephsson et al., 2000). Likewise, relying on informal caregivers to provide support has been suggested to be useful both in enabling persons with dementia to retain their present abilities as well as retaining their own sense of well-being (Bond & Corner, 2001; Bonner & O’Brien Cousins, 1996; Pratt et al, 2006). However, to provide support, the informal caregivers need support themselves. In an occupational therapy intervention (Dooley & Hinjosa, 2004) towards persons with dementia and their informal caregivers, caregivers were suggested to use one or several of the following strategies in their encounters with the person with dementia: give directions to take one
step at the time, suggest activity when the person with dementia was unoccupied, remind to use visual cues like instructive lists, or adaptive equipment. These strategies were reported to result in higher levels of independence in the persons with dementia and less experienced burden in the informal caregivers (Dooley & Hinjosa, 2004).

In addition, multidisciplinary interventions to support informal caregivers to persons with dementia have aimed at for example reducing distress and isolation (Brodaty, Gresham & Luscombe, 1997) or have focused on clarifying the caregiver’s role and helping the caregiver by provision of mastery-focused coaching (Hepburn, Tornatore, Center & Ostwald, 2001). For example, in a case study by Graff et al, (2006b) a MoHO- based guideline was applied that explored the impact on an individual patient and his caregiver through observation and through patient and caregiver narratives, out of which individual goals were set. Findings revealed that care recipients reported more initiative, autonomy and pleasure in performing daily activities, whereas informal caregivers reported improved communication and supervision skills. These qualitative findings were consistent with quantified assessments (Graff et al., 2006b). However, none of these studies identified convincing generalised benefits of the interventions.

Some intervention studies use a strong educational approach towards informal caregivers to persons with dementia. For example, programmes in which single group leaders teach or train the caregiver to improve their own mood and sense of mastery have been described (Gerdner et al, 2002; Teri 1999; Hoyt, 2001). In other educational programmes, informal caregivers have either been taught to improve their coping abilities (Bourgeois et al, 2002; Hebert et al, 2003) or received group activities with support and information from a home-care support centre (Nomura et al, 2007; Teri, 1999; Hoyt, 2001) often with the intention to empower the participants. In common for these educational efforts were that they all focused on the mental status of the caregiver which in some studies was assumed to positively impact the person afflicted with the disease. However, because these studies had limited success, the interventions did not target the individual persons’ problems (as suggested by Katona et al, 2007), and a design flaw that did not motivate them to learn. In a pedagogical paper, Coates (1995) argue that a learner needs to identify his/her individual need to learn, for that learning to be successful. To do so, it might be beneficial to identify what knowledge they perceive they lack and what skills caregivers possess (Briggs, Askham, Norman & Redfern, 2003).
In conclusion, common approaches to support caregiver management of everyday life with person with dementia are offerings of respite, increased sense of well-being through e.g. information and offerings of group-discussions and workshops. However, as can be seen from the review above, few studies have focused on the resources informal caregivers and the persons with dementia possess, and the strategies they use in their engagement and interaction with each other when performing an everyday occupation.

**Non-pharmacological interventions towards persons with dementia**

As noted earlier, persons with early dementia have shown that they are often aware of their disability. This awareness can be seen as a resource when discussing the current and forthcoming need for support in everyday occupations (Downs, 2005; MacQuarrie, 2005; Öhman et al, 2007; Nygård, 2004). This reasoning concur with Spencer’s (2001) call regarding the increasingly older population, stating that home-care ought to focus more on engaging the older person in everyday activities to secure their health and quality of life in the remaining years. Hence, interventions have been developed to support engagement in occupations for persons with dementia. For example, such interventions have offered environmental adjustments and/or suggestions for structuring occupations, and manifestation of occupational patterns in the person with dementia in everyday tasks. Usually these interventions are aimed at enhancing the individual functioning of the person with dementia (Gitlin et al., 2003a; Schulz et al., 2002).

Similar to the results of the studies referred to above, the individual performance of the persons with dementia was only partially affected when adjusting the environment, in a study by Josephsson, Bäckman, Borell, & Bernspång (1995). However, a relationship was found between the quality of the person’s performance, and the quantity of verbal support received in terms of encouragements and feedback they got from others. In a similar vein, most of the non-pharmacological interventions towards persons with dementia have come to the conclusion that even though environmental adjustments and compensatory strategies can be beneficial in early phases of the disease, ongoing support from others is required (Gräsel et al, 2003). Consequently, a focus on the
individual perspective might need to complemented with a social, interactive perspective on occupation (Josephsson et al., 2000).

In line with that reasoning, there are interventions that have aimed at focusing on the individual functioning of both the persons with dementia and their caregivers, in combination with environmental adjustments in the home (Bates et al, 2004; Graff et al., 2007). In the latter study, occupational therapists attempted to find motivational, motor, and process resources in the persons with dementia, as well as supportive resources in their close caregivers (Graff et al., 2007). Commonly the participants received environmental adjustments, information on the disease, assistance in prioritizing activities, and feedback on their own strengths in performing them. This intervention had statistically beneficial effects on quality of life, mood and health status (Graff et al., 2007). A strength in the study, seldom seen in others, was that the persons with dementia and their caregivers received assistance to highlight their most valued occupations, and focus was set on those. As a contrast to the occupationally focused interventions for persons with dementia presented above, interventions have also been applied on a functional level, particularly targeting memory functions.

Memory training for persons with dementia, have traditionally been suggested to build upon the functions that are relatively unaffected during the first phases of the disease, such as the procedural memory and the perceptual representation system (Bäckman, 1996; Camp, Bird & Cherry, 2000; Clare & Woods, 2004). Indications are that these functions may remain relatively intact as long as they are practiced (Cahn-Weiner, Malloy, Rebok & Ott, 2003; Hill, Bäckman & Stigsdotter Neely, 2000; Woods, Cook, Orell & Spector, 2005). However, as not everything a person needs to recall is reasonable to practice, studies that focus on supporting memory skills in persons with dementia have often aimed at enhancing a more narrow memory recall, not seldom with a specific purpose such as remembering a name or a way to act. More specifically, strategies such as the spaced-retrieval technique (Camp et al, 2000), cued recall (Bird & Luszcz, 1993), and the theory of errorless learning (Haslam. Gilroy, Black & Beesley, 2006) have proven to have some effect on the memory, and isolated actions in persons with dementia. However, although most studies using these strategies have shown beneficial results they have not been altogether consistent.
A variety of memory strategies encouraging encoding processes for learning specific facts have been employed with modest, but favourable outcomes for persons in the early stages of dementia (Bäckman, 1996; Thoene & Glisky, 1995). However, a conclusion from the latter studies is that cognitive support from others must be provided at both information acquisition and retrieval (Bäckman, 1996). Hence, a consistent, enhanced individual functioning in persons with dementia seems hard to reach.

Memory strategies to enhance memory performance related to tasks in everyday life in persons with dementia have also been used. These strategies include environmental adaptations such as signs, and marks on doors, external aids including lists with instructions or reminders of what to do and perhaps how to do it, and rehearsal and repeated encodings (Gitlin, 2003; Woods, 1999). Again, most studies show that reminders by others are crucial for a continued use of such aids. Interestingly, these strategies do to a large extent concur with the strategies persons with mild stage dementia have shown to use on their own initiative to handle difficulties in everyday occupations caused by memory problems (Nygård, 2004).

Hence, persons with dementia seem to practice their cognitive skills in everyday occupations on their own initiative, which in turn has been suggested to be important to avoid loss of remaining functions (Wilson, Scherr, Schneider, Tang & Bennett, 2007). Again, other studies have indicated that there might be beneficial gains by merely being continuously engaged in, and thus practice, everyday occupations (Barnes, Mendes de Leon, Wilson, Bienas & Evans, 2007; Bassuk, Glass & Berkman, 1999; Bennett Schneider, Tang, Arnold & Wilson, 2006; Karp et al, 2006; Lövdén, Ghisletta, and Lindenberger, 2005). Those studies all suggest, and show indications of, a possible decrease in rate of cognitive decline as a consequence of the increased occupational engagement. Consequently, it has been suggested that, if encouraged to be actively engaged in everyday activities, the time a person will remain in the mild- to moderate stage of dementia might be prolonged.

However, studies having enhancement of continued engagement in everyday occupations as a goal are rarely seen in dementia research. One exception was presented by Graff et al. (2006b) who, in a case-study had a social focus in their occupational therapy based intervention: they included both the person with dementia and his spousal caregiver. The intervention focused mainly on reaching beneficial
changes in the person with dementias occupational performance in everyday occupations and as well as in the caregivers caregiving role. As noted in the previous chapter, the intervention showed to be beneficial for the person with dementias occupational performance in that he took increased initiative to act, and showed an enhanced autonomy in, and appreciation for every day occupations. Also the caregiver improved their communication and supervision skills. This might indicate that also occupational based interventions might be beneficial for the persons with dementias occupational engagements.

However, in interventions towards persons with dementia and /or their caregivers, the factors addressed in interventions, and the ones measured to evaluate intervention outcome, has often been criticised for the uncertainty of what they actually target (Burgio et al, 2001). For example, enhancement of engagements in everyday occupations might have effects on the persons with dementia that does not necessarily show up in assessments with specific focuses on functions. Hence, a cause and effect relationship between what persons with dementia or their caregiver’s score in occupational assessments and what the same persons score in specific functional assessments is not often found (Guralnik & Kaplan, 1989; Nygård et al, 1998). Irrespectively of whether interventions are delivered with a focus on functions or occupations, a broad set of assessment that target different factors, preferably also including different data collection methods, has been recommended (Burgio, Corcoran, Lichstein, Nichols, Czaja, Gallagher-Thompson et al., 2001).

**Interventions including both persons with dementia and their caregivers**

Although the literature confirms the importance of including the social environment in interventions including persons with dementia, studies has traditionally been focused only on individual performance. Also, in a meta-analyses of studies which have focused on interventions made for increasing independence and wellbeing for persons with dementia, Woods ( 1999) conclude that the potential influence of the social environment provided by formal and informal caregivers is the appropriate target of future interventions. Furthermore, when Schulz et al (2002) charted the clinical significance in interventions studies made for persons with dementia they too welcomed studies where suggestions are that there might be important synergies achieved by simultaneously treating care recipients and the informal caregivers, and by
altering the social and physical environments via multi-component interventions. Schulz et al (2002) also point out that clients benefit from receiving support from an informal caregiver, even though they emphasize that there is a lack of knowledge on how informal caregivers support. Therefore, assessments that identify caregivers’ strategies need further development both in home care and in other community and institutional settings. This includes informal interview and observation techniques as well as more formalized evaluation tools. Similarly, Fidler and Velde (2002) highlight how significantly family and other relationships, and the broader social and cultural environment influence a person’s occupational performance. Again, a parallel to the systems theory approach used in MoHo, which also emphasise a similar spectrum of factors that affect the occupational performance of a person (Kielhofner, 2007) can be drawn.

Some researchers have shown that a group format, which may be one way to enhance social interaction, provides more benefits than individual training for healthy older adults (Flynn & Storandt, 1990), a conclusion that agrees with the idea that older people may benefit from engaging in (social) activities. In a recent review addressing whether people with dementia benefited from group-based cognitive interventions, it was shown that dementia patients could improve targeted cognitive skills following group training (Scott & Clare, 2003). However, it was also noted by the authors that a group format may be too taxing on the limited cognitive resources of the person afflicted with dementia, which may suggest against larger groups (Flynn & Storandt, 1987; Scott & Clare, 2003). Hence, a small group format, such as the closest family, may be optimal for persons with dementia. This was also supported in some home-based programmes supporting cognitive functioning for caregivers and spouses with Alzheimer’s disease (Quayhagen & Quayhagen, 1989,2001; Quayhagen, Quayhagen, Corbeil, Roth & Rodgers, 1995). The results from these studies demonstrated that for the participants with dementia, collaboration with their informal caregivers’ in cognitively demanding problem solving, function was enhanced and maintained over time compared to controls. The authors suggested that one potential factor contributing to these positive results was due to the increased social interaction between the spouses (Quayhagen & Quayhagen, 2001).

