EVERYDAY LIFE AND SOCIAL RELATIONS IN HOME-LIVING PATIENTS WITH MILD ALZHEIMER’S DISEASE AND THEIR CAREGIVERS: QUANTITATIVE AND QUALITATIVE ANALYSES

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This thesis was based on the following original papers:

**Paper I**
Sørensen, LV, Waldorff, FB, Waldemar, G.
Social Participation in Home living Patients with Mild Alzheimer’s Disease. (Submitted).

**Paper II**
Sørensen, LV, Waldorff, FB, Waldemar, G.
Coping with mild Alzheimer’s disease. (Submitted).

**Paper III**
Sørensen, LV, Waldorff, FB, Waldemar, G.
Early counselling and support for patients with mild Alzheimer's disease and their caregivers: a qualitative study on outcome. (Submitted).

*Front page, own photo of the sculpture “Hyldemor” by Hanne Varming (1990).*
PhD thesis

Everyday life and social relations in home-living patients with mild Alzheimer’s disease and their caregivers: quantitative and qualitative analyses.

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Preface

This PhD project was carried out between April 2004 and March 2007 during my employment as project coordinator in the Memory Disorder Research Group, the Department of Neurology, Neuroscience Centre, Copenhagen University Hospital, Rigshospitalet, Denmark, as part of the DAISY study, which was financially supported by the National Board of Specialised Consultancy and Social Services, the Ministry of Social Affairs, with contributions from the Ministry of Health, and the Danish Alzheimer Foundation. This PhD study was additionally supported by the Danish Health Foundation, the Research Council of the Copenhagen Hospital Cooperation.

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Lisbeth Villemoes Sørensen, Frederiksberg, March 2007.
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Abbreviations

_AChEI_: Acetylcholine Esterase Inhibitors

_AD_: Alzheimer’s disease

_ADL_: Activities of daily living: the performance of the basic activities of self-care

_ADCS-ADL_: Alzheimer’s Disease Cooperative Study - Activities of Daily Living Inventory

_APA_: American Psychiatric Association

_IADL_: Instrumental activities of daily living related to independent living, including preparing meals, managing money, shopping, using a telephone etc.

_ICF_: International Classification of Functioning, Disability and Health

_MMSE_: Mini-Mental State Examination

_NPI-Q_: Neuropsychiatry Inventory Questionnaire

_ROT_: Reality Orientation Therapy

_WHO_: World Health Organization
List of papers

Sørensen LV, Waldorff FB, Waldemar G.
Social Participation in home-living patients with mild Alzheimer’s disease.
Submitted (in review).

Sørensen LV, Waldorff FB, Waldemar G.
Coping with mild Alzheimer’s disease.
Submitted (in review).

Sørensen LV, Waldorff FB, Waldemar G.
Early counselling and support for patients with mild Alzheimer’s disease and their caregivers. A qualitative study on outcome.
Submitted (in review).
1. Introduction

The ability to cope with everyday life is important to peoples’ experience of wellbeing and social participation (Wilcock, 1998). The life of patients with Alzheimer’s disease (AD) is characterised by progressive impairment of abilities to cope with everyday life and social functions. In order to adjust the demands on patients with mild AD and to preserve their ability to cope with everyday life and social relations throughout the long course of the disease, support and care from informal caregivers and professionals is necessary (Basun et al., 1999; Engedal and Haugen, 2004). To plan this support and care it is important to know as much as possible about patients’ perspective of coping with everyday life and social relations in the mild phase of the disease, about their social participation, and of possible determinants for their low social participation. Informal caregivers of patients with AD are at high risk of psychological distress and morbidity (Sörensen et al., 2006). Psychosocial intervention with education, tailored counselling, and support groups for patients with mild AD and their caregivers is a possible support.

The thesis covers the following topics in mild AD: 1) social participation of patients; 2) the patient’s experience of and coping with everyday life and social relations; 3) the impact of psychosocial intervention: patients’ and caregivers’ perspectives.

1.1 Alzheimer’s disease

The estimated prevalence of dementia in Denmark is 65000; it predominantly affects persons ≥65 years old. AD accounts for 60-70% of all cases. Thus, 40000 persons are living with AD in Denmark (Waldemar et al., 2007).
AD is a degenerative cerebral disease resulting in the development of multiple cognitive
deficits and impairment in activities of daily living (ADL). Memory impairment is a
prominent early symptom, which typically affects the registration, storage, and retrieval
of new information; however, previously learned and familiar material may also be lost.
Other impairments are aphasia, apraxia and agnosia, and disturbances in executive
functioning. The impairments may be accompanied by deterioration in emotional control,
social functioning and behaviour, and motivation (McKhann et al., 1984; WHO, 1993;
American Psychiatric Association (APA), 2000).
Since pharmaceutical treatment of AD with Acetylcholine Esterase Inhibitors (AChEI)
has been accessible in Denmark in 1996, early diagnosis of the disease has received
increasing attention. Comprehensive research and the development of technologies have
enabled detection of AD at an early stage. Simultaneously, focus on continuity in the
treatment and care has increased; models for cooperation between primary and secondary
health-care systems have existed in all regions in Denmark since 2004 (Danish Ministry
of Social Affairs, 2001). It is estimated that only 28% of all AD patients in Denmark
receive pharmaceutical treatment for their disease (Waldemar et al., 2007).

1.2 Everyday life

AD influences the habitual rhythms of everyday life as the patients’ ability to cope with
the usual demands decreases as does their ability to solve abstract problems (Basun et al.,
1999; Engedal and Haugen, 2004). The level of independence in ADL is used to describe
the severity of dementia (World Health Organization (WHO), 1993). The ability
decreases to perform complex instrumental activities of daily living (IADL), such as
managing finances, medication and transports even in mild AD (Cooke et al., 2002;
Nygård, 2003). Most assessments of ADL in persons with dementia are based either on proxy reports or on observation.

Everyday life is like an anchor in our lives (Hasselkus, 2006). Based on the literature of Wilcock (1998), Keilhofner (2002) and Hasselkus (2002, 2006) I define everyday life as a complicated composition of demands, which include habitual rhythms of concrete basic tasks, demands of abstract organising of life in interaction within the physical and social environment, and decision making. The ability to cope with everyday life is important to peoples’ experience of wellbeing and in social participation (Wilcock, 1998).

1.3 Coping

Coping is a critical factor in the relationship between stressful events and physical and psychological adaptation. In the tradition of stress research coping is conceptualised as an active, conscious response to stressful life events. Lazarus and Folkman (1984, p. 141) define coping as constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person conceptualized. Lazarus (2000) described the conceptual bottom line of his approach as the relational meaning an individual constructs from the person-environment relationship. In a longitudinal study of the care giving partners of men with AIDS Folkman (1997) found co-occurrence of positive and negative psychological states - that positive affect was reported as frequently as negative affect, and that the findings were robust.
Coping in persons with mild AD

According to Harris and Durkin (2002) research is limited on the coping and adapting behaviours of individuals with AD. In their cross-sectional research on 22 patients with early stage AD and their caregivers, they found 12 innovative positive coping strategies they suggest can be mobilised to add to the resilience patients need to deal with the disease. In a meta-synthesis of 33 articles with qualitative research findings regarding the lived experience of having dementia Steeman et al. (2006) found that the memory impairment itself may make it difficult for an individual to deal with the changes arising from dementia disease, and that, in turn, this caused frustration, uncertainty and fear.

Coping in caregivers of persons with dementia

Kneebone and Martin (2003) conducted a critical review of 12 cross-sectional and four longitudinal studies on the coping of those caring for persons with dementia in the community. Based on Lazarus and Folkman’s stress and coping model, they suggest that a general tendency towards problem-solving and acceptance styles of coping is likely to be advantageous to caregivers of persons with dementia. They conclude that the ability of the research is severely limited in its ability to inform the clinicians providing interventions for caregivers about how they should work with their clients to develop problem-solving responses to the difficulties they face, where solutions are available. They also suggest that clinicians should encourage caregivers to adopt an acceptance style of responding to problems for which solutions may not exist.

