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TARJA VÄLIMÄKI

Family Caregivers of Persons with Alzheimer´s Disease: Focusing on the Sense of Coherence and Adaptation to Caregiving

An ALSOVA Follow-up Study

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ABSTRACT

Finland is facing a growing need to improve its healthcare services, in order to support the home care of persons with Alzheimer's disease (AD). Family care will become even more widespread in our society, and it has already become an integral part of the healthcare system in caring for people with memory disorders. Caring for relatives with memory disorder is consistently associated with noticeably higher stress levels and increased levels of psychological and physical morbidity. However, the current knowledge about health-promoting assets that contribute to family caregivers' subjective health is inconsistent and scanty.

The aim of this study is to describe and evaluate the sense of coherence (SOC) of family caregivers of persons with AD. A further aim of this study is to explore the effectiveness of psychosocial interventions on the SOC of caregivers.

This study forms part of a multidisciplinary ALSOVA study which was conducted over three healthcare districts in Finland during 2002-2011. The ALSOVA study (n=241) is prospective randomised controlled study, in which early psychosocial rehabilitation courses were used as the intervention. In the three year follow-up analysis the data of still eligible 94 dyads was analysed. The study also used data from diaries (n=83) written by family caregivers.

Family caregivers' SOC was associated with depressive symptoms, distress and health-related quality of life (HRQoL). During the three-year follow-up, SOC was found to have declined for all of the caregivers, including those with a strong SOC at the baseline. The psychosocial intervention could not prevent this increase in depressive symptoms and burdens or the decline in quality of life. Caregivers in the intervention group continued with the study for a longer period. In addition, caregivers who dropped out of the study were slightly more depressed and distressed when they began caring.

The diaries produced detailed and precise data without memory delay. Family caregivers' transformation into caregivers started in the pre-diagnostic phase. Caregivers' personal milieu and familial cohesion changed, and a new future was created for them.

In conclusion, SOC is not stable, as it decreases during the caring process. The diary method is suitable for data collection in nursing science. It may be that interventions including caregivers cannot give effective results, without taking into account their psychological morbidity.

Further studies are needed in order to identify vulnerable caregivers during the early stages of caregiving. These results can be used to develop support strategies for family caregivers.

National Library of Medical Classification: WY 200; WT 155; WL 359
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TIIVISTELMÄ

Suomalainen yhteiskunta ja terveydenhuolto kohtaavat muistisairauksista johtuvan hoidon tarpeen lisääntymisen. Suomessa on noin 120 000 muistisairasta, joiden kotihoidosta on tullut vakiintunut käytäntö. Omaishoitajat kuormittuvat monin tavoin hoitovuosien aikana. Tähänastinen tieto omaishoitajien terveydestä ja sitä edistävistä tekijöistä on ollut näkökulmiltaan rajoittunutta.

Tämän tutkimuksen tarkoituksena oli kuvata Alzheimerin tautia (AT) sairastavien henkilöiden omaishoitajien koherenssin tunnetta ja siihen liittyviä tekijöitä kolmen vuoden seurannassa. Lisäksi tarkoituksena oli arvioida psykososiaalisen intervention vaikutuksia koherenssin tunteeseen ja siihen yhteydessä oleviin tekijöihin. Päiväkirjojen avulla tutkittiin omaishoitajien elämänorientaatiota ja sopeutumista uuteen tilanteeseen omaishoitajana.

Tämä tutkimus on osa ALSOVA tutkimusta, joka on toteutettu vuosina 2002- 2011 Pohjois-Savon, Pohjois-Karjalan ja Keski-Suomen sairaanhoitopiirien alueella. ALSOVA (n=241) tutkimus on prospektiivinen randomoitu interventiotutkimus, jossa tarjottiin psykososiaalista kuntoutusta interventiona Alzheimerin tautia sairastaville henkilöille ja heidän omaishoitajilleen. Kolmen vuoden seurannassa analysoitiin kaikkien tutkimuksessa edelleen olevien 94 puoliso-omaishoitajien tiedot. Aineistona käytettiin lisäksi omaishoitajien kirjoittamia päiväkirjoja (n=83).