As mentioned earlier, Josephsson et al (2000), found that engagement together with a close relative in a moderate stage of dementia could be found beneficial for the performance of the person with dementia, and that the occupation used could be viewed
as a place to meet and communicate with each other. In addition, Miller and Butin (2000) found beneficial effects from letting both the persons with dementia and their informal caregivers participate in an activity-group programme (Miller & Butin, 2000). Hence, an occupational setting can also be a social arena. However, the everyday life activities and the social environmental focus was however adhered to in two intervention studies in dementia focus on supporting both spouses so that they more satisfactorily can live and function in their everyday lives together at home. Both studies succeeded in postponing institutionalization for the persons with dementia, but did not report increased wellbeing in the informal caregivers (Björkhem, Olsson, Rahm Hallberg & Norberg, 1992; Melzer et al, 1996). However, the difficulty of reaching positive outcomes in interventions with a social focus is a common criticism. Typically, studies are based on small samples (generating low statistical power) and lack follow-up data. Furthermore, although there are some promising exceptions, there is still a shortage of randomized clinical trials for persons with dementia and their caregivers (Schulz et al., 2002).

However, some studies that have a social focus - i.e., on both the persons with dementia and their caregivers - do exist. An example is a successful randomized control trial intervention study, where both education of caregivers and modifications of the environment was the focus (Gitlin, Corcoran, Winter, Boyce and Hauck, 2001). In this study, persons with dementia showed a decreased decline in occupational performance, and caregivers showed a reduced burden in some specific areas and to make extensive use of the modification, which the authors suggested would doubtfully be the case in interventions without extensive caregiver input. However, this study may not have fully considered the individual characteristics and preferences of the family members (caregivers). For example, the caregivers in that study could not build the intervention the way that they found suited them best, limiting their abilities to adjust their support as the dementia progresses.

Another encouraging finding suggests that interventions can be successfully applied in less controlled (real-world) contexts if they are directly focused on daily situations and include the perspective of the persons with dementia by letting them state their specific preferences concerning everyday occupations (Van der Linden & Juillerat, 2004). Hence, practicing in real everyday occupations could be of considerable importance to
postpone loss of remaining functions. However, the intervention cost of such flexible interventions has not yet been studied.

Since persons with dementia have very individual disabilities, and more importantly, as every other individual, have very different preferences and views in terms of their habits, roles and personal causation (Kielhofner, 2007), a more flexible solution for adjusting occupations is suggested. As indicated in the review, there are most likely, possible gains with introducing and combining support towards both persons with dementia and their close informal caregivers when forming interventions in their own home environment.

**The challenge of also engaging caregivers in dementia interventions**

Although several sources of literature recommend intervention for both the persons with dementia and their closest social environment (E.g. Katona, et al., 2007), such a focus might not be free from complications. One such complication could be the informal caregivers attitude. It has been empirically shown that a decreased sense of competence in persons with dementia does not necessarily derive from internal recognition (e.g. subjective experiences of failure), but also from external reactions, such as negative caregiver attitudes (Gillies & Johnston, 2004). Also, studies have indicated that caregivers to persons with dementia may react differently to the spouse’s disease and that caregivers are not equally suited, and probably not equally prepared, to collaborate with their spouses in solving everyday issues (Johansson, 2007; Sällström, 1994). There have been empirical studies showing that some caregivers have difficulties distancing themselves from the sometimes aggressive argumentation they face with their spouses with dementia, leading to a tension or even to a destructive home situation (Almberg, 1999; Sällström, 1994). Although caregivers have a potential to support the sense of competence in their spouses with dementia, support is not always easily provided (Gillies & Johnston, 2004).

The informal caregivers can modify their support to be either a responsibility of the caregiver herself, or to entail a mutual respect where the persons with dementia are invited to perform, under the support of the care-giving spouse. This agrees with some empirical findings that show that caregivers to persons with severe dementia might promote and enhance the episodes of lucidity (where a person function more
adequately), by having a supportive attitude during conversations. Such an attitude includes confirming the person as an important and valuable individual (Normann et al, 2002). In contrast, a case-study finding refined the focus on the necessity for caregivers to provide support. Sabat, Napolitano & Fath (2004) showed that in early dementia, the positioning of the person with dementia - i.e., accepting or resisting support and engagement with others - also influence the outcome. The study showed that people with a negative attitude might limit themselves to the social identity of a dysfunctional patient, in contrast to, if acceptance to care, experience a greater sense of competence (Sabat et al 2004).

In summary, relationships where one is a caregiver and one is dependent are always relationships with power structures built in them. Also, some relationships have been suggested to lack the depth and quality that might be needed as a foundation for engaging together (Chee, Gitlin, Dennis & Hauck, 2007; Johansson, 2007). To understand the everyday life situation for persons with dementia and their families, it has been recommended to take into consideration both parties’ (the caregiver and the person with dementia) perceptions on their practical everyday situation (Lyons, Zarit, Sayer & Whitlach, 2002) including the transitional processes they go through (Efraimsson, Höglund & Sandman, 2001).
2.5 IDENTIFICATION OF PROBLEM AREA

As the above literature review suggests, although healthcare professionals and researchers in health-care recently increased attention on assisting persons with dementia and their caregivers in their everyday occupations at home, few have empirically explored how both parts in a couple practically manage everyday occupations on their own initiative or identified how they perceive their different engagements in daily occupations.

The review also shows that few interventions have a) included both persons with dementia and their caregivers, b) focused on introducing strategies to possibly be used during the declining course of the dementia disease, c) adhered to the resources and potentials that the persons with dementia and their caregivers possess.

The focus in this thesis is twofold. It explores how persons with dementia and their caregivers perceive their engagement in everyday occupations as well as the caregiver’s self-initiated supportive acts in mutual everyday performance with their spouse with dementia. Furthermore, the effects of a collaborative intervention programme on memory performance in the participating individuals, and on caregivers’ communication and interaction towards their spouses with dementia in an everyday occupation are studied.
3 RESEARCH AIMS

OVERALL AIM
The overall aim of this thesis was to investigate how persons with dementia and their informal caregivers do every day activities together and in addition evaluate the result from an intervention designed to encourage mutual engagement.

AIMS
The specific aims of the studies incorporated in this thesis were:

Study 1: To identify self-initiated support strategies that co-habiting caregivers of persons with dementia provide when performing an everyday occupation together with the partner with dementia. The aim was also to identify negative aspects in the caregiver support.

Study 2: To identify and describe how persons with dementia and their care giving spouses perceive their own, the spouse’s and their mutual engagements in everyday occupations.

Study 3: To evaluate the effects of a home-based collaborative intervention on individual and mutual mnemonics in persons with dementia and their caregivers.

Study 4: To evaluate the effects of a home-based collaborative intervention on caregivers’ communication and interaction skills in everyday occupations together with their spouses with dementia.
4 METHODS
4.1 CONTEXT

The two qualitative studies presented in this thesis contain material collected as part of a data-collection set performed with an intervention-approach. The design in the intervention study is of assessments pre- and post and 8 th months follow-up data on the cognitive and occupational performance in 30 couples where one spouse have been diagnosed with mild to moderate dementia. The 30 couples have been randomized into three groups; one intervention-group who got 8 week collaborative intervention aiming at evaluating support to be used by the spouse towards the person with dementia. Another intervention-group received a traditional individual intervention programme where the therapist supported the individual persons with dementia in their occupational and cognitive performance in two everyday activity tasks. Finally, a third group of ten couples consisted of a traditional control group, who received no intervention or other stimuli during the eight week period that passed between the first and second assessments. The material for the first two studies where collected along with the first (pre-) assessments, before the interventions had been introduced, and the material for the last two studies were collected pre- and post intervention. The qualitative data was collected along with questionnaires about burden (Zarit et al, 1980), depressivity (Beck, Steer & Brown, 1996), Dementia Behaviour Disturbance Scale (REF) and Personality check and Health register form assessments of the couples individual cognitive abilities (MMSE, word fluency, digital-scan) etc., as well as their collaborative cognitive abilities (i.e. memory, and communication skills).

The video recording of the couples performance in an everyday activity, which form the foundation for the analysis in Study 1, was mostly collected during the second encounter between the therapist and the researcher(s). In the interviews which was the material in Study II, each spouse was interviewed individually was with a few exceptions performed during the third visits to the couple’s homes. Field notes on events that might affect the performance of the activity were written down in immediate connection to the home visits (Bogdan & Biklen 1998). These field notes also contained information on the occupational therapist’s perceptions of the social and physical environment. They could also entail background data of events that could be important in order to interpret the couples’ different performances on the tapes.
Design

In the data collection of Study I, the focus lied both on identifying the social context in which the caregivers act when they support their spouses with dementia in an everyday activity. Further, the data collection in Study II focused on understanding the meaning that participants in these studies place on their everyday engagements.

Intervention programme design (Study III+IV)

The participating caregiving dyads in both the collaborative and the individual programmes were offered a one-hour session of home-based training each week over a period of eight weeks. (See Table 1).

Table 1. Design of studies

<table>
<thead>
<tr>
<th>Test/training occasions</th>
<th>Study</th>
<th>Collaborative group</th>
<th>Individual training group</th>
<th>Control group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-tests including test-activity</td>
<td>I</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Pre-tests including interviews</td>
<td>II</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>8 weeks training</td>
<td>III + IV</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Post-test including test-activities</td>
<td>III+IV</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Post-test incl. Interviews &amp; Memory tests</td>
<td>III</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>
The collaborative programme. In the collaborative programme both the caregiver and the person with dementia together acquired and practiced strategies to support everyday mnemonic and occupational performance. The intervention was multifactorial in that it focused on three different learning strategies which were practiced on two types of task, a face-name recall task and an occupational table-setting task. These support strategies were introduced within the philosophy of providing “the just right challenge” as discussed by Yerxa (1998). Here the goal was to encourage optimal performance in the person with dementia by providing neither too little, nor too much support, thereby avoiding failure arising from the provision of insufficient support or passivity as a result of receiving too much support. All three support techniques used in this intervention (see below) are hierarchical in nature and thus they can be adjusted to correspond to the performance of the subject.

As mentioned above two tasks were used in training, a face-name task and an occupational table-setting task; these tasks were trained in this order in all sessions. In the face-name recall task the person with dementia had to learn the name of a person shown on a picture. Two techniques were used to acquire the face-name association, spaced retrieval (Camp et al, 2000; McKitrick & Camp, 1993) and graded cues (Bird & Luszcz, 1993).

In the table setting task, the caregiver and the person with dementia were asked to set a table together. In each case, the requirements of the task were adjusted to slightly exceed the performance capacity of the person with dementia. To find that level of difficulty, we used the valuable information we received in observing and measuring the performance of the persons with dementia in an individual, ‘standardized’ table-setting, in forehand. From that information we were able to adjust the level of difficulty to be high enough for assistance and guidance to be necessary for the person with dementia when performing the task. A typical table-setting instruction would include the following: We have agreed that you should set a table for four persons including the following items: glasses, utensils, plates, napkins, a flowerpot and a candle.

In the table-setting task, the caregivers were taught to provide verbal guidance in the form of questions/prompts in a hierarchical manner, starting from a general/abstract level of support provision and moving stepwise towards a more specific/concrete level of support, to find the optimal level at which the person with
dementia could perform the task. Four generally formulated suggestions of support levels were introduced as explained in Table 2.

Table 2  The Recommended Support Levels Used to aid the Persons with Dementia

<table>
<thead>
<tr>
<th>Hierarchical Support Levels</th>
<th>Type of Cue</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>The most abstract/general level</td>
<td>A general question</td>
<td>“What did we agree to do?”</td>
</tr>
<tr>
<td>A semi-abstract level</td>
<td>A general cue</td>
<td>“We need something to drink from”</td>
</tr>
<tr>
<td>A semi-concrete level</td>
<td>A more specific cue</td>
<td>“We need glasses too.”</td>
</tr>
<tr>
<td>A concrete, hands-on level</td>
<td>An even more specific cue</td>
<td>“The four glasses are here in this cupboard.”</td>
</tr>
</tbody>
</table>

The caregiver was encouraged to formulate the verbal guidance in a way that he/she thought would be understood by, and thereby helpful to, the person with dementia. During the performance of the table-setting task, the caregiver was asked to be attentive to the spouse and to provide guidance according to the mentioned support-levels as soon as the spouse seemed to have problems in performing the task. The pedagogic strategy of role-modelling was used (Minton, 2005) in teaching the hierarchical verbal-guidance technique. Thus, during the first sessions the research-assistant interacted with the caregiver by providing verbal support cues, or by assisting caregivers to formulate verbal cues in line with the hierarchical support levels.