1.4 Social participation and dementia

Participation is a central concept in the WHO’s International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). In the ICF participation is
defined as involvement in a life situation and categorised into several domains including domains important for social participation namely: communication, and interpersonal interactions and relationships.

In a longitudinal, cohort study of elderly people without known dementia, participants at inclusion underwent a comprehensive assessment of neurological and neuropsychological performance, depressive symptoms, chronic diseases, cognitively stimulating activities, and physical and social activities. Brain autopsy was done at the time of death to decide the level of AD pathology. Analyses of 89 autopsies suggested that social networks modify the relation of some measures of AD pathology to the level of cognitive function. They conclude that the extent of the social network, or something related to social networks, provides some type of reserve that reduces the deleterious effect of AD pathology on cognitive abilities in old age (Bennett et al., 2006).

Social disengagement, social isolation, and infrequent participation in social activities may be risk factors for cognitive decline in aging (Bassuk et al., 1999; Zunzunegui et al., 2003; Barnes et al., 2004). Engagement in stimulating social activities, an extensive social network, and a socially integrated lifestyle may reduce the risk of dementia (Fabrigoule et al., 1995; Fratiglioni et al., 2000; Wang et al., 2002; Fratiglioni et al., 2004). According to Kitwood (1990), the consequences of dementia should be considered as embedded in the context composed of interactions between the neurological impairments, the life history of the person, health status, personhood and social psychology.
Conceptualisation of social relations and social participation

In the literature, the term *social relations* is a comprehensive concept, and there are several conceptual models that form the foundation for the empirical investigation of social relations and their influence on health. According to Berkman et al. (2000) there is still a lack of consensus regarding the conceptualisation of social relations; the key terms - social support, social network, and social relations - are used loosely and interchangeably.

The conceptual framework by Due et al. (1999) with social relations as the main concept and the structure and the function of social relations as sub-concepts was chosen for the present study (fig. 1).

**Fig. 1. Social Relations. Conceptual Framework.**

![Diagram](image)

The *structure of social relations* is defined as the individuals with whom one has a *formal* or *informal relation* (*social network*). *Formal relationships* are defined as social relations arising from one’s position and role in society; they include various professionals, e.g. homecare assistants, dentists, lawyers. *Informal relationships* are defined as the social network, i.e. individuals and linkages between individuals with whom one has a close family relationship or friendship. *Social participation* describes how people participate in
social activities, e.g. by (a) receiving visitors at home, (b) visiting others, and (c) participating in social activities outside the home (Avlund et al., 1999; 2002, 2004a, 2004b; Sørensen et al. 2002). The function of social relations covers the qualitative and behavioural aspects of the social relations and comprises social support, relational strain and social anchorage.

1.5 Psychosocial intervention

Psychosocial interventions for caregivers

The negative impact of dementia caregiving on health as well as on personal and social issues has been well documented (Schulz et al., 1995; Ory et al., 1999; Schulz and Beach, 1999; Croog et al., 2006; Sörensen et al., 2006). Many psychosocial interventions for caregivers have been suggested and tested. In a review of 127 intervention studies, Pinquart and Sörensen (2006) identified eight categories of psychosocial interventions: psychoeducational, cognitive-behavioural therapy, counselling/case management, general support, respite, training of care recipients, multicomponent interventions, and miscellaneous interventions. They found that longer interventions were more likely to improve depression in caregivers and to decrease the risk of institutionalisation of the care recipients; samples with a high percentage of female caregivers showed greater improvement in depression and knowledge, a greater delay in institutionalisation of the care recipients, but less improvement in subjective wellbeing; a greater delay in institutionalisation was also found in studies with higher percent of spousal caregivers; and reduction in caregiver burden was shown to be higher in more recent studies. Other recent reviews (Cooke et al., 2001; Pursey and Richards, 2001; Schulz et al., 2002; Pinquart and Sörensen, 2006; Sörensen et al., 2006) and meta-analysis (Brodaty et al., 2003; Pinquart and Sörensen, 2003) have emphasised that the diversity of interventions,
their broad range of outcome measures, small sample sizes and poor descriptions makes it difficult to reach strong conclusions for recommendations. In a meta-analysis of 30 psychosocial intervention studies for caregivers, Brodaty et al. (2003) found that some interventions can reduce psychological morbidity in the caregivers and help persons with dementia remain living at home for longer. In a systematic review of 62 psychological interventions, Selwood et al. (2006) found extensive evidence that a minimum of six one-to-one sessions in behavioural management technique gave both immediately and long-term alleviation of caregiver depression. They also found substantial evidence that both one-to-one and group caregiver support provided immediate and long-term relief of depression and distress. None of these studies have included caregivers for patients with mild dementia.

**Psychosocial interventions for persons with dementia**

Once a diagnosis of dementia is made, focus becomes centred on the disability, rather than the capability (Goldsilver and Grunier 2001). Psychosocial interventions for persons with dementia, also called non-pharmacological interventions, are predominantly directed towards those with moderate and severe dementia. In a review, Woods (1999) found that most interventions attempted to improve the patient’s level of independent functioning through programmes with training and support for self-care skills, mobility, continence, orientation and participation in activities; wellbeing was less often addressed. In a review of 6 psychosocial interventions for individuals with dementia Kasl-Godley and Gatz (2000) found that psychodynamic approaches appeared helpful for understanding the intrapsychic concerns of the demented person; reminiscence, life reviews and reality orientation (ROT) promoted interpersonal functions; behavioural approaches and memory training targeted towards the specific impairments helped optimize the
remaining abilities; and support groups and cognitive/behavioural therapy assisted early-stage individuals in building coping strategies and reducing distress. In a systematic review of psychosocial interventions in groups for persons with mild dementia only four studies met the criteria for inclusion (Bates et al., 2004). Two of the studies used ROT in small groups, one study used training of ADL skills for procedural memory stimulation in small groups, and one study used counselling and information for individuals. Evidence was found that ROT is an effective intervention in improving cognitive ability measured using MMSE. The evidence was based on pre- and post-test data and three months’ follow-up. No evidence was found that ROT is effective in improving communication, functional performance, cognitive ability measured in terms of memory recall, or in improving wellbeing. Neither was evidence found of the effectiveness of counselling and procedural memory stimulation on the outcome measures used.

2.0 Study rationale

Persons with dementia have commonly not been included as informants in research, because their cognitive deficits have been regarded as a hindrance. Consequently, the knowledge about the patient’s perspective of the disease is sparse; however, realisation is increasing of its importance in planning and providing support and care (Lyman, 1989; Cotrell & Schulz, 1993; Kitwood, 1997b; Downs, 1997; Whitlatch, 2001; Steeman, 2006). Most of the research has focused on dementia in general terms. However, there are several types of dementia, and the patients are characterised by different profile symptoms and needs. AD accounts for the largest proportion of persons with dementia, thus it is particularly important to know more about the perspective of individuals with AD.
The social participation of persons with mild AD may be an important aspect of their ability to cope with the consequences of the disease in everyday life; nevertheless, no reports from studies on this subject were found in my literature search. Those in the early stages of dementia have had few places to turn to for support (Goldsilver and Grunier, 2001). Little account has been taken of the appropriateness of psychosocial interventions for persons with mild AD. To support these individuals in preserving social relations and in coping with everyday life is a constant challenge to informal and professional caregivers throughout the long course of the disease (Ory et al., 2000). Thus, it is important to know more about how patients with mild AD and their caregivers experience the impact of a psychosocial intervention programme with education, tailored counselling and support groups on their coping with everyday life and social relations.

2.1 Study objectives
This PhD study focused on quantitative and qualitative aspects of everyday life and social relations in mild AD. The overarching objective was to examine patients’ perspectives of the impact of mild AD on coping with everyday life and social relations, and the impact of a psychosocial intervention programme on patients and caregivers. The specific objectives of the study were:

1) to examine social participation in patients with mild AD and to analyse predictors of low social participation.

2) to analyse how patients with mild AD cope with the changes they face concerning everyday life and social relations.

3) to identify and analyse the experience of patients with mild AD and their spousal caregivers concerning the impact of the intensive, structured psychosocial
intervention programme with education, tailored counselling and support groups concerning their coping with everyday life and on social relations.