Omaishoitajien koherenssin tunne oli yhteydessä depressiivisiin oireisiin ja rasittuneisuuteen. Matala koherenssin tunne oli yhteydessä matalaan elämänlaatuun. Kolmen vuoden seurannan aikana kaikkien omaishoitajien koherenssin tunne heikkeni. Se heikkeni myös niillä omaishoitajilla, joilla lähtötilanteessa oli ollut korkea koherenssin tunne. Interventio ei voinut estää koherenssin tunteen ja elämälaadun heikkenemistä eikä vähentää depressiivisten oireiden tai rasituksen tunteen kokemista. Interventioryhmään osallistuneet omaishoitajat keskeyttivät tutkimuksen harvemmin kuin kontrolliryhmään osallistuneet.

Omaishoitajien muutosvaihe perheenjäsenestä omaishoitajaksi oli alkanut jo ennen diagnoosin saamista. Omaishoitajat jäsentävät uudelleen elämäänsä sekä henkilökohtaisella että perheen elämän tasoilla. Lisäksi he muodostavat uuden kuvan omasta ja perheen tulevaisuudesta.

Yhteenvetona voidaan todeta, että koherenssin tunne heikkenee läheisen sairauden myötä ja varhaiskuntoutuksella tätä heikkenemistä ei voida estää. Päiväkirjamenetelmä sopii hyvin hoitotieteellisen ja terveystieteellisen tutkimusaineiston keruumenetelmäksi.

Jatkotutkimusta tarvitaan tunnistamaan haavoittuva ryhmä omaishoitajia. Tutkimuksen tuloksia voidaan käyttää omaishoitajien tukimuotojen kehittämisessä.

Luokitus: WY 200; WT 155; WL 359
Yleinen Suomalainen asiasanasto: Alzheimerin tauti; muistisairaudet; omaishoitajat, koherenssi; sopeutuminen; päiväkirjat

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This study was carried out as a part of the ALSOVA study in cooperation with the University of Eastern Finland Faculty of Health Sciences, School of Medicine Institute of Clinical Medicine Neurology, Department of Nursing Science, School of Pharmacy, The Finnish Brain Research and Rehabilitation Center Neuron , Alzheimer's Society of Finland and Kela, the Social Insurance Institution of Finland.

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Tarja Välimäki

List of original publications

This dissertation is based on the following original publications:

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II Välimäki, T., Vehviläinen-Julkunen, K., Pietilä, A.-M., & Pirttilä, T. (2009). Caregiver depression is associated with a low sense of coherence and health related quality of life. *Aging & Mental Health, 13*(6), 850-858.

III Välimäki, T., Vehviläinen-Julkunen, K., Pietilä, A.-M., & Koivisto, A. M. Life orientation in Finnish family caregivers' of persons with Alzheimer's disease: a diary study. (Resubmitted 2012).

IV Välimäki, T., Hongisto, K., Fraunberg, M., Hallikainen, I., Sivenius, J., Vehviläinen-Julkunen, K., Pietilä, A.-M., & Koivisto, A. Sense of coherence in spouse caregivers of persons with mild Alzheimer's disease – the Kuopio ALSOVA study. (Submitted 2012).

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Abbreviations

15D	Health-related quality of life (HRQoL) instrument
AD	Alzheimer's disease
ADCS-ADL	Alzheimer's Disease Cooperative Study – Activities of Daily Living
BDI	Beck Depression Inventory
CDR	Clinical Dementia Rating
GHQ	General Health Questionnaire
GRR	General resistance resources
MMSE	Mini Mental State Examination
NINCDS/ADRA	National Institute of Neurological Communicative Disorders and Stroke/Alzheimer Disease and Related Disorders Association
NPI	Neuropsychiatric Inventory
QoL	Quality of life
SOC	Sense of coherence
VAS	Visual analogue scale