The research-assistant also provided encouragement and feedback to the caregiver on his/her attempts to use the proposed support levels and to the person with dementia for attempting to perform the task. For example the research-assistant could stand beside the caregiver and suggest what level of support was appropriate, and in what way a support could be formulated, saying for example, “After this you could again start with a question like “What else do we need?” And then, if necessary, add: “We need something to dry our mouths with”.” As the training progressed, the spouse gradually took charge of the provision of support.
**The individual programme.** In this programme the person with dementia received the exact same training regimen as described above for the collaborative intervention group, with the exception that the training was conducted without any involvement of the caregiver. Instead the support strategies were provided by a research-assistant, rather than by the spousal caregiver. The caregiver did not participate in, or view the intervention, but remained at home while it was performed.

**Control group.** The caregiving dyads in the control group did not receive any intervention in between the pretest and posttest.

In conclusion, the intervention included in this thesis has been developed with the intention to enhance episodic memory functioning and learning in the persons with dementia by teaching them and their co-habiting spouse to adopt two supportive strategies and the spaced retrieval technique to support occupational performance and everyday mnemonics, based on their own resources where ones resource (the caregiver) can compensate for the limited resources in the other. However, in a belief that one strategy must not exclude the other, we have combined them in the same intervention, suggesting that the couples, when using them in collaboration can reach a more beneficial outcome.

In addition, we suggest that caregivers to persons with dementia could be the guide to provide support on a level that correlates with Yerxa’s (1998) “just the right challenge” in combination with, (Bird & Luszcz’s (1993) ideas on Graded cues. Further, the hierarchic levels of support suggested to be used in the intervention in this thesis, are based on Lawton & Nahemows’ (Lawton, 1999) ideas of persons’ potential to reach a zone of maximum comfort if relieved from environmental press.

In conclusion, in the intervention in this thesis, we have a design that take the learning-potential of the persons with dementia (and their caregivers) into account, and incorporates familiar tasks, in the participants' home-environment.

### 4.2 PARTICIPANTS AND CRITERIA FOR SELECTION

The sample consisted of 30 cohabiting couples, where one of the spouses was the primary caregiver for a partner diagnosed with mild to moderate dementia (See
Table 3). The participating couples were recruited from two large outpatient memory investigation units in the Stockholm area. The persons with dementia had been examined and diagnosed with having mild to moderate Alzheimer’s disease or Vascular dementia according to the criteria established by DSM-IV (American Psychiatric Association, 2000) within the last eight months before the study. Additionally, the patients needed to have a cohabiting significant other that considered himself or herself to be the primary caregiver. The Mini Mental State Examination (MMSE; Folstein et al, 1975) was performed within one week prior to the data collection. The cut-off point for suspicion of a dementia diagnosis is 23 points out of 30 points. Subsequently, persons with a MMSE score below 23 can be suspected of having cognitive impairment in one or several of the cognitive dimensions investigated.

Table 3  
**Participant Characteristics for the Persons with Dementia and for the Caregivers**

<table>
<thead>
<tr>
<th></th>
<th>Collaborative intervention</th>
<th>Individual intervention</th>
<th>Control group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Dementia</td>
<td>Caregiver</td>
<td>Dementia</td>
</tr>
<tr>
<td>Female/Male</td>
<td>7/3</td>
<td>3/7</td>
<td>4/6</td>
</tr>
<tr>
<td>Age</td>
<td>74.4 (6.0)</td>
<td>74.1 (8.6)</td>
<td>74.8 (6.7)</td>
</tr>
<tr>
<td>Subj. Health</td>
<td>3.3 (.9)</td>
<td>4.2 (.8)</td>
<td>3.2 (.6)</td>
</tr>
<tr>
<td>MMSE</td>
<td>21.0 (3.3)</td>
<td>28.8 (1.5)</td>
<td>22.9 (4.15)</td>
</tr>
<tr>
<td>Verbal ability</td>
<td>18.6 (5.4)</td>
<td>22.6 (4.9)</td>
<td>15.5 (7.8)</td>
</tr>
<tr>
<td>Verbal fluency: letter</td>
<td>26.8 (12.4)</td>
<td>41.1 (9.7)</td>
<td>29.1(15.3)</td>
</tr>
<tr>
<td>Verbal fluency: category</td>
<td>16.0 (7.4)</td>
<td>31.4 (7.6)</td>
<td>15.5 (4.4)</td>
</tr>
<tr>
<td>Digit symbol</td>
<td>17.6 (9.15)</td>
<td>37.0 (8.8)</td>
<td>12.2 (4.9)</td>
</tr>
<tr>
<td>Digit span Forward</td>
<td>6.7 (1.3)</td>
<td>5.8 (1.9)</td>
<td>5.4 (2.1)</td>
</tr>
<tr>
<td>Digit span Backward</td>
<td>5.0 (1.5)</td>
<td>6.6 (2.1)</td>
<td>3.8 (2.0)</td>
</tr>
</tbody>
</table>

Note. * differs significantly (p < .05) from the persons with dementia in the collaborative group.
In the records, patients with a MMSE score of less than 16 points out of 30 in the medical charts were excluded. Also, for a patient to be included, the records of the person with dementia were required to show evidence of problems in remembering and performing everyday occupations. Written or verbal medical approvals were received from the physicians responsible for the different participants involved in the study. All potential participants were then sent a letter with information about the study including a request for their participation in the study. The first 30 to accept the invitation to participate when contacted on the telephone were selected. Seventeen refused participation. Arguments for refusal to participate were mainly too little time or family-related reasons. It turned out that all participating couples had a history of a long marriage or partnership. In this thesis however we have chosen to call all participants “spouses” whether they were married or not.

During the first visit to each of the 30 participating couple’s home, verbal information on the aim and nature of the study was provided and participants also gave their written consent to the planned video-documentation of their performances in a common everyday activity. Their right to withdraw from the study at any time, without any further notice and explanation was emphasized, as was the confidential use of documented data. In Study 2, four of the 30 couples were excluded, due to limited or low quality in the data from one or both of the spouses. In Study III and IV all 30 participation couples contributed with pre- and postdata.

As it was important for the statistical analyses that the participants in the three groups were as equal pre-testing as possible, a block-randomization to decide group-attribution was conducted on each couple before they were contacted in person by the researchers. As indicated by one-way ANOVAs separately performed on the three groups of dementia participants and on the three groups of caregiving spouses, no significant differences (ps > .10) were revealed with respect to age, depression as measured with Beck Depression Inventory (Beck, Steer, & Brown, 1996), global cognitive functioning measured with Mini-Mental State Examination (Folstein, Folstein & McHugh, 1975), subjective health rated on a scale from 1 indicating very bad to 5 reflecting very good, verbal ability measured with a Swedish synonym test, SRB 1 (Dureman & Sälde, 1959), verbal fluency measured with FAS letter and category (Benton, 1989), and digit symbol measured according to WAIS-R (Wechsler, 1981). Although, for digit span forward and backward from WAIS-R (Wechsler, 1981), a significant difference
emerged showing that for the persons with dementia, the control group performed less well compared to the collaborative group ($p < .05$).

### 4.3 DATA COLLECTION

**Data collection (I)**

The data collection incorporated observational data from video-recordings collected in the participants’ homes. Each couple was informed about the desired details to be included in the everyday occupation that they were asked to perform together. The occupation agreed on was preparation of afternoon tea (including tea or coffee and cake), since such an occupation is highly prevalent in the culture of Swedish socializing. After a discussion concerning what should be included in the activity and how the couple usually prepared it, the activity was altered accordingly. For example, some couples made coffee boiling it on the stove, some boiled water and added instant coffee-powder or the-bags, but most used a coffee-brewer.

The agreement that had been made on what to include in the activity was thereafter verbalised like an instruction initiating the activity. The spouses were then asked to begin the activity, and to work naturally together as would please them best. All verbal and practical performance of the spouses in the activity was documented on videotapes using a camera fixed on a tripod in one corner of the kitchen. Field notes on aspects that might affect the performance of the activity were written by the first author, who conducted the data collection from all couples, immediately following the home visits (Bogdan & Biklen, 1998). For example, field notes would include information on perceptions of the social or physical environment as well as background data of aspects that could be important in order to accurately remember the different couples’ performances on the tapes during analyses. The first author, who observed and filmed the couples’ performances, did not take part in the activity, and did not speak or interfere unless her actions or responses were sought. The time the participants used to perform the activity ranged from 10 to 25 minutes.

For each of the 30 couples, the entire dialogue and each spouse’s acts were transcribed from the video-tapes, by the first author. To verify their accuracy, the detailed transcribed texts from the dialogues, along with the observations of the spouses’ interactive acts performing the activity (such as pointing etc) and the recorded field notes were compared, and adjusted when needed, to the videotapes by the first and forth author. Such adjustments could concern explanations to certain remarks the
spouses made to each other in the dialogues. For example, one particular person with dementia who wanted to set the table in the living-room where they normally receive guests had to be asked to perform the task in the kitchen, since the camera could not be moved from that setting. Even though such interaction from the researcher might have some disturbing effect on the naturalism in the collected data, it is not believed to have any major effect the performance of the activity (Briggs et al, 2003).

**Data collection (II)**

The interview-data presented in Study II were collected during the third visit in the participants home, and the purpose of the interviews had been presented to the participants at least one week prior to the interview. Hence, the data consisted of tape-recorded interview data collected in a secluded locality in the participants’ homes. Each person interviewed was asked to describe how he/she perceived how he/she and the spouse engaged in everyday occupation separately, as well as together.

Field notes on aspects that might affect the data were written down by the researcher immediately following the home visit (Bogdan & Biklen, 1998). For example, field notes could include information on perceptions of the social or physical environment as well as background data of aspects that could be important in order to accurately understand the context the different couples’ found themselves in. The interviewer did not interrupt unless the interviewee indicated that he/she had finished elaborating on a topic, or if a follow-up question was of interest to reach further depth in the descriptions. Sometimes, however, the participants needed to be reminded of the researchers focus of interest, which was done by interruption and a repetition of the question. The time the participants used to describe their and their spouses engagement in everyday life activities ranged from 10 to 50 minutes.

**Data collection (III)**

To capture effects of training four memory tasks were administered as well as two inventories to measure depressive symptoms and perceived caregiving burden. All the participating couples underwent pretesting which comprised two sessions á one hour, and two sessions á one hour of immediate posttesting. The couples were tested both individually and collaboratively, and the assessments were conducted in the home of the couples.
The Collaborative Tasks

Collaborative object recall, random. In this task the couple was seated in front of a covered tray with 15 categorizable every-day objects. The 15 objects belonged to five categories and were randomly placed under a cloth on a table. The couple was instructed that the tray contained a number of common every-day objects that they were going to be shown for one minute, and that their task was to encode in collaboration as many objects as possible and that they were allowed to touch but not move the objects and talk to each other during encoding. Thereafter the tray was uncovered and they viewed the objects during one minute, after which the tray was covered up and removed and the couple was asked to recall in collaboration as many of the objects as possible. Number of objects recalled together and by each person respectively served as dependent measures. This task was videotaped in order to analyze verbal as well as non-verbal communications between the spouses. Two parallel versions of this task was developed which were identical in terms of frequency of objects.

Collaborative object recall, clustered. This task was administered in the exact same way as the task above with the only difference that the objects were not randomly placed on the tray instead the objects were arranged in category clusters on the tray. Hence, the two tasks differed in terms of support provided at encoding.

Individual Tasks

Recall of non-categorizable words. In this task 12 concrete nouns were read one at a time at a rate of five seconds per word. The task was to remember as many words as possible for immediate recall (Bäckman & Small, 1991; Fratiglioni et al, 1991). This task was administered individually to the caregiver and to the person with dementia.

Recall of categorizable words. In this task 12 concrete categorizable nouns were read one at a time at a rate of five sec per word (Bäckman & Small, 1998; Fratiglioni et al, 1991). The task was to remember as many words as possible for immediate and category recall. Again these two individually administered memory tasks differed in terms of support provided at encoding.

Two parallel versions were developed for each of the individually assessed memory tasks which were equivalent with respect to visual imagery, meaningfulness and frequency (Molander, 1984).