2.2 Preconceptions

The preconceptions of the researcher are to be taken into account when assessing qualitative research. Preconceptions are the personal and professional experience the researcher has before initiating the project, prestudy beliefs about how things are and what is to be investigated, motivation and qualifications for exploration of the field, and perspectives and theoretical foundations related to education and interests (Malterud 2001). My preconceptions consist of more than 10 years of clinical experience working as an occupational therapist with moderately and severely demented persons in the community. I experienced that people with dementia often had resources that were overlooked and that the main focus of the caregivers and the professionals was predominantly on the disabilities of the individual. I also experienced that patients with moderate to severe dementia could express relevant reflexivity on their situation, that they wished to know more about their diagnosis and to discuss the consequences, and that they wanted opportunities to use their remaining resources. Before the start of this study, I participated in planning the DAISY study and during the study I was part of the DAISY research group.

3. Materials and methods

Study design

The three studies were based on the population from the Danish Alzheimer Intervention Study (DAISY) (Waldemar et al., 2006). Study I was a quantitative study based on caregiver questionnaires, rating scales, and a cognitive test on the patients. For study II, a
qualitative approach was used. Eleven couples participating in the DAISY intervention programme were selected for individual semi-structured research interviews (Kvale, 1996). The interviews of patients were analysed using grounded theory (Strauss and Corbin, 1998), a theory generating method. For study III, a qualitative longitudinal approach was used. Semi-structured interviews were conducted with ten of the eleven couples participating in study II one to three months after the intervention. The interviews were analysed for each participant in the longitudinal perspective using a combination of open coding and a template organizing style of interpretation (Crabtree and Miller, 1999).

3.2 DAISY

DAISY (Waldemar et al., 2006), is a longitudinal multi centre study investigating the efficacy of an intensive, structured psychosocial intervention programme with education, tailored counselling, and support groups for patients with mild AD and their primary caregivers.

DAISY was designed as a multi-centre, single-blind, randomised controlled trial, with randomisation to the intensive programme or to usual care and one year follow-up. The DAISY study ran in five Danish centres: three in rural regions, one in an urban region and one in the capital area. A project coordinator (health professional) was employed in each of the 5 regions. Prior to the data collection at baseline the project coordinators were educated in communication with the patients and caregivers and in the use of the questionnaires and rating scales, and inter-rater reliability tests between the project coordinators were conducted. In all procedures rigour was secured by a ‘site file’ in each region, where all procedures were written. The site file was revised in all regions whenever changes were made. Finally, all results were checked for accuracy by monitors.
and a continual quality check of data was carried out while transforming them to electronic data files.

### 3.3 Study population

Patients were recruited from local memory clinics; local specialists in psychiatry, neurology, and geriatrics; and GP’s. Those included were home-living patients with a recent (<12 month) clinical diagnosis of probable AD, mixed AD (McKhann et al., 1984; WHO, 1993; APA, 2000), or dementia with Lewy bodies (McKeith et al., 1996) established or confirmed by the local specialist referral unit (memory clinic); they were age $\geq 50$ years, and had an MMSE $\geq 20$ point (range 0-30 point) (Folstein et al., 1975), and had given informed consent to participate in the study. Further, the patients participating had at a minimum of one weekly contact with a primary caregiver willing to participate in the study, and who had given informed consent. Those excluded were patients with severe somatic or psychiatric co-morbidity, including impaired hearing or vision, which would significantly impair cooperation in the programme, and those participating in other intervention studies at inclusion or during the study. Inclusion was from April 2004 to July 2005; 330 pairs of patients and caregivers were included (table 1). It is estimated that the project coordinators had contact with a least double the number included. It is not known how many refused to participate and how many were excluded, because no screening was done before baseline.
Figure 2. The DAISY study. Design and study population.

### Baseline
330 patients
330 caregivers
Questionnaire data, rating scales, cognitive test

**Data collection for study I**

Randomisation

<table>
<thead>
<tr>
<th>Control Group</th>
<th>Intervention Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>165 patients</td>
<td>165 patients</td>
</tr>
<tr>
<td>165 caregivers</td>
<td>165 caregivers</td>
</tr>
</tbody>
</table>

Usual care

<table>
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<tr>
<th>Psychosocial intervention</th>
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6-month follow-up
Questionnaire data, rating scales, cognitive test

12-month follow-up
Questionnaire data, rating scales, cognitive test

Sample for study II and III and data collection

11 couples selected for individual interviews. First interview before intervention

10\(^1\) of the selected couples for individual interviews. Second interview 1-3 month after the intervention

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\(^1\) One patient died between the first and second interview

### 3.4 The DAISY intervention programme

The intensive intervention programme was organised and run by the project coordinator in each of the five centres. The programme aimed at providing patient education, tailored counselling and support groups simultaneously with caregiver education, tailored counselling and support groups.
The six-months intervention programme had four main components: 1) tailored individual and family counselling, 2) separate education courses for patients and caregivers, 3) outreach telephone counselling, and 4) a logbook to be kept by the patient and caregiver in separate books (not part of the thesis) (figure 3).

Figure 3. The DAISY intervention programme.

Tailored counselling, 7 sessions

- 2 sessions with patient and caregiver together
- 2 sessions with the patient
- 2 sessions with the caregiver
- 1 session with patient, caregiver and family network

Education courses

- Education course for patients:
  - 5 scheduled sessions
  - 12 participants
  - Information about AD, textbook produced for this specific group
  - Discussions about AD and its impact
  - Support group activities

- Education course for caregivers:
  - 5 scheduled sessions
  - 12 participants
  - Information about AD, textbook produced for this specific group
  - Discussion about AD and its impact
  - Support group activities

Outreach telephone counselling, 6 sessions

Logbook kept by patient and caregiver in separate books
3.5 Study I

Data collection
At baseline all primary caregivers were interviewed using structured questionnaires. The interviews were performed by the local project coordinator in each of the five centres. An MMSE (Folstein et al., 1975) was performed on all patients.

| Table 1. Socio-demographic characteristics of patients (N=330) and caregivers (N=330) |
|---|---|---|
| **Age, mean (± standard deviation)** | Patients | Caregivers |
| | 76.2 (±7.2) | 66.0 (±12.7) |
| **Male/female, N/N** | 151/179 | 110/220 |
| **Diagnosis: Probable AD/ Mixed AD/DLB, N/N/N** | 239/82/9 |
| **Living alone/ Living with partner, N/N** | 102/228 | 38/292 |
| **Relation to patient** |  |
| |  |
| Spouse, N (%) | - | 215 (65.2) |
| Child, N (%) | - | 92 (27.9) |
| Other relation, N (%) | - | 23 (6.9) |
| **Vocational education** |  |
| |  |
| None, N (%) | 117 (35.5) | 79 (23.9) |
| <3 years, N (%) | 74 (22.4) | 95 (28.8) |
| ≥3 years, N (%) | 125 (37.9) | 142 (43.0) |
| Unknown, N (%) | 14 (4.2) | 14 (4.2) |
| **Contact frequency to patient** |  |
| |  |
| Daily, N (%) | 251 (76.0) |
| > Once a week, N (%) | 61 (18.5) |
| Once a week, N (%) | 18 (5.5) |
Assessment of social participation

The social participation of patients was assessed in the caregiver questionnaire and measured by three questions concerning the preceding month: (a) how often did he/she receive visitors at home? (b) how often did he/she visit others? and (c) how often did he/she participate in social activities outside the home? The possible answers were: “once a week or more” (score 1), “less than once a week or never” (score 0), and “don’t know” (no score). Each patient was assigned a score of either 0 or 1 for each of the three questions; thus the total composite score ranged from 0-3. The Pearson Correlation Coefficient between (a) and (b) is 0.567 (p=0.0001), between (a) and (c) 0.223 (p=0.0001) and between (b) and (c) 0.143 (p=0.0018) (Avlund et al. 1999). According to previous studies (Avlund et al., 1999, 2002, 2004a, 2004b; Sørensen et al., 2002) we dichotomised patients into two groups, low social participation (total score 0-1 points) and high social participation (total score 2-3 points), respectively. If the information was not available for one or more of the three questions, patients were excluded from the analyses.