Caregiver burden. To evaluate the extent of subjective caregiver burden, the Zarit Caregiver Burden interview was used (Zarit et al., 1980). In this self-report
inventory the caregiver is asked to respond to 22 items concerning the strain caused by the patients’ disabilities. A five point scale ranging from “0 = never” to “4 = nearly always” was used. Dependent measure was the summed score across the 22 items. A high score indicated a higher degree of burden.

Depressive symptoms. To measure depressive symptoms in the caregivers, Beck Depression Inventory was used which consists of 21 items measuring the degree of self-reported depressive symptoms (Beck et al, 1996). The caregivers were asked to mark the statement that best described how they had been feeling in the last two weeks, including the day of the interview. Dependent measure was the summed score, where a high score indicated more depressive symptoms.

At the first pretest session the order of test presentation was as followed: (a) Collaborative object recall (random); (b) Health questionnaire; (c) MMSE (Folstein et al, 1975); (d) Digit span forward and backward (WAIS-R)(Wechsler, 1981); (e) Recall of non-categorizable words (individual)(Bäckman & Small, 1998); (f) Zarit Caregiver Burden Interview (Zarit et al, 1980); (g) and Beck Depression Inventory (Beck et al, 1996).

At the second pretest session the test presentation was as follows: (a) Interview concerning every-day life; (b) Collaborative object recall (displayed in clusters); (c) Verbal fluency task; (e) Recall of categorizable words (individual); (f) Digit symbol (WAIS-R) (Wechsler, 1981); (g) Verbal ability: Swedish synonym test, SRB1(Dureman & Sälde, 1959).

Data collection IV

The data to be analyzed consisted of the observations made from the video-recordings of the performance of the assessment tasks, recorded in the participants’ own homes. The verbal summary of the agreement of the task to be assessed, along with the spouses’ actions when performing it, was documented on videotapes using a VHS-compact-camera fixed on a tripod in one part of the kitchen. The research-assistant did not take part in the activity, and avoided speaking or interfering unless she was asked to provide some input, e.g. to reconfirm to the person with dementia that the cake brought to their home was to be sliced and served, as part of the task.

In the pre-test conducted prior to the assessment the couples had the possibility to choose one of five pre-set activities to be used as the pre and post criterion activity. Of the 30 couples who participated, 28 couples chose preparing coffee as their assessment task, while two chose sorting and folding their laundry.
Hence, the occupational assessment task used in the pre and posttest to evaluate the caregivers’ communication and interaction skills was slightly different from the table-setting task performed during the intervention.

After a discussion concerning the items that should be included in the assessment task, and how the couples were used to performing it, the task was altered accordingly. The agreement made on what to entail in the task was thereafter stated verbally by the research-assistant. For example she might say: “We have agreed that you are to prepare three cups of coffee, and to prepare and serve the cake and cookies on a platter and to set the table with plates, cups, spoons, milk, sugar, paper napkins and finally a candle and/or flower.”.

4.4 DATA ANALYSIS
Data analysis of studies I+II

The data analysis in the two qualitative studies were very similar even though the data in Study II derived from interviews and the data in Study I derived from transcriptions from observations. In both cases we started of from the raw data transcripts, and then analysed them using a constant comparative method as described by Strauss & Corbin (1990). Data from all interviews and observations were read repeatedly to get a profound understanding of their contents. When coding the material from each participant the first author searched for expressions and practical examples in the data that illuminated or described how each individual participant perceived their experiences of engagements (II) or how the caregivers acted towards their spouse (I) in everyday life occupations. All according to the aim of each study. In the coding process, such description in the text was given a conceptual code.

In order to stay close to the data, these codes were formulated in everyday language, as close as possible to the words used by the participants. All transcript codes were then compared and systematically sorted into categories. These could for example concern the participants’ descriptions of change of their responsibilities in everyday life occupations (II), or they could be environmental adjustments in the kitchen area (I). This approach was done with the intention to provide a nuanced picture on how different engagements in everyday life occupations were perceived, or performed. The categorization-process involved the first and third authors in the studies. In the following step, the categories where read through repeatedly in search for identification of a possible emerge of a thematic structure.
Again, the emerging themes were compared to the transcripts, to secure the correspondence with the original data. In this process, all authors were included. To further increase credibility and truthfulness of the material, the codes and themes were yet again compared to the original data through a peer examination now involving the colleagues from the research group (Bogdan & Biklen, 1998). Finally, consensus was reached between the authors concerning codes and themes and the systematic relations between the found concepts.

**Data analysis Study III**

To answer the question: Does the collaborative intervention group improve mutual memory performance more relative to the individual training group and to the control group?, a 3 (Group) x 2 (Test occasion) ANOVA with repeated measure on the last factor was conducted for the two collaborative object recall tasks, respectively.

To further analyse the data from the collaborative memory tasks we were interested to see how many objects were recalled by the caregiver and by the person with dementia respectively. These impressions were confirmed by four 3 (Group) x 2 (Test occasion) ANOVAs, with repeated measure on the last factor, conducted on the caregivers’ as well as the persons with dementias free recall performance for both the collaborative memory tasks respectively.

Also an ANOVA test for identification of improvement in recall-performance for the individual persons with dementia compared to the other groups was conducted.

*To test differences in the groups* in the collaborative object recall task (cluster) an ANOVA test was also administered. This could tell if the caregivers in the collaborative group showed a any substantial difference in decline in performance from pretest to posttest compared to the two other groups.

An (Group) x (Test occasion) ANOVA was also performed on each memory task separately for the group of dementia participants, to reveal a potential difference in performance as a function of training.

*Assessment of Caregiver Burden and Depressive Symptoms*

In order to investigate whether training affected depressive symptoms and caregiver burden in the caregivers, we analysed the data as before with a 3 (Group) x 2 (Test occasion) ANOVA with repeated measure on the last factor, for the Beck
Depression Inventory (BDI) and the Zarit Burden Interview (Zarit et al., 1980) respectively.

Data analysis of Study IV

In this study we used the observational rating scale, the Assessment of Communication and Interaction Skills (ACIS) (Forsyth, Lai & Kielhofner, 1999) to measure the collaboration and interaction in-between the participants. The ACIS is designed to capture a person’s ability to successfully engage in social interaction while participating in meaningful occupations, and has been validated on a Swedish sample (Kjellberg et al., 2003).

To fulfil the aim to evaluate the effects of a home-based collaborative intervention on caregivers’ communication and interaction skills in everyday occupations with their spouses with dementia the Swedish version of The Assessment of Communication and Interaction Skills (ACIS-S, Version 2.0) (see the manual, Haglund & Kjellberg, 1998) was used. As touched upon earlier, the ACIS-S is an observational instrument designed to capture a person’s communication and interaction skills in detail, while participating in occupation in a social context.

The original ACIS is conceptually based on the Model of Human Occupation (Kielhofner, 2007) that, in turn, defines the discrete performance elements that together comprise everyday occupation referred to as ‘skills’. Three types of skills can be observed when a person is engaged in occupational performance, motor skills, process skills and communication and interaction skills. Communication and interaction skills are defined as the observable operations used to communicate intentions and needs, and to coordinate one’s performance for interacting with other persons. The version of the ACIS-S used in this investigation is a translation of the American ACIS (Forsyth et al., 1999), that is accompanied by a detailed manual which provides information about and a descriptions of the theoretical background, the scale, the administration and research information, detailed definitions of verbs, scoring criteria with performance related examples and a sample score form (Haglund & Kjellberg, 1998).
The ACIS has been tested for its validity and reliability and has been shown to have acceptable internal, construct and personal validity and good inter-judgemental reliability (Forsyth et al, 1999). The validity of the Swedish version was also found to be satisfactory (Kjellberg, Haglund, Forsyth & Kielhofner, 2003).

The ACIS-S comprises 20 observational skill items categorized into three theoretical domains: physicality, information exchange and relations. The therapist rates clients for each skill incorporated in the assessment as they participate in a social situation that is determined to be relevant and meaningful to them. The performance was scored from one to four, where four being indicative of a skill that supports ongoing communication and interaction to a maximum extent, and where one indicates a performance that impedes communication and interaction and yields an unacceptable outcome. Furthermore, the stability of the ACIS-S assessment have been analyzed, and judged stable, with the exception of measurements in varied environment settings where it was questionable (Haglund & Thorell, 2004).

The ACIS-S (Haglund & Kjellberg, 1998) was used on the spousal caregiver, in their communication and interaction with the persons with dementia, when performing the assessment task. To avoid bias, the first author who collected the data did not assess the couples. Instead, the third author, who had no personal knowledge of the participants, was provided with all the pre and post intervention video material for the three groups and performed a blinded ACIS-S scoring of the caregivers in all 30 couples, i.e., the tapes were not marked making it impossible to identify to which group the dyads belonged or whether a pre or post session was rated.

Differences between the performance of the chosen everyday activity, in three groups at the pretest and then at posttest were analysed by performing a Kruskal-Wallis test on each of the 20 items in the ACIS-S instrument.

In order to analyse improvement from pretest to posttest for each group respectively, Wilcoxon Matched-Pairs Signed-Ranks tests were performed on each of the ACIS-S-items.

In addition, we were interested in the number of participants that improved from pretest to posttest across the three groups. Based on our clinical experience and judgement it has been suggested that a gain that goes from either 1 to 3 or 2 to 3 are perceived as more clinically relevant than compared to changes that do not involve a change from 2 to 3, such as a change from 3 to 4 or 1 to 2. Based on this clinical wisdom we decided to examine the number of caregivers within each group that
showed a clinically relevant improvement. In order to do that, we dichotomized all scores into two new scores, so that a person with a score of 1 or 2 was categorized as “low score” reflecting less functional performances and a person with a score of 3 or 4 was grouped into a ”high score” reflecting more functional performance.

Thereafter we counted the number of people that gained from the “low score” to the “high score” to estimate (what may be considered) a clinical significant change (for method see Engman, Andersson-Roswall, Svensson & Malmgren, 2004).
5 ETHICAL CONSIDERATIONS

There are several ethical issues involved in dementia research, one of the more important being the procedure of collecting informed consent from the person with dementia (Kim & Karlawish, 2003). However, the outcomes of most ethical decisions have social effects. Therefore it has been recommended that, before acting according to ethical convictions, healthcare professionals or researchers should solicit the support from others who will be affected by the intervention (Kim & Karlawish, 2003). In many instances of ethics in healthcare, this means communicating with the client, the client’s family, and other staff members. But even though others are considered, the usual practice in the western healthcare units take into consideration the autonomy of adult clients above those of others, even when the adult client’s wishes run counter to expert opinion (HSL, 2007). However, regarding persons with dementia, they have been shown to vary in their independent functioning, as do their capacities for autonomous decision making (Kim, Caine, Currier, Leibovici & Ryan, 2001). In line with that reasoning, it has also been shown that a person with Alzheimer’s disease may be fully alert at certain times of the day than at others (Normann, Norberg & Asplund, 2002). Thus, a person with dementia might agree to the research project and sign the informed consent one day, and disagree with the intervention the next. In accordance with this notion, research has called for directives on how to collect informed consent in cognitively impaired persons (Kim & Karlawish, 2003). For example, a common question asked is how researchers could determine that someone is too impaired to give informed consent. In this study, we were helped by the caregivers in reminding the persons with dementia of the potential value of the research project. In a way, the caregivers could also be regarded to function as guarantors for the persons with dementia, in that the caregiver presence secured that the persons with dementia were not taken advantages of, due to their vulnerable situation.

In these four studies, all participants, persons with dementia, as well as their caregivers, gave informed written consent for participating (Kim & Karlawish, 2003). Furthermore, the responsible physicians for each person with dementia were asked to consider medical aspects of participation. Thus, all participants had received a medical approval for participate in the study. Finally, the study received ethical approval from the Regional Ethical Committée of the Karolinska University Hospital (Dnr. 327/98). During the first contact, all couples were told of the aim of the study, and of their right
to withdraw from the study at any time, without any further notice or explanation. Also, all data were treated confidentially.

Including persons with dementia is further supported by research that have shown that even though interviews can be perceived as disturbing, or discomforting for the person with dementia, there is a growing opinion underscoring the importance for persons with dementia to be able to focus on descriptions of their life as a way of retaining self and the emotional memories of one’s self (Hubbard, Downs & Tester, 2003). In our studies, no person with dementia objected to, or expressed discomfort with participating in the interviews or other parts of the data collection. Again, in our research, caregivers might have been able to soothe the situation, or to call our attention to such experiences, had they come up.

Lastly, previous studies have indicated the risk of participants becoming emotionally involved with the researcher. This is especially the case in data collection scenarios where the researcher has been let in to the home, and got access to information of sensitive character, for example difficult situations in the final disengagements from researchers and the participant have occurred (Briggs et. al, 2003). In the data collection for this thesis participants were not only informed verbally about the frequency of the visits and for what amount of time the researcher would want to come, but the participants were also provided with a calendar, where every part of the intervention was listed specifically. Hence the participant received a tool to get an overview of the intervention design. Well before the last visit, the researcher reminded the participants of the forthcoming separation, and when that day came, the participants was also offered to contact the researcher if they felt they needed advice in issues related to the intervention project. One caregiver used that opportunity, and received assistance in solving issues that he wanted help solving.
6 FINDINGS

6.1 STUDY I: CAREGIVERS’ SELF-INITIATED SUPPORT TOWARDS THEIR PARTNERS WITH DEMENTIA WHEN PERFORMING AN EVERYDAY OCCUPATION TOGETHER AT HOME.

The observational documentation in Study I aimed to identify the support caregivers provide by their own initiative when performing an everyday occupation together with their spouse with dementia. In the analyses, three major themes characterising the caregiver support emerged, namely, provision of a supportive working climate, practical involvements and negative aspects in the caregivers support that lead to failure (See Table 4).

Table 4. The Structure of Caregivers’ Support Toward Their Partner in Everyday Occupations.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Supportive working climate</th>
<th>Supportive practical involvement</th>
<th>Negative aspects in the caregiver support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subthemes</td>
<td>Creates comfort</td>
<td>Adapts the physical space and objects</td>
<td>Provides insufficient support</td>
</tr>
<tr>
<td></td>
<td>Takes responsibility for the activity</td>
<td>Alters the activity to make it easier</td>
<td>Provides inappropriate support</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Supports the performance</td>
<td>Failure to respond to support need</td>
</tr>
</tbody>
</table>

The results showed that the caregivers often contributed to a supportive working climate in two ways: by creating comfort and by taking responsibility for the task. When creating comfort, the caregivers used four techniques, namely being attentive, offering time, being encouraging and being permissive. Further, caregivers showed three different ways to take responsibility for carrying out the occupation. These ways were reassuring partners’ involvement, asking check-up questions and keeping track of the agreement.

The analysis further showed that, apart from providing a supportive working climate, the caregiver also supported the spouse with dementia through the following practical involvements: adaptations of the physical space and objects, alterations of the occupation to make it easier and support for the performance.
The caregiver adapted the physical space and also objects in the performance area through providing space, removing irrelevant objects and through prominent placement of objects relevant to the occupation. Two kinds of alterations of the occupation that caregivers provided seemed to have the purpose of making the tasks easier, namely preparing and adjusting the task. The caregivers also supported their spouses in their performance by providing guidance, providing reminders and clues, and by providing problem solutions. The most common support provided by the caregivers was verbal guidance.

A few negative aspects in the caregiver support from which the performance of the person with dementia was not shown to benefit were also identified. The analyses showed that failure in the performance of the person with dementia often was related to insufficient support from the caregiver. Sometimes caregivers lacked attentiveness towards their spouses, and other times they were not present and did not take responsibility for the task. The different nature of these non-supportive acts seemed to create confusion in the persons with dementia because support they expected was provided either too late, or not at all.

The results of this study have implications on how occupational therapists and caregivers in dementia care can support and guide primary caregivers in their homes, since they show that caregivers have several self-initiated support strategies that they use naturally. If identified in each individual caregiver, they could be feasible building-blocks on which interventions could be built.

6.2 STUDY II: ENGAGEMENT IN OCCUPATIONS: EXPERIENCES OF PERSONS WITH DEMENTIA AND THEIR CAREGIVING SPOUSES

In Study II, the analysis lead to the identification of four major themes that characterized engagement in everyday life from the perspective of participants, specifically the themes are perceived changes in occupational engagements; consequences of experienced changes; dilemmas experienced by the caregivers and management approaches to handle a changed everyday life (See Table 5).
Table 5. Themes and sub-themes emerged in the analysis.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Perceived changes in activity engagements</th>
<th>Consequences of experienced changes</th>
<th>Dilemmas experienced by the caregiver</th>
<th>Caregivers’ Management approaches to handle changes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sub-themes</td>
<td>Decreased activity</td>
<td>Loss of social engagements</td>
<td>Interfering with the spouses´ engagement or not</td>
<td>Encouraging initiatives from the partner or taking over chores</td>
</tr>
<tr>
<td></td>
<td>Extra workload needed to perform everyday activity</td>
<td>Changes in the relationship</td>
<td>Placing the spouse´s or ones own needs first</td>
<td>Lowering demands or avoiding potentially problematic engagements</td>
</tr>
<tr>
<td></td>
<td>Change in the responsibility</td>
<td></td>
<td></td>
<td>Collaboration</td>
</tr>
</tbody>
</table>

All the participants in this study described a number of perceived changes in the occupational engagements that they had undergone in their practical engagements in everyday occupations. These changes were for example, altered efforts put in performance, which to a major extent meant that both spouses perceived that the persons with dementia performed less and the caregiver performed more of the everyday tasks. Another alteration described by both spouses was that the responsibility for everyday matters in general now lay on the caregiver.

The second theme concerned consequences of experienced changes, where both the persons with dementia and the caregivers perceived that their social engagements, outside the relationship as well as within it, had decreased. In conjunction with the decreased engagement in occupation of the persons with dementia, both the persons with dementia and their caregivers perceived the necessity of an increased nearness and dependency between themselves and their spouses in everyday life. This nearness was mostly described as an asset by the persons with dementia, while described in more complex terms by the caregivers. Another complexity found in the analysis was that caregivers described a complex mixture of feelings of loneliness as well as a need for solitude. In contrast, several persons with dementia expressed a reduced need or wish to meet other people but they did not express a need for solitude.
The third theme concerned dilemmas experienced by the caregivers, where analysis revealed that several of the caregivers perceived difficulties in knowing whether to interfere with the person’s occupational performance or not, and how to deal with those engagements that the person with dementia still wished to do independently, but which the caregiver considered not being adequately performed. Analysis also revealed that the caregivers’ efforts of keeping track of their spouse’s engagements took time from their own private engagements. Thus they faced the dilemma of deciding whether to give priority to their own needs or those to the person with dementia.

Most caregivers seemed to have developed management approaches that helped them make everyday matters work efficiently. Some caregivers described how they solved problems through collaboration rather than interfering in the spouses’ performance of the task. Several caregivers were balancing between two seemingly contrasting management approaches; managing by taking over or by encouraging initiatives from the partner. A third and last management approach identified was that caregivers lowered the demands on certain occupational performance outcomes.

The findings in this study can contribute to an increased understanding of the complex everyday situation in which persons with dementia and their spouses find themselves. Some findings, for example the caregivers’ dilemmas shed light in issues that occupational therapists and other healthcare professionals might be able to support caregivers in solving.

6.3 STUDY III: COLLABORATIVE MEMORY INTERVENTION IN DEMENTIA: CAREGIVER PARTICIPATION MATTERS

As previously stated the objective of this study was to examine the effectiveness of a collaborative intervention programme for persons with dementia and their spousal caregivers, where the couple acquired and practiced memory supportive strategies (spaced-retrieval and hierarchical cuing) to learn a face-name association and to set a table for coffee or tea, in comparison to an individual intervention programme and to a control group of couples. Both individual as well as collaborative episodic memory tests were used as outcome measures. As can be seen in Table 6 the groups did not differ in terms of collaborative memory performance nor did any improvements
occur as a function of training. The ANOVAs basically confirmed these conclusions by showing no main effects of group and test occasion, or interaction effect for the collaborative object recall task (random) \((ps > .10)\). The ANOVA for the collaborative object recall task (clustered), showed a reliable main effect of test occasion, \(F (1, 26) = 11.4, MSE = 3.4, p < .01\), indicating that collaborative memory performance declined across time for all groups. Hence, collaborative recall performance is neither affected by collaborative memory nor by individual intervention.

Table 6. 
*Mean Number Collaborative Recall as a Function of Group and Test Occasion.*

<table>
<thead>
<tr>
<th></th>
<th>Collaborative intervention</th>
<th>Individual intervention</th>
<th>Control group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pretest</td>
<td>Posttest</td>
<td>Pretest</td>
</tr>
<tr>
<td>Collaborative object recall,</td>
<td>12.2 (1.75)</td>
<td>11.7 (1.3)*</td>
<td>11.5 (3.0)</td>
</tr>
<tr>
<td>random</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Collaborative object recall,</td>
<td>13.7 (1.2)</td>
<td>11.6 (2.5)</td>
<td>12.8 (2.7)</td>
</tr>
<tr>
<td>clustered</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Standard deviations in brackets.

However, when viewing the number of recall from the caregivers and the spouses with dementia across groups and occasion the results showed that following collaborative memory training recall performance in the collaborative tasks became more shared between the spouses, reflected in a decrease in recall for the caregiver and an increase in recall performance for the spouse with dementia between pre- and posttest, whereas for the other two groups the caregivers dominated collaborative recall both at pre- and posttest (Table 7).

This change in division of recall labour following collaborative training may indicate that the caregivers became more able to use the memory supportive strategies taught in training to support recall performance in the spouse with dementia. Furthermore, the results also showed that the persons with dementia in the collaborative group improved individually assessed episodic memory performance as compared to the persons with dementia in the other two groups.
Table 7. Mean Number Recall from the Caregiver and the Spouse with Dementia in the Collaborative Memory Tasks across Groups and Test Occasions.

<table>
<thead>
<tr>
<th></th>
<th>Collaborative intervention</th>
<th>Individual intervention</th>
<th>Control group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pretest</td>
<td>Posttest</td>
<td>Pretest</td>
</tr>
<tr>
<td>Caregivers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Collaborative</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>object recall,</td>
<td>10.2 (2.6)</td>
<td>7.2 (2.8)</td>
<td>8.4 (2.6)</td>
</tr>
<tr>
<td>random</td>
<td>10.4 (3.5)</td>
<td>6.4 (2.5)</td>
<td>9.0 (3.2)</td>
</tr>
<tr>
<td>Person with dementia</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Collaborative</td>
<td>2.0 (1.7)</td>
<td>4.5 (2.8)</td>
<td>3.1 (2.7)</td>
</tr>
<tr>
<td>object recall,</td>
<td>3.3 (3.7)</td>
<td>5.3 (2.7)</td>
<td>3.8 (4.2)</td>
</tr>
<tr>
<td>random</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

In order to investigate whether training affected depressive symptoms and caregiver burden in the caregivers, we analysed the data as before with a 3 (Group) x 2 (Test occasion) ANOVA with repeated measure on the last factor, for the Beck Depression Inventory (BDI) and the Zarit Burden Interview (Zarit et al., 1980) respectively (Table 8).

Table 8 Mean Number Individual Word Recall for the Caregivers and the Persons with Dementia across Groups and Test Occasions.

<table>
<thead>
<tr>
<th></th>
<th>Collaborative intervention</th>
<th>Individual intervention</th>
<th>Control group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pretest</td>
<td>Posttest</td>
<td>Pretest</td>
</tr>
<tr>
<td>Persons with</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dementia</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Word Recall:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-cat</td>
<td>2.7 (1.9)</td>
<td>2.9 (1.9)</td>
<td>3.8 (1.9)</td>
</tr>
<tr>
<td>Word Recall: Cat</td>
<td>2.4 (2.3)</td>
<td>4.1 (2.3)</td>
<td>3.2 (1.9)</td>
</tr>
<tr>
<td>Caregivers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Word Recall:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-cat</td>
<td>5.9 (2.1)</td>
<td>5.6 (1.0)</td>
<td>7.0 (1.6)</td>
</tr>
<tr>
<td>Word Recall: Cat</td>
<td>7.6 (1.5)</td>
<td>8.0 (2.0)</td>
<td>6.9 (2.2)</td>
</tr>
</tbody>
</table>

Note. Non-cat = a list of none categorizable words; Cat = a list of categorizable words.
The ANOVA for the BDI showed a reliable main effect for test occasion, $F(1, 25) = 6.24, MSE = 4.13, p < .02$, indicating that the groups expressed slightly more depressive symptoms at post- ($M = 9.18$) compared to pretest ($M = 7.82$). The ANOVA on the global score of the Zarit Burden Interview (1980) did not demonstrate any reliable differences in the groups as a function of training. Taken together, no effects were seen on caregiver rated burden or depressive symptoms following intervention.