Assessment of ADL, neuropsychiatric symptoms, and cognitive function.

The caregiver interview included the Alzheimer’s Disease Cooperative Study - Activities of Daily Living Inventory (ADCS-ADL) (Galasko et al., 1997), with 32 questions - range 0 78 points with 78 points indicating high ADL function. The interview also included the Neuropsychiatry Inventory Questionnaire (NPI-Q) (Kaufer et al., 2000), which has 2 scores: a score for severity and a score for distress. In this study we used the score for severity (range 0 36) with 0 points indicating no neuropsychiatric symptoms. An MMSE (Folstein et al., 1975) was performed on all patients - range 20 30 points, with 30 points indicating high cognitive function.
Quantitative analysis and statistics

Due to a possible cluster effect between the five centres the regression models were fitted using Generalized Estimating Equation techniques, which provide standard errors and 95% confidence intervals that are robust to misspecification of the correlation between subjects. A multivariate model with backwards elimination was applied with a 5% significance level in the final model in order to identify predictors of low social participation. The following variables were included in the model: age, sex, MMSE, living alone measured in the questionnaire by yes or no, vocational education measured by questions of length: less than 3 years = short vocational education, and more than 3 years = long vocational education, ADCS-ADL, and NPI-Q severity scores. In the multivariate analysis the ADCS-ADL score was categorised into three groups: severe ADL impairment = 0–50 points, moderate ADL impairment = 51–70 points and minor ADL impairment = 71–78 points. The NPI-Q score for severity was dichotomised into: mild neuropsychiatric symptoms = score 0–9 points, and moderate to severe neuropsychiatric symptoms = score 10–36 points. Pearson’s chi-square was used to evaluate Goodness of Fit for the reduced model. A deviance approximately equal to its degrees of freedom was used as an indicator of a good model fit. All statistical analyses were performed using SAS, version 9.1, proc Gee (SAS Institute Inc (2006), Cary, NC).
3.6 Qualitative studies, study II and III

Sampling

The selection of participants for the 2 qualitative studies took place among patients randomised to the intervention in DAISY (Waldemar et al., 2006) (fig. 2). Participants were sampled by purposeful sampling i.e. selecting the cases from which the most is learnt (Crabtree and Miller, 1999). To increase the likelihood of capturing the broadest scope of information and perspectives among the participants in the DAISY intervention the strategy of maximum variation sampling was used (Crabtree and Miller, 1999; Maunsbach and Lunde, 1995); thus, the selection of couples ensured representation from all five regions, both sexes, and maximal variation in age, and MMSE (table 3). The sample size was preliminarily estimated to be about 10 couples based on inclusion of two couples from each region. Another important factor for that choice was the time limit for the study.

I selected potential couples in a close cooperation with the DAISY project coordinator in each area. The project coordinators were verbally informed about my studies and supplied with written information. They were asked to identify possible couples as candidates by using the aforementioned criteria; additionally, the candidates should be: married or cohabiting, be willing to talk about their situation and willing to be interviewed. Potential couples were asked by the project coordinator during the first session of counselling if they were willing to participate in the study. Eleven potential couples were identified; they gave verbal permission to be contacted by me for further verbal and written information about the project and they all agreed to participate. To ensure the maximal variation, I frequently informed the project coordinators about which criteria would meet the then current demands of my studies, e.g. which region I needed the next couple from, what sex and approximately what age and what MMSE. Only 10 of
the 11 couples participated in study 3 because one patient died between the first and second interview. Inclusion was from November 2004 until August 2005. The last interview for study III was in January 2006.

### Table 2 Characteristics of the couples included in study II and III

<table>
<thead>
<tr>
<th>Patients' no.</th>
<th>Patients' age</th>
<th>Patients' MMSE</th>
<th>Patients' ADL 2)</th>
<th>Patients' awareness scale 3)</th>
<th>Caregivers' sex</th>
<th>Caregivers' age</th>
</tr>
</thead>
<tbody>
<tr>
<td>1, ♂</td>
<td>73</td>
<td>27</td>
<td>73</td>
<td>full</td>
<td>♂</td>
<td>65</td>
</tr>
<tr>
<td>2, ♀</td>
<td>80</td>
<td>26</td>
<td>45</td>
<td>shallow</td>
<td>♂</td>
<td>85</td>
</tr>
<tr>
<td>3, ♂</td>
<td>71</td>
<td>26</td>
<td>57</td>
<td>shallow</td>
<td>♂</td>
<td>69</td>
</tr>
<tr>
<td>4, ♂</td>
<td>74</td>
<td>23</td>
<td>74</td>
<td>full</td>
<td>♂</td>
<td>67</td>
</tr>
<tr>
<td>5, ♀</td>
<td>80</td>
<td>26</td>
<td>73</td>
<td>full</td>
<td>♂</td>
<td>76</td>
</tr>
<tr>
<td>6, ♂ diagnoses</td>
<td>83</td>
<td>26</td>
<td>56</td>
<td>full</td>
<td>♂</td>
<td>81</td>
</tr>
<tr>
<td>7, ♂</td>
<td>73</td>
<td>22</td>
<td>71</td>
<td>shallow</td>
<td>♂</td>
<td>78</td>
</tr>
<tr>
<td>8, ♀</td>
<td>81</td>
<td>25</td>
<td>68</td>
<td>full</td>
<td>♂</td>
<td>83</td>
</tr>
<tr>
<td>9, ♂</td>
<td>66</td>
<td>24</td>
<td>43</td>
<td>shallow</td>
<td>♂</td>
<td>71</td>
</tr>
<tr>
<td>10, ♂</td>
<td>71</td>
<td>22</td>
<td>65</td>
<td>full</td>
<td>♂</td>
<td>75</td>
</tr>
<tr>
<td>11, ♂</td>
<td>65</td>
<td>26</td>
<td>68</td>
<td>full</td>
<td>♂</td>
<td>65</td>
</tr>
</tbody>
</table>

1) Eight couples from rural regions, one from the urban region and 2 from the capital area.

2) ADL function measured by Alzheimer’s Disease Cooperative Study, Activities of Daily Living Inventory (ADCS-ADL) range 0–78 (Galasko et al., 1997).

3) Awareness of AD assessed on a three-step scale: full awareness, shallow awareness, and no awareness (Reed et al., 1993).

4) Patient died.
Interviews, study II and III

The interview form was chosen as a feasible way of attaining knowledge about the perspectives of the patients and their caregivers. The interviews were prepared according to Kvale (1996) for the semi-structured research interviews, and also inspired by Crabtree and Miller (1999) for the in-depth interview.

An interview guide was prepared for the first interview covering the following themes: activities in everyday life and recent changes; and social relations with spouse, family and friends, and recent changes. All themes had additional questions: what the participants most appreciated, if they felt something was lacking, if something worried them, and what importance AD had to them. In the second interview the same themes were covered with emphasis on recent changes; in addition, participants were asked to describe their experiences of the intervention.

I conducted all interviews and each interview took place in couple’s home. The date and time of the interview were arranged to suit each couple. The interviews began with an informal conversation while the couple welcomed me into their home and we became familiar with each other.

During the interview the cognitive impairments of the patients were taken into consideration. I adapted my style of questioning to suit the capacity of each patient; I kept a clear sentence structure and avoided complex concepts. Additionally, I was responsive to the cues provided by the patients and followed their train of thoughts. When patients became confused or were unable to continue their report, I helped them to continue. This was done, for example by repeating and summarising what had been said, repeating the patient’s actual train of thoughts and giving encouraging and supportive comments. The interviews were audio recorded and notes of other impressions were made in a logbook.
The interviews for study 2 were conducted before the intervention was initiated; the
interviews for study 3 were conducted 1–3 months after the intervention. The mean
duration of the interviews with patients was 44 minutes, range 23–90 minutes, for
caregivers 59 minutes, and range 26–105 minutes.