### 6.4 STUDY IV: CAREGIVERS’ SELF-INITIATED SUPPORT TOWARD THEIR PARTNERS WITH DEMENTIA WHEN PERFORMING AN EVERYDAY OCCUPATION TOGETHER AT HOME

Study IV aimed to evaluate the effects of the same collaborative intervention on caregivers’ communication and interaction skills in occupations together with their spouses. First, we conducted descriptive analyses on medians and ranges as a function of group and time of testing across all ACIS-S Items (see Table 9).

<table>
<thead>
<tr>
<th>Domain/item</th>
<th>Collaborative Programme</th>
<th>Individual Programme</th>
<th>Controls</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pre</td>
<td>Post</td>
<td>Pre</td>
</tr>
<tr>
<td><strong>Physicality</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contacts</td>
<td>3.0 (2-4)</td>
<td>3.5 (2-4)</td>
<td>3.0 (2-4)</td>
</tr>
<tr>
<td>Gazes</td>
<td>3.0 (1-4)</td>
<td>3.0 (2-4)</td>
<td>2.5 (1-4)</td>
</tr>
<tr>
<td>Gestures</td>
<td>3.0 (2-4)</td>
<td>3.0 (1-4)</td>
<td>3.0 (1-4)</td>
</tr>
<tr>
<td>Maneuvres</td>
<td>2.5 (1-4)</td>
<td>3.0 (1-4)</td>
<td>3.0 (1-4)</td>
</tr>
<tr>
<td>Orientes</td>
<td>2.5 (1-4)</td>
<td>4.0 (2-4)</td>
<td>2.0 (1-4)</td>
</tr>
<tr>
<td>Postures</td>
<td>3.0 (2-4)</td>
<td>3.2 (1-4)</td>
<td>2.0 (2-4)</td>
</tr>
<tr>
<td><strong>Information</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Exchange</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Articulates</td>
<td>3.5 (2-4)</td>
<td>3.0 (2-4)</td>
<td>4.0 (1-4)</td>
</tr>
<tr>
<td>Asserts</td>
<td>2.5 (2-4)</td>
<td>2.5 (2-4)</td>
<td>3.0 (2-4)</td>
</tr>
<tr>
<td>Asks</td>
<td>2.0 (1-4)</td>
<td>3.0 (2-4)</td>
<td>2.0 (1-4)</td>
</tr>
<tr>
<td>Engages</td>
<td>2.5 (1-4)</td>
<td>3.5 (2-4)</td>
<td>2.0 (1-4)</td>
</tr>
<tr>
<td>Expresses</td>
<td>2.0 (2-4)</td>
<td>3.5 (1-4)</td>
<td>3.0 (1-4)</td>
</tr>
<tr>
<td>Modulates</td>
<td>4.0 (2-4)</td>
<td>4.0 (2-4)</td>
<td>3.5 (2-4)</td>
</tr>
<tr>
<td>Shares</td>
<td>2.0 (1-4)</td>
<td>4.0 (1-4)</td>
<td>3.0 (1-4)</td>
</tr>
<tr>
<td>Speaks</td>
<td>4.0 (2-4)</td>
<td>4.0 (3-4)</td>
<td>3.5 (2-4)</td>
</tr>
<tr>
<td>Sustains</td>
<td>2.0 (1-4)</td>
<td>3.0 (1-4)</td>
<td>3.0 (1-4)</td>
</tr>
<tr>
<td><strong>Relations</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Collaborates</td>
<td>2.0 (1-4)</td>
<td>3.0 (1-4)</td>
<td>2.5 (1-4)</td>
</tr>
<tr>
<td>Conforms</td>
<td>3.5 (2-4)</td>
<td>4.0 (2-4)</td>
<td>3.0 (2-4)</td>
</tr>
<tr>
<td>Focuses</td>
<td>2.5 (1-4)</td>
<td>2.5 (2-4)</td>
<td>3.0 (1-4)</td>
</tr>
<tr>
<td>Relates</td>
<td>3.0 (1-4)</td>
<td>3.5 (1-4)</td>
<td>3.0 (1-4)</td>
</tr>
<tr>
<td>Respects</td>
<td>3.0 (2-4)</td>
<td>3.5 (2-4)</td>
<td>3.0 (2-4)</td>
</tr>
</tbody>
</table>

Note: ACIS-S = Assessment of Communication and Interaction Skills. Ranges are given within parentheses.
Further, the Kruskal-Wallis test analyses on differences between the performance of the chosen everyday activity, in three groups at the pretest and then at posttest on each of the 20 items in the ACIS-S instrument, revealed that, at the pretest, the three groups did not differ from each other on any of the 20 skill items (ps > .10). At posttest, only one item out of 20 showed a significant group effect, $\chi^2 = 6.65$, df = 2, $p < .04$, indicating that the collaborative group performed better compared to the two other groups on the item “orients” from the physicality domain, which was confirmed by significant Mann-Whitney U-tests ($U = 147.42$, N=10, $p = .01$).

In order to analyze improvements from pretest to posttest for each group, respectively, Wilcoxon Matched-Pairs Signed-Rank tests were performed on each of the ACIS-S-items. In line with the result above, the caregivers in the collaborative group showed an improvement in the item “orients” ($p < .03$), while in the individual group the caregivers showed an improvement for the item “expresses” ($p < .01$). In contrast, the control group showed a decline between pre- and posttest for the item “modulates” ($p < .05$). In summary, these analyses yielded modest pre- to posttest improvements for the caregivers receiving either collaborative or individual interventions, where only one skill out of 20 showed any reliable improvement.

As the results showed limited statistical significance, we were interested in identifying the number of participants that improved from pretest to posttest across the three groups differentially. An increasingly common method to detect trends in intervention materials, arisen from intervention studies with small groups of participants, is to illustrate the movements in the materials from pre- to posttest (See, e.g., Engman, Andersson-Roswall, Svensson & Malmgren, 2004).

As can be seen in Table 10, a rather consistent pattern of positive gains in terms of the number of participants who improved are shown for the caregivers who received collaborative intervention compared to the control group where the opposite pattern was more frequent. Furthermore, for some items within the domain of information exchange (e.g., asserts, asks, shares and sustains) the number of caregivers gaining were more pronounced for the collaborative intervention group compared to the individual group. Hence, a tendency for a more favorable outcome for the collaborative group is evident.
### Table 10

*Number of Caregivers Declining, Remaining Stable, and Gaining between Pretest and Posttest across all ACIS-S Items for the Three Groups.*

<table>
<thead>
<tr>
<th>Domain/item</th>
<th>Collaborative Programme</th>
<th>Individual Programme</th>
<th>Controls</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Decline</td>
<td>Stable</td>
<td>Gain</td>
</tr>
<tr>
<td>Contacts</td>
<td>0</td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td>Gazes</td>
<td>0</td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td>Gestures</td>
<td>1</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>Maneuvers</td>
<td>0</td>
<td>9</td>
<td>1</td>
</tr>
<tr>
<td>Orient</td>
<td>0</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Postures</td>
<td>1</td>
<td>9</td>
<td>0</td>
</tr>
</tbody>
</table>

**Information Exchange**

| Articulates | 1     | 8     | 1    | 1   | 6   | 3   | 0   | 10   | 0   |
| Asserts     | 0     | 6     | 4    | 1   | 8   | 1   | 6   | 4    | 0   |
| Asks        | 0     | 4     | 6    | 1   | 6   | 3   | 5   | 5    | 0   |
| Engages     | 1     | 4     | 5    | 0   | 6   | 4   | 3   | 6    | 1   |
| Expresses   | 1     | 4     | 5    | 0   | 6   | 4   | 3   | 6    | 1   |
| Modulates   | 2     | 6     | 2    | 1   | 7   | 2   | 4   | 4    | 2   |
| Shares      | 1     | 4     | 6    | 0   | 8   | 2   | 3   | 4    | 3   |
| Speaks      | 0     | 7     | 3    | 2   | 5   | 3   | 4   | 3    | 3   |
| Sustains    | 0     | 5     | 5    | 2   | 6   | 2   | 2   | 6    | 2   |

**Relations**

| Collaborates | 0     | 6     | 4    | 0   | 7   | 3   | 1   | 8    | 1   |
| Conforms     | 0     | 8     | 2    | 0   | 8   | 2   | 5   | 4    | 1   |
| Focuses      | 0     | 6     | 4    | 0   | 9   | 1   | 1   | 7    | 2   |
| Relates      | 1     | 7     | 2    | 0   | 7   | 3   | 2   | 8    | 0   |
| Respects     | 0     | 8     | 2    | 1   | 8   | 1   | 1   | 7    | 2   |

In conclusion, the intervention addressing collaborative performance which consisted of the basis for Study III and IV, did not show a consistent statistical significant result in favour of the training. However, indication in study number III are, that the spouses’ in the collaborative training group showed a more shared engagement in occupations among the persons with dementia and their caregiving spouses after the training programme. Likewise, in Study IV, caregivers showed some clinical significant improvement in communication and interaction skills after participation in collaborative training as well as in individual training.
7 DISCUSSION

7.1 GENERAL DISCUSSION

The overall aim of this thesis was to investigate how persons with dementia and their informal caregivers do everyday activities together and to evaluate the result from an intervention designed to encourage mutual engagement.

The findings from the studies provide material for a discussion on “doing together” or engagements in occupation together for persons with dementia and their caregivers, and the possibilities in supporting such engagements.

Study I identified that informal caregivers to persons with dementia have resources, in that they use self-developed strategies to support their spouses with dementia. These findings will be discussed in relation to their implications for future interventions aiming to enable engagement in occupation for persons with dementia.

Study II identified that the participants had complex perceptions of their own and their mutual engagements in everyday occupation. Both the persons with dementia and their caregiver spouses experienced that the disease had changed the conditions for how everyday life was lived in daily occupations, and that the consequences of the dementia brought forward some challenges for both of them, including some dilemmas for the informal caregivers. These challenges have been identified and addressed earlier in empirical research, however rarely in studies involving both the persons with dementia and the caregiver spouse. These findings will be discussed in relation to implications for interventions including the social environment in terms of the spouse.

The third study showed how the spouses’ involvement became more shared in a training programme addressing collaborative memory performance among persons with dementia and their caregiving spouses. This finding will be discussed in relation to possibilities to enable caregivers and persons with dementia to work together in handling cognitive dysfunction following dementia.

A similar finding was seen in Study IV, where caregivers showed some improvement in communication and interaction skills after participation in collaborative training as well as in individual training. These finding will be discussed in relation to the resources persons with dementia and their caregivers have. Also, some
beneficiary aspects of undertaking interventions in the home environment will be discussed.

7.2 SELF-INITIATED SUPPORT STRATEGIES IN CAREGIVERS

One important finding within this thesis is that it is demonstrated how informal caregivers to persons with dementia have resources to provide support to their spouses with dementia in everyday occupations.

In the two qualitative studies caregivers both demonstrated (I) and told of (II) their efforts to create a comforting climate in everyday occupations as part of the support towards their spouses with dementia. Also, in a collaborative memory-assessment, the caregivers in the collaborative training group (III) showed to withhold their recall responses, and provide time and memory cues to their spouses with dementia.

On the basis of these findings, future research involving caregivers to persons with dementia might benefit from, not only asking them to describe and show what support strategies and management approaches they use, but also to ask them to describe their different rationale for using them. Drawing parallels to occupational therapy literature, it seems that, already before the intervention, the informal caregivers in our studies, to some extent, expressed an experience (II) and showed skills (I) in providing what Yerxa (1998) called “the just right challenge”. For example in Study I, caregivers supported their spouses with dementia by providing support that only partly solved the task. Typically they could place forward items needed in the task, and if more support was needed provided cues rather than answers.