Grounded theory, study II

The objective of study II was to analyse how patients with mild AD cope with the
changes they face in relation to everyday life and social relations. For the analysis of the
interviews the “grounded theory” approach was used.

The grounded theory method was developed by the sociologists Glaser and Strauss
(1967) resulting from the need for a special methodology for the study of human
behaviour and the social world based on the assumptions and theoretical underpinnings of
symbolic interactionism.

Grounded theory was originally developed to study basic social processes and to generate
new theory. As the purpose of my study was to investigate the basic social processes
experienced by persons with a recently disclosed diagnosis of AD and possibly to
develop theory on the subject, the choice of grounded theory as the method used for the
analysis seemed suitable. Other reasons for choosing grounded theory were that the
method is suitable for analysing interviews, it is based completely on data and, thus, its
use is not determined by the researcher’s knowledge of humanistic text analysis, and it is
very systematic, which makes the validation process transparent and visible.

I used the grounded theory method as described by Strauss and Corbin (1998). They
developed the original method by precise descriptions of the analytic process and by
supplying it with an analytic step, the axial coding, a validation process that forces the
researcher to argue for all conclusions grounded in the data. The analytic process
described by Strauss and Corbin (1998) is quality assured to a higher level than the original description of the method: it assures that conclusions are grounded in data.

**Data analysis, study II**

The first interviews with the 11 patients were transcribed verbatim and checked for accuracy by me. Open coding was initiated after the first four interviews, using detailed line-by-line in-vivo coding. Open coding means the process through which concepts are identified and their properties and dimensions are discovered in the data and related to categories. The initial open coding led to minor revisions of the interview guide. All subsequent interviews were coded. The coding resulted in the development of 4 higher order conceptual categories and 42 sub-categories (study II table 2). During analysis of the first eight interviews, new conceptual categories or subcategories continually emerged. Analysis of the last three interviews did not reveal new conceptual categories. The new conceptual categories and subcategories constituted the basis for further conceptual analysis; the axial coding. Axial coding is the process of relating categories to their subcategories. In this study it was done by asking the questions: what, where, when (structure) how, why (process), and what were the results. For this step in the analysis an organisational scheme, called the paradigm by Strauss and Corbin (1998), was used as a device for the systematic gathering and ordering of data. In the interpretation, structure and process were integrated; categories and subcategories were combined, related and refined according to their properties and dimensions; and relationships between categories were revealed. Open and axial coding were not sequential acts. The open coding was the first step, but was not carried through for all data before starting the axial coding process; the open coding for concepts properties and dimensions was continued
while the development of relationships between categories and subcategories was ongoing in the axial coding process.

During axial coding and in the writing of the story line, the process moved towards more complete explanations about phenomena. The connection between categories gradually became apparent during selective coding. The categories were organised around a central explanatory concept, the core category, and the tentative theory was formulated.

A basic tool in the grounded theory method is the constant comparison at every stage of the analytic process to successively generate increasingly abstract concepts. This contributes to ensuring validity of the conceptualisation. Validity was further ensured through discussions throughout the analysis with other involved and non-involved professional peers. This facilitated conceptual clarification, challenged assumptions, and brought additional perspectives to the data.

**Data analysis, study III**

Study three includes 40 individual interviews with patients and caregivers from ten couples conducted before and after the intervention. The objective of the analysis was to identify the experience of patients and their caregivers concerning the impact of the intensive and structured psychosocial intervention programme on coping with everyday life and on social relations before and after the intervention.

For the analyse of data a combination of open coding and a template organizing style of interpretation (Crabtree and Miller, 1999) was chosen. The method allows the researcher to organise the text according to pre-existing theoretical or logical categories to generate new descriptions of previously known phenomena. Consequently, the method allows focus on particular aspects of the text and is less time consuming than line-by-line coding. I transcribed the interviews verbatim and checked for accuracy. After open
coding of the interviews a preliminary code manual was prepared to identify changes between the first and second interview. The interviews were read through and coded according to the preliminary code manual, supplemented with emerging categories; interviews with the patients and caregivers were coded separately. The two interviews with each individual were analysed together; thus, the identification of changes was separate longitudinal analyses of each patients and caregivers’ experiences. The preliminary codes were refined and modified during the analytic process. The analytic/interpretive process consisted of iterative cycles between organising, connecting, and corroborating codes, and collecting them into increasingly abstract concepts. After several readings of the interviews the main categories became clear and a coding scheme was created to serve as a template for organising the data into interpretations (fig 4). To enhance the dependability and validity of the study an independent researcher performed observer triangulation by coding several interviews. The results were a consensus of the coding and the organising of data.

**Figure 4. Template for organisation of data in study III**

<table>
<thead>
<tr>
<th>Recognition of the changes caused by the disease before and after the intervention:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Range of awareness of the changes</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Reactions to changes caused by the disease before and after the intervention:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Everyday life</td>
</tr>
<tr>
<td>Communication</td>
</tr>
<tr>
<td>Role patterns</td>
</tr>
<tr>
<td>Social relations</td>
</tr>
</tbody>
</table>
3.7 Ethical considerations

The DAISY project was approved by the Danish Data Protection Agency (j. nr. 2003-41-3178). The local Scientific Ethics Committee evaluated the project protocol (j. nr. (KF) 02-005/04) and the project was registered in the Clinical Trial Database, ISRCTN74848736. All patients and caregivers gave informed consent regarding participation in the DAISY study. The couples selected for study II and III received additional verbal and written information before the first interview. The interview data were treated confidentially and individual persons cannot be identified after the analysis. The interviews were considered not to be harmful to the participants.
4. Results

This chapter is a summary of the results presented in the three papers.

4.1 Social participation in home-living patients with mild Alzheimer’s disease. Study I

Objective

The objective was to examine social participation in patients with mild Alzheimer’s disease (AD) and to analyse predictors for low social participation.

Material

The data were drawn from the DAISY baseline examination; they were proxy reported by the caregivers, except for the MMSE.

Results

The cumulated score for social participation could be calculated for 308 patients (93.3%), of whom 54.2% had low social participation (score 0–1) and 45.8% had high social participation (score 2–3).

The results of the three items in social participation were: 66.6% received visitors at home once a week or more; 39.9% visited others once a week or more; and 36.4% participated in social activities outside the home once a week or more. In the multivariate analysis with backwards elimination, significant predictors of low social participation were ADCS-ADL ≤50 (OR = 3.1, 95% CI = 1.8 – 6.9), ADCS-ADL 51–70 (OR = 1.5, 95% CI = 1.1 – 1.9), and NPI-Q total 10–36 (OR = 2.2, 95% CI = 1.1 – 4.3); sex, age, living alone and MMSE were not independent determinants.
4.2 Coping with mild Alzheimer’s disease. Study II

Objective

The objective was to analyse how patients with mild Alzheimer’s disease (AD) cope with the changes they face in relation to everyday life and social relations.

Material and methods

The grounded theory analysis was based on data from semi-structured research interviews with 11 patients randomised to participate in the DAISY intervention programme.

Results

During the process of open coding, 4 main categories and 42 subcategories were revealed. The main categories and the subcategories were refined during the axial coding where the paradigm model was used. The analysis revealed that the basic social psychological problem faced by patients with mild AD, the core category, was their awareness of decline in personal dignity and value.

Coping strategies to meet these problems were adaptations to the altered situation in order to maintain a feeling of well-being. Adaptive strategies included concentrating their energy and resources on the everyday life activities that were still possible to perform, positive thinking about the disease, thinking and talking about life and oneself as before the disease, and withdrawal from activities and social situations that no longer gave the experience of well-being. The spouse appeared to be the most important social relation. The most significant worries of the patients’ were about communication in relation to their spouse, and about the reaction of the spouse to the consequences of their disease.
4.3 Early counselling and support for patients with mild Alzheimer’s disease and their caregivers. Study III

Objective
The objective was to identify and analyse the participants’ experienced outcome of an intensive structured psychosocial intervention programme with education, tailored counselling and support groups for home-living patients with mild Alzheimer’s disease and their spousal caregivers.