Still, we could identify both good support and support that lead to failure (I). This indicates how the informal caregiver might need assistance for other people in identifying the good support. Also, the reflective skills and practical knowledge, possibly present in caregivers, that perhaps help them to see to it that the spouse gets the right type of challenge (Yerxa, 1998) is something that occupational therapists and other health care professionals could take into account when setting up interventions to increase the occupational engagement in everyday life for persons with dementia and their spousal caregivers. It should be noted, however, that development of an understanding for the person with dementia’s situation and using a supportive confirmatory attitude, cannot be expected from all informal caregivers (Johansson, 2007). In the present studies, caregivers accepted to participate in an extensive
intervention programme. Therefore, the participants in the studies should not be seen as representatives for the whole dementia –caregiver population. Hence, the findings of these should be read and interpreted with some caution.

### 7.3 OCCUPATIONAL DILEMMAS IN CAREGIVING.

In Study II, caregivers described some dilemmas in handling their spouses’ everyday problems. One of the dilemmas concerned whether to interfere with the spouses’ social and occupational engagements or not. Caregivers could for example ask themselves what challenges the person with dementia should be let to handle alone, and when it would be suitable for them, as caregivers, to provide support. Similarities to such reasoning can, again, be found in the philosophical notion of providing ‘the just right challenge’ where a support provider is recommended to start with sparse support and then increase it if needed. Due to the progress of the dementia, caregivers would most likely benefit from receiving assistance in solving such dilemmas, including both if to interfere as dilemmas on when to interfere.

Caregivers further reflected on how to view the person with dementia - as autonomous or as a part of the two of them as a unit (Sällström, 1994). For example, in our findings, caregivers described the dilemma of not knowing whether to interfere in the conflicts that appeared with the persons with dementia and their private friends, or to let there be negative consequences for the person with dementias social life. Viewing the persons with dementia, their caregivers or families as a unit or as one client (Lieberman & Fisher, 1999; Sällström, 1994) might result in a call for a discussion on how to handle such an approach, when individuals in this collective understanding of “client” have different opinions. Already, there are questions challenging health care regarding such issues. For example, Carpenter & Dave (2004) describe that there are those caregivers who do not wish the diagnosis to be disclosed to the person with dementia. Such findings indicate the kinds of ethical dilemmas that come with the “one family-one client” viewpoint.

Some of the caregivers in our study emphasized their spouses’ rights to be treated like any other adult, for example, they wanted their spouse to pay for their groceries although they were slow and created queues without risking being stigmatised. Hence, these caregivers had a tendency to disagree with the conventions, and, if viewed from a social constructivist view (Berger & Luckman, 1966) construct their and their spouses
living rules to what suited them best, although it might have risked stigmatising them both. In line with such actions and thoughts, another common caregiver dilemma identified was whether to place one own interest before the interest of the spouse with dementia or not. One caregiver argument for not accepting care from others (e.g., friends or society) was that the persons with dementia might not appreciate it (II). Hence, several caregivers chose the take on the challenging caregiving single-handedly. These dilemmas might further add to the burden caregivers are known to experience (Andrén, 2006). There are also examples of how spouses who are offered respite, or short term care say no to the offer because they do not trust that the persons with dementia will be treated well and have something meaningful to do in an institution (Johansson 2007).

Since healthcare resources often only provide caregivers with some respite and both spouses described a loss of social contacts (II), health care professionals could assist couples to remain socially active. This might also be part of a solution to alleviate loneliness (Beeson, 2003) and meet the need for solitude that caregivers described (II). Also, other studies have shown that caregivers are not always aware of the support the society has to offer (Brodaty et al., 2005), and also, that they tend not to use e.g. day-care services because their fixed hours does not always match the daily rhythms of the couples (Johansson, 2007). In our findings (II), this was confirmed in that the couples commonly described how they, to get a good climate in-between them, chose to partake in activities they did not have to promise to be in time for. (Also, no couple was ready to have visits from the researchers before 10 am in the morning). Hence, it might be beneficial to persons with dementia and their caregivers if support from society could offer supportive care that is flexible to its character to suit the daily rhythms of the couples.

Furthermore, in reasoning on occupational justice, meaning a practice that involves enabling empowerment through occupation, it has been discussed how important the organisation of society can be in whether or not there for example, will be an exclusion from opportunities, lack of respect and fairness for individuals (Christiansen & Townsend, 2004). It has even been suggested that if people do not get fair opportunities to interact with others, they risk entering a state of occupational disengagements that to its extreme have been called occupational deprivation. Based on such occupational justice reasoning, I would argue that the way daily life in
society is organized might lead to social disintegration and occupational disengagement in both the persons with dementia and their spouses, in that they do not manage to adjust to the everyday situation of couples similar to the ones in the studies in this thesis. The, caregivers who might not dare to leave the home due to safety concerns for the person with dementia at home (Jansson et al 2001), might also, in the long run, experience that they are becoming alienated from society with the sometimes lonely and monotonous work they perform at home (Ziff & Schaffner, 2000). A threat of occupational alienation in caregivers might prevail (Christiansen & Townsend, 2004). Perhaps, it would be beneficial to assist caregivers, so that they, in turn, have the continued strength to care over time (Hjulström, 2007).

7.4 INVOLVEMENT IN EVERYDAY OCCUPATIONS MATTERS

Another aspect from the four studies is that collaborative involvement in performance of everyday occupations for persons with dementia and their caregivers matters. For example, in Study III it was identified that training caregivers to support and collaborate with the persons with dementia can enhance memory performance in persons with dementia (III). Moreover, an intervention programme where caregivers are taught general, hierarchical support strategies such as ‘The just right challenge’ (Yerxa, 1998) & Cued recall (Bird & Luszcz, 1993), according to the spaced retrieval strategy (McKitrick & Camp, 1993) might be beneficial effects on the support they provide to their partners in a transferred assessment task (IV). In fact, these findings are in line with indications that both the caregivers and persons with dementia can enhance cognitive functioning as a consequence of a collaborative intervention that has been shown earlier by Bäckman (1996) and Quayhagen & Quayhagen (2001). Comparing the findings of individual episodic memory functioning in the participants in the collaborative group to that of the individual training control group it can be assumed that collaborative training have beneficial effects compared to an individual one (III). It must be noted however, that the outcome measurements used to evaluate the episodic memory aspects of the intervention (III) does not show unanimous beneficial results from the collaborative training. Also, despite that the intervention programme in Study III and IV had both memory training components and an occupational training condition, the results from the post test memory assessments showed more consistent results than the post test communication and interaction assessment in an occupational performance setting. Reasons for that are elaborated on below.
As alluded to in the introduction, enhancement of engagement in everyday occupations might have effects on the persons with dementia that does not necessarily show in assessments with specific focuses on functions (as e.g. ACIS-S). Also, it has been previously shown that a cause and effect relationship between what persons with dementia or their caregivers perform in occupational assessments and what the same persons perform in specific functional assessments is not often found (Guralnik & Kaplan, 1989; Nygård et al, 1998). On the basis of such reasoning, the effects of our training in an everyday activity (setting a table) might not show in the Assessment of Communication and Interaction skills. Rather, it might have been more beneficial to (in line with Burgio et al, 2001) use a broader set of measures assessing e.g. the quantity of occupational engagements during a day, quality of occupational performance in a specific occupation performed by the persons with dementia, their sense of competence and perhaps their own perceptions of the occupations they do. Measuring such outcome factors in interventions would be interesting focuses for future research.

As identified in Study IV caregivers’ communication and interaction skills when performing an everyday activity together with the person with dementia had a tendency to increase as a function of training. In accordance to the discussion of how important the social climate is (Mead, 1967) and social responsiveness is for the withheld perception of oneself as a meaningful acteur in society (Asplund, 1987), or a contributor in everyday occupations (Christiansen, 1999) this finding might in itself suggest that there could be a point in advocating for a social approach in future interventions as a complement to an individual one. However, it should be noted that memory as well as caregivers’ communication and interaction skills are two components among numerous others playing part in occupational performance. Despite that, using a social focus on performance of occupations as outcome measures might be an avenue for future research.

7.5 SUPPORT FROM THE SOCIAL ENVIRONMENT

As also discussed in Study II, some of the caregivers’ supportive acts and management approaches might be invisible to the persons with dementia (Jansson et al., 2001). Also, in Study I, such acts became apparent in that caregivers e.g. showed attentiveness to the needs of the person with dementia and that they offered them a chance to reflect on their next step and/or take command. Caregivers further performed physical acts that might be invisible to the persons with dementia, for example when they made the
environment less confusing by adapting the workplace and objects within it. Such potentially invisible acts can also be seen as a form of doing together, where the caregiver uses knowledge of the persons with dementia to tune in to their occupational performance capacities and adjust to the actual situation. Further, they may not only be beneficial for the socio-environmental climate between the spouses in the day-to-day occupations, but they might also, in line with Christiansen (1999) be beneficial in supporting the sense of competence in the persons with dementia, since they do not have to encounter as many problems in their daily life. Furthermore, as identified in Study II, the caregivers also described how the persons with dementia were encouraged to choose things when engaging in occupations, such as, for example, choosing flowers or groceries when shopping. Thus, parallels could be drawn to the findings by Politis et al (2004) that being able to participate in choosing activities from one’s own interest (Politis et al, 2004) or at least stating one’s own preferences (Van der Linden & Juillerat, 2004) can enhance engagements in occupations, and most likely also withhold a sense of competence (Christiansen, 1999). Hence, it could be suggested that caregivers and healthcare professionals support the engagements in self-chosen everyday occupations. Evaluating those aspects would be interesting avenues for future research.

Typically, current healthcare services for persons with dementia put much effort in identifying losses of memory capacities and awareness thereof (Ott et al, 1996) as well as identifying losses of abilities to perform everyday occupations in the person with dementia. Such assessments need to be performed as part of the diagnostic and care-planning process. However, focus on such individually focused assessments identifying lacks and dysfunctions might also undermine the person with dementias sense of competence (Gillies & Johnston, 2004). In fact, some of the participants in our studies anecdotally described their dubious feelings towards the regular visits they needed to undertake to the out-patient clinic. Caregivers described that, the assessments of the cognitive functions often was perceived by the person with dementia as an unwanted reminder of the negative progress of the disease. As demonstrated (I+II), and shown in earlier research (Jansson et al., 2001) a common caregiver strategy was to avoid highlighting the dementia diagnosis by making the care in everyday life invisible. Accordingly, if persons with dementia and their caregivers live without acknowledging the presence of the disease, that could be a reason for not accepting assistance from others in everyday occupations. In such situations, healthcare professionals might be
able to help both parts by e.g. offering, daycare as an attractive occupation for persons with dementia. Thus, these indications call for a discussion on what interventions healthcare practice should provide to best support both the persons with dementia and their caregivers.

7.6 BENEFICIARY ASPECTS OF HOME BASED INTERVENTIONS

Studies on interventions supporting persons with dementia in their occupational performance at home are not common (Gitlin, 2003). One probable reason for that may be that home intervention research is costly. Also, in home based interventions it is difficult to control for various factors impacting the intervention (Stephenson & Wiles, 2000). However, from a long-term cost effectiveness view, it has been argued that provision of support in occupation for caregivers might allieviate some of the perceived burden and postpone institutionalization in the persons with dementia (Hjulström, 2007). The findings in this thesis, give some material that can be discussed in the development of such support.

In this thesis, adapting the physical environment was used as supportive acts that caregivers used to support the occupational performance of the persons with dementia. In Study I, we used identified if, and how the social environment (i.e. the caregiver’s) and other environmental factors influenced the person with dementia, and if they did so, how the caregivers managed to support the performance of their spouses. Not surprisingly, adjustments of both the physical environment and the task, was performed by the caregivers (I). Similarly environmental strategies have shown to have beneficial effects on persons with dementia as they can function as cues that remind the person of where they are (Nolan, Mathews, Truesdell-Todd & Van-Dorp (2002) and what should be the next step in performance in an everyday occupation (Gitlin & Corcoran, 1996). On the basis of such findings, being in the own home environment, knowing the items and the way one usually performs a task can be important for a beneficial environmental and task adaptation for a person with dementia. This indicates that performing interventions in the home-environment can have advantages before training in an institutional setting.
8 METHODOLOGICAL REFLECTIONS

8.1 LIMITED CONGRUENCE BETWEEN THEORY AND CLINICAL ASSESSMENTS

There are several matters worth critical attention in the findings from this thesis. First, the present research have an ambition to be theory based, identifying occupational engagement as a dynamic system interacting with a variety of components including the social environment (here the informal caregivers and friends) and changing over time (Kielhofner, 2007). Within this complexity, the interventions researched present the dynamic notion of providing ‘the just right challenge’, promoting collaboration in performing everyday occupations for the participating persons with dementia and their spouses (Yerxa, 1998). However, intervention instruments within occupational therapy research and healthcare research are still tailored to assess individual performance and further measure performance at a given situation rather than unfolding as a process over time, which in turn might lead to misinterpretations of data (Guralnik & Kaplan, 1989). Consequently, the instruments used in Study III & IV in this thesis measure individual performance at a given time, rather than collaborative performance as an unfolding process. Thus, it can be argued that the study design has not fully matched the theoretical foundations of being system theory (Kielhofner, 2007) and process oriented (Lawton, 1999). Hence, an important future avenue for occupational therapy research is to develop assessments that match the current theoretical foundations of the profession.

Another implication for taking a system theory approach to human occupation is the interplay between cognitive functioning (such as memory) and engagement in occupation within the present research. We know that research has had difficulties to establish an overall causal relation between improvement in cognitive function and performance of occupation (Guralnik & Kaplan, 1989; Nygård et al., 1998). This has been explained with the complex interplay between various external and internal factors that constitute occupational performance (Kielhofner, 2007). Although the Model of Human Occupation (Kielhofner, 2007) introduces a spectrum of possible factors that influence human occupation, there is little said on how to best train and measure occupational performance in individuals. This becomes evident especially when setting up interventions and making efforts to operationalize the spectra of factors that MoHO (Kielhofner, 2007) suggests influence human occupation. To our
knowledge, such an inclusive instrument is not yet available. Again, the outcome measures used within this thesis could be discussed regarding how they match the theoretical frame for the intervention.

Furthermore, there is also a lack of instruments that measure social consequences of a disease between two individuals in a collaborative setting. Hence, the assessments used in this thesis were the best the research team could come up with to measure intervention impact on collaboration at the time of the intervention. Further research is needed to explore relations between factors such as cognition, social relations and engagement in occupation.

8.2 VIEWING THE COUPLE AS THE CLIENT CALLS FOR A NEW TERMINOLOGY

Another issue for discussion is the terminology used. In the present thesis, the ambition has been to take the social dimension of performance of everyday occupations into account. However, it could be questioned if the interventions within this thesis really could be identified as collaborative, since the strategies introduced in the interventions were aimed for caregivers to use, rather than for mutual use by both parts. However, within the intervention (presented in Study III & IV) both the persons with dementia and their caregivers were actively participating. For example, in introducing the intervention, both parts in the couple were informed of the potential benefits with creating new ways of working together, and of the probable beneficial gain from introducing such working strategies in early stage dementia, when a potential to remember them, and make them a habit is high. Hence, the intervention strategies used, and the theories behind them, such as providing the ‘just right challenge’ (Yerxa, 1998) and provide graded cues (Bird & Luszcz, 1993) have been introduced to both participants as avenues to take when/if the person with dementia get stuck in performing everyday occupations or in remembering.

As much as we have trained the caregivers to provide support, we have also prepared the persons with dementia to accept this support and ask for assistance when problems in performing everyday occupations or memory related tasks occur. In the light of that reasoning, the use of the word collaboration might be reasonable. Further, it could also be added that, in Study IV, we chose to administer the Swedish Assessment of communication and interaction skills (ACIS-S) (Haglund & Kjellberg, 1998) on the
caregiver. However, based on anecdotal data from the intervention it is our belief that also some of the persons with dementia altered their communication and interactions towards their spouses during this intervention. However, measuring their skills was not part of this thesis.

8.3 CRITICAL ASPECTS OF THE STUDY DESIGN

A critical point that could be raised concerning the study design might be that, the intervention within this thesis did no build upon the discoveries in Study I and II. This meant that the strategies and management approaches that the caregivers to the persons with dementia used on their own initiative were not taken into consideration in the intervention. The reason for this was the design of the study, where the data for Study I and II were gathered in connection to the pre-test period of the intervention study. For future interventions, identifying and using the self-initiated support and approaches caregivers use might be a fruitful avenue.

In explanation of the inconsistencies in intervention effectiveness, one major limitation is often addressed: Failure to examine multiple outcome variables, due to the fact that one outcome measure might be more sensitive to change than others (Sörensen, Pinquart & Duberstein, 2002). In our intervention, the communication and interaction skills, measured with the ACIS-S (Haglund & Kjellberg, 1998) did not show as clear intervention gains as did the memory assessments. Examining the effect of the intervention, as in this thesis, only with one assessment might therefore underestimate the effectiveness (Burgio et al, 2001). This is one of the reasons the clinical significance in the ACIS-S data was also reported in Study IV.

Another reason for limited significances in post test assessments of the effects of the intervention in this thesis can, beside the obvious lack of intervention effect, also be a consequence of design. In the data collection in this thesis we combined qualitative and quantitative methods for the same sample of participants. We also assessed and trained the participants in their own home-environment. From a qualitative methods point of view, 30 participating couples were perceived as a reasonable amount for reliability of analyses, whilst it from a quantitative methods viewpoint is considered low. For the purposes of performing qualitative analysis the ‘relatively large’ amount of participants provided rich data. However, for the analysis of intervention outcomes, a larger group of selected participants would have contributed to more statistical power, which could
have enhanced the possibility for statistical significant results, which in turn vouch for an increased reliability of the results (Kirkwood & Sterne, 2003). If more statistical reliability had been reached, some generalisations from the sample to the general population of persons with dementia and their caregivers could have been drawn. Hence, future interventions need to include a larger sample to have more statistical power, and verify differences with more accuracy.

The design of the intervention in this thesis was created to enable identification of transfer of learning. Transfer of learning is the ability to apply strategies learned in one task and situation to other tasks and situations (Neistadt, 1998). The demand on the supporting strategies we taught the caregiver to use, therefore aimed to be flexible and general enough to be useful also through changing/worsening conditions. In our intervention, we trained one everyday activity and one memory activity, and assessed the potential outcome in two other activities having the same two focuses. Generally, as transfer of learning has been proven difficult to reach (Guralnik & Kaplan, 1989), it could perhaps to some extent explain why we did not reach consistent results (and rather low significances) in the test-scores. However, the beneficial outcomes we received in the two memory tasks in Study III indicate that caregivers working together with their spouse with dementia in a memory task can use their acquired knowledge of support strategies in a new context, and that their spouse with dementia can benefit thereof. Since previous studies on memory intervention for older people, and persons with dementia, have not always been able to show transfer effects, the findings in that study is a welcome contribution to this field (Hill et al, 2000; Quayhagen & Quayhagen, 1995).

Finally, some reflections on the data collection methods. One of the data gathering methods in the present research was observation. Is has been suggested that in the observational role the researcher can be one of four types of observer: a complete participant, participant-as-observer, observer-as-participant, or a complete observer (Domholt, 2000). Even though the researchers in this data collection tried to assume the role of complete observer, who does not change the situation being observed, the mere presence of the investigator probably changed the dynamics of the situation. Consequently, the most proper way to define the researchers’ participation in these studies would be that I assumed the role described in the observer-as-participant model. But even though the observer role included participation of the researcher, the
reliability of the data, e.g. avoiding biasing the data (Kirkwood & Stern, 2003), was a concern. Thus, the researchers did not assume family membership roles, and were not available besides during the brief periods during which observations took place. However, the very process of conducting the study probably changed the environment to some extent, since observations are complicated processes, dependent on a subjective, interpretative, observer (Domholt, 2000). Although both researchers involved in the data-collection phase were trained observers from their experiences as practitioners in health care video-recording was used to provide the non-biased co-authors with the material, to score the data (using the ACIS-S) (Kirkwood & Sterne, 2003). Other ways to evaluate communication skills through observations have been practiced by Burgio et al, 2001) who, instead of videotaping the performance and communication between couples in an everyday activity, chose to bring the couple to a clinic where they communicated in a staged social activity. In our study, some couple’s occupational engagements were in part performed under silence, although together. Hence, although it is our belief that the natural home-environment is the best setting to be in, we did not have a large amount of communicative material to assess the spouses from. This might have affected the richness of data and thus the reliability of the results.

Interviewing persons with memory impairment has been suggested to be potentially problematic (Nygård, 2006). A common problem is that persons with dementia might have difficulties recalling answers to specific questions and staying on subject. Furthermore, a common argument is that the memory loss is not static, which means that the person with dementia sometimes remembers more aspects on a topic than at other times (Hubbard, Downs & Tester, 2003). This was the case in four of the participants, whose interviews were excluded from the analyses (in Study II) due to quality limitations in the data. Overall, interview data in Study II were surprisingly rich, considering the limited length and depth of the interview. This might partly be explained by the thorough provision of information and preparation of the participants by the researcher. This exclusion could possibly have been avoided if we had adhered to recommendations from the literature stating that repetition of interview occasion can be fruitful to receive rich interview data (Nygård, 2006). All participants were informed at least two weeks in advance that an interview on the topic of engagements in everyday life occupations, was to take place. By the time of the interview, they had got acquainted with the researchers, and might have had a notion on the purpose of
their presence. This familiarity between the researchers and the couples probably contributed to the highly focused and well considered descriptions we received, thus strengthening the reliability of the material in accordance with suggestions by Nygård (2006).

Consequently, the two qualitative data collection methods used seemed to be fruitful ways of gaining rich information about the everyday situation for persons with dementia and their spouses. Inclusion of the person with dementia in interviews as suggested by (Nygård, 2006) also proved to be fruitful, especially considering the findings in Study II, where a complex picture of their perceptions of occupational engagement became visible. To discover each person’s unique, individual descriptions, we chose to interview the participants separately. From an ethical viewpoint, this also seemed a fair approach for both partners, since they were equally acknowledged by the researcher. Inclusion of both the persons with dementia and their caregivers have also been recommended by Kim, Karlawish & Caine (2002) as important for the preserving the autonomy and welfare of persons with dementia. Consequently, since the participants were well prepared for the interviews, and got individual attention during the interview, we collected a wide spectrum of information making the collected interview data trustworthy despite the relatively limited design that allowed for only one interview (Bogdan & Biklen, 1998).

In conclusion, in using a spectra of data collections methods in this thesis, we adhere to literature suggesting to not only limit the qualitative data to interview data, but to acknowledge that larger, multitude of data collection models are beneficial (Harding & Meldon-Smith , 2000; Morse, 2002; Nygård, 2006). For example it is suggested that observational research provides different information that informs and complements interview studies (Domholt, 2000; Nygård, 2006). In line with such reasoning it must be noted that in our findings, we identified that, in some aspect, the observation we made in Study I was described, and were given rational for in the interviews we made. In accordance with the recommendations from e.g. Nygård (2006) and others, future research might benefit from using mixed data collections methods.
9 CONCLUSION

Four major contributions to contemporary research on persons with dementia and their caregivers are presented in this thesis. First, we showed how informal caregivers to persons with dementia give support by their own initiative (I), and that they have the potential to develop support if introduced to a general, hierarchical support strategy (III). Second, findings showed that both the persons with dementia and their spouses experience consequences in their everyday occupations due to the dementia. Further, caregivers to persons with dementia described rationales for their acting and engagement in everyday occupations, ranging from dilemmas they experience in handling challenging situations, to management approaches they had come up with to solve them. Hence, some caregivers provided resources for future healthcare interventions to build on.

Third, the results from the home-based collaborative intervention programme showed that, after the programme, the persons with dementia and their caregivers started to share memory recall in a memory task more equally between them, compared to persons not receiving this particular training. This indicates that the caregivers became more able to use the memory support strategies taught in training to support their spouse with dementia. Further, individual assessments of the persons with dementia showed an improvement in the persons who received collaborative training, which was not visible in the two control conditions. Hence, training together with a close informal caregiver might be beneficial for the persons with dementia.

Lastly, effects of the home-based collaborative intervention on caregivers’ communication and interaction skills were measured. Analyses indicated that both the collaborative and the individual intervention programme had some influence on caregiver skills compared to the controls. Thus, the results give some support for the notion that home-based programmes are beneficial for caregiver communication and interaction skills.

Finally, the findings from the present studies indicate that, listening to, and observing both partners, in a couple where one has a dementia diagnosis, and building on both persons’ resources and learning potentials in interventions built on memory- and occupational enhancing theories, can be beneficial for successful support towards the person with dementia.
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You are my North, my South, my East and West.
My working week and my Sunday rest.
My noon, my midnight, my talk, my song.
I hope our love will last forever, and be strong.
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