Material and methods
Data were collected by semi-structured research interviews conducted separately with each person in 10 couples before the intervention and 1–3 months after the completed intervention. For the analysis, a template organising style of interpretation was used.

Results
The analysis revealed that patients found support groups relevant: they found it stimulating to be with peers - it supported their self-esteem, and it supported them in finding new ways of managing everyday life and social relations. During and after the intervention, caregivers were better able to cope with the challenges their partner’s disease involved, and they were able to face everyday life and social relations with more serenity and competence. After the intervention both patients and caregivers sought suitable support groups to join as a permanent activity, and caregivers sought permanent counselling.
5. Discussion

5.1 Main findings of the three studies

Low social participation was frequent in patients with mild AD, and was associated with decline in ADL and with the presence of neuropsychiatric symptoms. In the qualitative study II, the core category was: patients’ awareness of decline in personal dignity and value. Coping strategies used to meet these problems were adaptations to the altered situation in order to maintain a feeling of well-being. In the qualitative follow-up study, patients and caregivers appeared to benefit from psychosocial intervention with education, tailored counselling and support groups. The intervention supported patients’ self-esteem and their coping with everyday life and social relations. Caregivers improved their ability to cope with the challenges their partner’s disease involved, and they were able to face everyday life and social relations with more serenity and competence.

Quantitative as well as qualitative analyses were used as a consequence of the aims and focuses of the individual studies. Several perspectives of everyday life and social participation in mild AD were revealed. Because the three studies used different design and data they revealed different aspects of everyday life with mild Alzheimer’s Disease. These data supplement each other and contribute as a whole to a deeper insight into factors that are important in the lives of these families.

For example social participation was found to be quantitatively low in the majority of patients and it was possible to identify predictors of low social participation because of the statistical analyses of quantitative data. In the qualitative study II patients’ awareness of decline in personal dignity and value was revealed in a way that would have been difficult to catch in a quantitative study. The coping strategies they used to meet these problems aimed at maintaining a feeling of well-being. Consequently, patients may
refuse to participate in social activities in order to avoid a possible painful experience of social participation in which they are confronted with their reduced ability to perceive, understand, and come to terms with many impressions. Study III revealed that both patients and caregivers sought suitable support groups to join as a permanent activity after the intervention. The patients particularly appreciated being with peers, which could indicate that social participation can be stimulated if adapted to the patients’ capacity. These findings appear so lively that it would have been difficult to get the same in-depth experience by the use of quantitative data.

5.2 Social participation in mild AD

According to McKhann et al. (1984), WHO (1993), and APA (2000), deterioration and impairment of social function and behaviour is an integrated part of the Alzheimer’s disease syndrome, although none of the clinical diagnostic criteria includes specific criteria for the level of social impairment. To my knowledge no previous studies have addressed the question of social participation in mild AD defined as the frequency of receiving visitors at home, visiting others, and participation in social activities outside the home. Longitudinal studies have found that a low level of social participation in general populations of elderly people may be related to mortality as a precursor (Bennett, 2002; Maier and Klumb, 2005). Others (Lee, 2000; Avlund et al., 2004b) found that a high amount of social activity significantly reduced the risk of functional decline and mortality in elderly people. Several studies have found that social disengagement is a risk factor for cognitive decline (Bassuk et al., 1999; Zunzunegui et al., 2003; Barnes et al., 2004). Determinants of social participation among elderly persons have not been well addressed in the epidemiological literature, and research on the relation between health status and social networks is limited (Cerhan and Wallace,
Despite careful literature search, only few other studies on social relations among patients with mild AD appeared. Werner (2005) has examined determinants of social distance against persons with AD by face-to-face interviews with 206 adults using an experimental vignette methodology, varying in the severity of the disease. One finding was that increased severity of AD was associated to increased discrimination. According to Werner (2005) a possible explanation of the low social participation found in study I could be the stigma felt by friends and family regarding the person with AD.

In a qualitative study of 22 patients with mild AD, Harris and Dunkin (2002) found that telling friends, family members, neighbours, and acquaintances that they had been diagnosed with probable AD was a powerful emotional release and coping strategy for many of the patients. Patients’ awareness of decline in personal value and dignity, as found in study II, might be a barrier for sharing their experience with friends and family. However, even in this study population of resourceful patients social participation was found to be low in most participants.

5.3 Study population

The participants in DAISY belonged to a resourceful part of the AD population, as they were diagnosed in the mild phase of the disease, were willing to participate in a comprehensive social research and intervention programme, and had a primary caregiver. Another resource was that 96% of the patients were treated with AChEI. In contrast, it was estimated that only 28% of all patients with AD (all stages) in Denmark are treated with anti-AD drugs (Waldemar et al., 2007). Further, the patients’ level of vocational education was somewhat higher than in the general population (Danish health interview survey, 2000, Kjøller M, 2006, personal communication) and, finally, all patients had close contact with a caregiver. The special attributes of this study
population indicate that a selection bias must be taken into account when the results are compared to other clinical and community based study populations. The results do not necessarily cover the socially less resourceful individuals with AD, the socially isolated, or the undiagnosed patients’ situation. However, it is assumed that low social participation may be present to a greater extent in a less resourceful population. Further research is needed to clarify this.

5.4 Patient and proxy reports in research on AD patients

Traditionally, patients with dementia have been excluded from studies about dementia as their cognitive deficits have been regarded as a hindrance (Bond and Corner, 2001; Hubbard et al., 2003; Moore and Hollet, 2003; Nygård, 2006). Consequently, most of the research on this patient group is based on proxy reports from spouses or other caregivers. There is growing attention to the importance of taking the patient’s perspective into account when planning and providing support and care (Lymann, 1989; Cotrell & Schulz, 1993; Kitwood, 1997b; Downs, 1997; Whitlatch, 2001; Steeman, 2006); thus, it is important to learn more about the patient’s perspective. However, there are many methodological challenges in elucidating the perspective of patients with AD. According to Bond and Corner (2001) the complex nature of dementia and dementia care highlight the methodological challenges of investigating any complex social phenomenon.

In study I, several informant-based measurements were used. Few studies have compared the accuracy of indirect reports of IADLs with objective measures. When comparing direct assessment with caregiver reports Loewenstein et al (2001) indicated that direct assessment was superior to caregiver reports. They suggested that errors in caregiver judgement reflected incorrect attributions (e.g. patient’s unwillingness to
perform the task may be interpreted as inability), positive or negative reporter biases, or simply limited opportunity of the caregiver to observe certain functional abilities. In a study of 49 community-dwelling primarily female spouse caregivers Davis et al. (2006) investigated factors influencing caregivers’ perceptions of patients daily functioning. They found that well-educated spousal caregivers estimated IADL functions of their spouse with AD generally accurate as compared with an objective measure, and were not influences significantly by their own emotional state, their sense of self-efficacy, the quality of their relationship with the patient, or the severity of patients’ cognitive impairment. Karagiozis et al. (1998) found when comparing objective assessment with patients self-report and informant report, that patients’ performances were lower than they estimated and informants tended to underestimate patients’ abilities.

In study II and study III, the semi-structured research interview was used to reveal patients’ experience of coping with everyday life and social relations. In a review of qualitative interview research with people with expressive language difficulties, Lloyd et al. (2006) found that comparably few researchers have explored the experiences, emotions, and beliefs of individuals with dementia. In some of these studies, the information obtained through interviewing patients was supplemented with additional data collection, which suggests that interview accounts provided by individuals with dementia alone were deemed potentially insufficient. Additionally, there has been a tendency to rely on proxy opinions of caregivers, which is likely to provide more information about the experience and subjectivity of caregivers than about the person with dementia (Lloyd et al., 2006). One of the first symptoms of AD is problems with the language, mainly difficulties in finding nouns (Engedal and Haugen, 2004). According to Haak (2002), the language remains relatively intact in the early stages of
AD but the content of speech often changes from more complex units of language to more simple components.

### 5.5 Patients’ perspectives

In study II and study III, the patients’ perspective on everyday life and social relations was emphasised. In study II, a tentative theory was developed from the grounded theory analysis of interviews with patients: patients were aware of the changes in their cognitive and behavioural functions; they adapted to the changes by using comprehensive coping strategies such as changing their activities, attitudes and values in order to preserve their personal value and dignity. This is in line with the findings of Clare (2003) in a qualitative study of 12 patients with mild AD. She found that patients were engaged in the process of acknowledging, reacting, explaining, experiencing the emotional impact, and adjusting. In a qualitative study over six months in patients with mild AD, with the aim to better understand the subjective experience of memory loss, Beard (2004) found that patients deliberately managed their interactions to make sense of their lives and preserve themselves. This is also in line with the findings in study II. In contrast, in a study of how people with mild to moderate dementia live with the illness and the meaning it had for them, Phinney and Chesla (2003) found three: being slow, being lost and being blank. Holst and Hallberg (2003) conducted an interview study on 11 people (eight of them living a partner) with moderate AD concerning their experience of dementia from the moment they recognised the presence of the disease and its impact on their daily living and contact with others. Their findings showed that people with dementia withdraw from social activities because they were unable to reach out to other people. This is unlike the findings in study III where the process of meeting peers in the support groups appeared to be of great importance for patients and provided them with
an experience of not being alone with the consequences of the disease. The findings in study III are in line with Kitwood (1997a p. 98), who declares: **people with dementia are markedly sociable, and there are many who are positively relationship-seeking, whereas our culture often engenders withdrawal or self-isolation.** May be the findings in study III were due to the research approach, where questions about impact of the intervention on everyday life and social relations was the main focus.

### 5.6 Psychosocial intervention for patients with AD and their caregivers

The findings in study III suggest that the psychosocial interventions supported the patients’ self-esteem and improved the patients’ and the caregivers’ ability to cope with everyday life and social relations.

Psychosocial interventions for patients and caregivers are most often conducted separately. Interventions for patients are traditionally conducted with programmes of ROT, reminiscence and equivalent training programmes with focus on patients’ impairments. In the DAISY programme with tailored counselling, education, and support groups the intervention for patients and caregivers was simultaneous with sessions for the couple and for the individual person. In an intervention programme with supportive seminar groups for 15 patients with mild AD and their caregiver separately and together Snyder et al. (1995) found that the intervention facilitated participants’ ability to see the positive aspects of their situation and their options in coping responses. Tailored counselling and education by highly trained professionals was also used by Withlatch et al. (2006) in a psychosocial intervention programme for 31 pairs of patients with mild dementia and their caregivers. The programme focused on patients’ active participation in their care plan, development of positive communication patterns between patient and caregiver, increase of knowledge and understanding about available
services, and assistance to the couple during the emotional turbulence of a diagnosis of AD or other dementia conditions. Participants and counsellors found the intervention acceptable and satisfactory, and it was concluded that patients with mild dementia are able to participate and benefit from a structured intervention that focuses on care planning and future needs. These findings are in line with the findings in study III. In a study with 128 participants in education for caregivers of patients with dementia Wettstein et al. (2004) found that people from the lower socioeconomic strata were clearly underrepresented. Future studies should aim at understanding the needs for support and intervention of the less resourceful patients and caregivers.

5.7 Methodological considerations
Quantitative and qualitative research methods were used as required because the research questions pointed to the use of multiple study designs and data collections.

Context of the study
This study on the impact of social and subjective elements in patients with in mild AD and their caregivers was conducted in the context of the Danish welfare state with a free and comprehensive and tax-financed provision of services for those in need. In Denmark the health sector and the social services sector are organised separately. The DAISY study was an unusual construction with the health sector as the host, which provided social services in the form of psychosocial intervention in the community. Specialised units in the health sector approved the diagnosis of patients before inclusion, and the DAISY study was conducted with the scientific rigor and quality which is characteristic for randomised clinical trials in clinical research.
It is an important overarching mission for both the health sector and the social sector to collaborate in order to assure coherence in the treatment of patients. The DAISY project contributed to fulfilling that aim. In the health sector persons with dementia are referred to as ‘patients’. This gives the individual the right to receive treatment with respect to their impairments. The use of the name ‘patient’ does not imply an ignorance of the individual person.

**Strengths and limitations of the quantitative study. Study I**

The DAISY population with 330 participants diagnosed mild AD is large compared to other controlled trials of psychosocial interventions for patients mild AD (Bates, 2004) and caregivers of patients with AD (Brodaty, 2003; Pinquart and Sörensen, 2006); data were collected in five different regions in Denmark over a relatively short period of 16 months, which contributed to the strength of the study. However, a selection bias must be taken into account for two reasons. First, the study population had several favourable attributes compared to the general AD population; second, the number of possible eligible participants is unknown.

The baseline examination was carried out by health professionals with specific training and with access to the ‘site file’ with written instructions on all procedures, which contributed to the reliability of the study. Additionally, the data were quality checked at several steps. Also contributing to the strength of the study was the inter-rater reliability tests on main outcome measures conducted with the project coordinators before the DAISY study start.

The three questions used as measurement for social participation was previously used for persons self-report (Avlund et al., 1999, 2002, 2004a, 2004b; Sørensen et al., 2002). In this study it was used from informant-based reports. It is a limitation that it was not
tested for validity and test-retest reliability when used from informant-based reports. However, the caregivers had close contact with the patients, which allows for the assumption, that the answers were valid.

**Strengths and limitations of the qualitative studies. Study II and III**

**Sampling**

The couples selected for the semi-structured research interviews were probably the most resourceful participants in the DAISY project. They managed both to participate in the comprehensive intervention programme and to give interviews. The sampling was purposeful and aimed at the maximum variation within the DAISY intervention population. The method can document the range of variations and can identify important common patterns. By looking for this broad range of perspective, the researcher is purposefully challenging his or her own preconceived understandings of the phenomenon and developing them during study (Crabtree and Miller, 1999).

The principles and consequences of sampling are closely related to validity (Malterud, 2001). The validity in study II and III was reinforced by the systematic and transparent method used for sampling, the variations in characteristics of the participants, the systematic data collection with semi-structured interviews, and the considerations of the patients’ cognitive impairments during the interviews. An additional advantage concerning the internal validity of both studies was that the participants were all included in the DAISY intervention population. Patients with mild AD without close contact to a caregiver were not covered in the sample, which is a limitation of the study. Consequently, the findings of this study should be investigated in people with AD and with other social characteristics.
The role of the author’s preconceptions and involvement

The author was involved in planning and completion of the DAISY study, which reinforces the innate risk within qualitative techniques of imposing own views and perspectives on the accounts of participants. However, I was very aware of this risk throughout the whole process. The participants were informed about my involvement in the DAISY project and about my interest in knowing their experiences and perspectives in order to challenge and develop understandings. It was my impression that the participants accepted my attempt to enlighten disadvantages as well as advantages of the intervention. The patients recounted in an engaged manner their experience of coping with everyday life and social relations. They revealed in confidence their worries and let me know about the things they disliked. Concerning the intervention, all participants talked most about positive aspects of the intervention. The caregivers also talked about expectations that were not met by the intervention. The positive attitude might be because participants felt the intervention gave them somewhere to turn to; however, they might have said more about negative aspects to a person who was completely uninvolved.

Validity of study II

In study II, a grounded theory approach was used for the analyses. The method systematically ensures the validity of the analyses as every emerging concept, property, dimension or category must be confirmed in the data as well as in the relation between categories. If data do not confirm the findings, concepts should be moved from one category to another, categories should be redefined or the relation between them might be described in a new way. This process, the constant comparative method, is an essential supplementary instrument for raising questions concerning the organisation of
data and the definition of categories. Further, the validity was ensured by discussions throughout the analysis with other involved and uninvolved professional peers. This facilitated conceptual clarification, challenged assumptions, and brought additional perspectives to the analysis.

Validity of study III
A template organising style of interpretation was used for the analysis. The coding process was conducted in several steps and codes were refined and modified during the analytic process. In order to enhance the dependability and validity of study III, an independent researcher performed observer triangulation by coding several interviews. This resulted in consensus of the coding and the organising of data, which supports the validity of the findings. The analysis in study III was done on all the interviews in a longitudinal perspective of the individual persons to identify their experience of the impact of the intervention. The longitudinal analysis contributes to the strength of the study.

Potentials for data analyses in study II and III
The objectives of the studies suggested cross-sectional analysis of interviews with patients in study II and longitudinal analysis of all participants’ experience of the impact of the psychosocial intervention in study III. However, the interview data potentially allows for cross-sectional analysis of individual participants, longitudinal analyses of the coping of all the participants, and cross-sectional and longitudinal analysis of the couple seen as a unit. Therefore, the present analyses have not utilised the data set in its full potential.
6 Implications and Perspectives

The main implication of the three studies is related to the documentation of the relevance of psychosocial intervention for patients’ and caregivers’ even in mild AD. It seems to be possible to support patients and caregivers’ ability to cope with the consequences of the disease in everyday life and social relations.

In study I, low social participation was associated with ADL impairment and neuropsychiatric symptoms, in study II patients’ awareness of changes was revealed, and study III showed patients’ and caregivers’ benefits of the intervention. The association between patients’ low social participation and impaired ADL indicates that patients’ social participation should be taken into consideration when assistance for ADL is required. Study III showed that patients are willing to participate in new tailored social activities. According to Bennett (2006), the network size modifies the association between pathology and cognitive function, which is an argument for establishment of tailored social activities for people with mild AD. However, more research is needed to identify ways to stimulate patients’ social participation from the mild stages to the severe stages of the disease.

Low social participation was frequent in this resourceful AD population. A hypothesis is that low social participation is even more frequent in a less resourceful AD population; this should be investigated in future studies.

Study II demonstrated patients’ awareness of changes and the strategies they developed to cope with everyday life and social relations. Additionally, the findings in study III emphasised that patients should be included in discussions about the impact of the disease and in the planning of everyday life and care. According to Wells and Dawson (2000), patients need support to develop and adjust their coping strategies throughout the course of the disease to prevent incapacity that is beyond that accounted for by the
disease. To meet that demand Öhman and Nygård (2005), studied an intervention for six patients with mild and moderate AD using qualitative methods. They found that therapists and caregivers might contribute to the well-being of individuals with AD by identifying and supporting everyday occupations with personal meaning and value in the patients own homes. More research is needed to identify possibilities to support patients’ development and adjustment of coping strategies in order to maintain their active engagement in everyday life and social participation.

The study population was highly selected and did not cover segments of the AD population without close contact to a caregiver. Future studies should aim at understanding the needs for support and intervention of the less resourceful patients and caregivers.

The results from the DAISY randomised controlled trial on the primary outcome measures are not yet available. However, the present qualitative study demonstrated that caregivers seemed to benefit from the intervention and were better able to cope with the consequences of their partners’ disease after the intervention. The intervention was comprehensive and it is unknown which elements, or which combination of elements were the most effective in quantitative terms. The findings in the present study suggest that support groups may be the most effective supporting patients, and tailored counselling and outreach counselling may be the most effective supporting caregivers. This should be scrutinised in future research.
References


Summary

Everyday life and social relations in home-living patients with mild Alzheimer’s disease (AD) and their caregivers: quantitative and qualitative analyses.

This PhD project was carried out between April 2004 and March 2007 during my employment as project coordinator in the Memory Disorder Research Group, Department of Neurology, Neuroscience Centre, Copenhagen University Hospital, Rigshospitalet, Denmark, as part of the DAISY study.

The overarching objective of the PhD project was to investigate patients’ perspectives of the impact of mild AD on coping with everyday life and social relations, and the impact of a psychosocial intervention programme on patients and caregivers.

To meet the objective three studies were conducted: 1) to investigate social participation in patients with mild AD, and to analyse predictors of low social participation; 2) to analyse how patients with mild AD cope with the changes they face in relation to everyday life and social relations; and 3) to identify and analyse the experience of patients and their spousal caregivers concerning the impact of an intensive psychosocial intervention programme with tailored counselling, education courses and support groups, conducted in the mild phase of AD.

In the first study, social participation was assessed quantitatively in 330 patients with mild AD. Low social participation was found in 54.2% of the patients. Independent, significant predictors of low social participation compared to high social participation were: ADL impairment and the presence of neuropsychiatric symptoms.

In the second study, data were collected using semi-structured research interviews with 11 patients before their participation in the DAISY intervention programme. Grounded theory analysis of the interview data revealed that the basic social psychological problem faced by the patients was: their awareness of decline in personal dignity and value.
Coping strategies used to meet these problems were adaptations to the altered situation in order to maintain a feeling of well-being.

In the third study, data were collected using individual semi-structured research interviews with 10 couples before and after the intervention programme. For the analysis, a template organising style of interpretation was used. Patients and caregivers found good support for coping with everyday life and social relations by participating in the intervention programme. Early counselling and support may improve patients and caregivers opportunities to adapt to the challenges of the progressive AD, and to maintain well-being.

The studies suggest that impaired social participation is an important aspect of deficits in mild AD; that the perspective of the patients should be taken into account when planning everyday life, psychosocial interventions, and care; and that early psychosocial intervention may offer important support to improve coping with everyday life and social relations in patients with mild AD and their caregivers.

Future studies should focus on the long-term perspective of social participation in AD patients and their caregivers, as well as the impact of AD on the dynamics of couples during the course of the disease.
**Résumé in Danish**

**Hverdagsliv og sociale relationer hos hjemmeboende patienter med Alzheimers sygdom (AD) og deres pårørende: kvantitative og kvalitative analyser.**


Hovedformålet med studiet var at undersøge, hvorledes patienter med af AD i tidlig fase oplever virkningen af sygdommen på deres mestring af hverdagslivet og sociale relationer, samt at undersøge hvorledes patienter og pårørende oplevede virkningen af at deltage i det psykosociale interventionsprogram i DAISY projektet.

Tre undersøgelser blev gennemført for at opfylde formålet: 1) at undersøge social deltagelse hos patienter med AD i tidlig fase og analysere prædiktorer for lav social deltagelse, 2) at analysere hvorledes patienter med AD i tidlig fase mestrer de forandringer, som de møder i relation til hverdagslivet og sociale relationer og 3) at identificere og analysere patienters og deres samlevers oplevelse af et intensivt psykosocialt interventions program med individuel rådgivning, kurser med information og støttegrupper, afholdt i tidlig sygdomsfase.

I den første undersøgelse blev social deltagelse målt kvantitativt hos 330 patienter med AD i tidlig fase. Lav social deltagelse blev fundet hos 54,2 % af patienterne. Uafhængige, signifikante prædiktorer for lav social deltagelse sammenlignet med høj social deltagelse var nedsat ADL funktion og neuropsykiatriske symptomer.

I den anden undersøgelse blev data indsamlet ved semi-strukturerede interviews med 11 patienter for deres deltagelse i DAISY programmet. Grounded theory analyse af interview data viste, at det basale social psykologiske problem patienterne mødte var:
deres bevidsthed om reduktion af personlig værdighed og værdi. Mestrings strategier, som blev anvendt til at møde disse problemer, var tilpasning til den ændrede situation med det formål at bevare en følelse af velbefindende.


Undersøgelserne tyder på at nedsat social deltagelse er et vigtigt aspekt af patienters svækkeligelse allerede i tidlige fase af AD, at patienternes oplevelse bør medinddrages, når hverdagsliv, psykosociale interventioner og omsorg planlægges, samt at tidlig psykosocial intervention måske giver vigtig støtte, som forbedrer patienternes og de pårørendes mulighed for at mestre hverdagslivet og de sociale relationer.

Fremtidige undersøgelser bør fokusere på hvad der sker med patienters og pårørendes sociale deltagelse i et longitudinelt perspektiv, og der bør fokuseres på at undersøge dynamikken hos samlevende par gennem sygdomsforløbet.
How can you gather together
the thousand fragments
of each person?

Giorgos Seferis, 1940.
Translated from Greek by Edmund Keeley and Philip Sherrard.

Hvor skal du samle
de tusind små stykker
af hvert menneske.

Giorgos Seferis, 1940.
Oversat fra græsk af Ole Wahl Olsen og Poul Borum.