1 Introduction

Finland is growing old rapidly. The frequency of disorders such as Alzheimer's disease (AD) increases with age (Jalbert, Daiello, & Lapane, 2008). Currently, approximately 120,000 persons in Finland have a memory disorder. Many families are facing issues concerning the responsibility for care; approximately 1.2 million people are currently involved in family care in Finland (Kattainen et al., 2008). Finnish population stood in 5, 4 million at the end of the year 2011. Currently 18, 1 % of population is 65 years or older. (Stat, 2012.) Aged spouses, adult children or other relatives usually take care of family members with AD. Family care will become even more common in our society, and it has already become an integral part of the healthcare system for people with a memory disorder. There is an international consensus on the promotion of earlier diagnosis and treatment in AD (Prince et al., 2011; Waldemar et al., 2007). Family caregivers encounter the transition to caregiving at a substantially earlier phase of the memory disorder process than they did a decade ago. They provide the majority of home care, and this responsibly continues into the advanced stages of the memory disorder. Caregivers are responsible for daily care, including the implementation of pharmacological and non-pharmacological treatment, as well as promoting the AD sufferer's general health, well-being and quality of life. Health and social care policies are facing challenges in providing support for home care. Multicomponent services tailored in collaboration with families are necessary for the continuation of home care. (Raivio et al, 2007; Elonimi-Sulkava et al, 2009.)

It has been acknowledged that family caregivers face various obstacles in their family life as well as in terms of their psychological, physical, social and economic well-being. The consequences of caregiving are diverse and complex (e.g. Brodaty & Donkin, 2009). Caring for relatives with a memory disorder is consistently associated with noticeably higher stress levels and a high probability of psychological and physical morbidity (Pinquart & Sorensen, 2003). Family caregivers' poor physical and psychological health is particularly interconnected with the caregiver's old age, whether or not they are the patient's spouse, and whether or not they are caring for a person with memory disorder (Pinquart & Sörensen, 2003). However, the current knowledge of health-promoting assets that contribute to family caregivers' subjective health is inconsistent and scanty. The accumulated knowledge of family caregiving has revealed that caregiving is both a burden and a positive experience for family caregivers. It is important to establish family caregivers' subjective views (Andrén & Elmståhl, 2005). There has been some criticism of the overly narrow theoretical views and concepts regarding caregiving (see Kramer, 2002; Nolan et al., 2002).

One essential question concerns the factors that contribute to caregivers' health. A sense of coherence (SOC) explains life orientation as the capability to comprehend the situation and the capacity to use the available resources. It is a global view of life as comprehensible (the cognitive component), manageable (the instrumental component) and meaningful (the motivational component). It is assumed to be relatively stable in adulthood and to increase over time (Lindström & Eriksson, 2010). Furthermore, SOC tends to increase with age, and men usually have higher scores for SOC than women. SOC seems to fluctuate moderately within the level at which it has developed (Eriksson, 2007). The positive relationship between SOC and health seems to be fairly clear for persons with a strong SOC. However, there is no clear indication of where the cut-off point is, at which SOC loses its protective effect (Lindström & Eriksson, 2010). Previous research in aged people has associated a strong SOC with subjective health, resourcefulness and self-preserving processes (Wiesmann & Hannich, 2010). There is a negative correlation between family caregivers' burden and SOC. In another study on spouse caregivers, SOC was not associated with satisfaction in caregiving (Kristensson Ekwall et al., 2007). Lindström and Eriksson (2010) state that there is a strong negative association between SOC and anxiety, anger, hostility and depression, and a positive association with optimism, hope, learnt resourcefulness and constructive thinking (Lindström & Eriksson, 2010).

Disease with progressive memory disorder is the strongest predictor of institutionalisation in part due to the inability of family caregivers to continue to care for persons with memory disorder in the home and community (Gilley et al, 2005; Luppa et al., 2008; Yaffe et al, 2002). Various kinds of interventions have been conducted with the aim of alleviating caregivers' burden (Pinquart & Sörensen, 2006; Selwood et al, 2007; Schoenmakers et al, 2010). Thus far, the results have been modest. Only very few studies have succeeded in postponing the institutionalisation of the person with AD (Brodaty et al. 1997; Elonimi-Sulkava, 2009, Mittelman, 2006). The majority of interventions have focused on heterogeneous populations (Spijker et al., 2008). The type of memory disorder has not been controlled or the person with memory disorder had variable cognitive performances and had been receiving care for different lengths of time. Early-stage interventions could serve as a window of opportunity. At this stage, discussions and plans for future care with caregivers and the person with AD may guide family caregivers in making future care arrangements. Interventions could benefit both the caregiver and the person with AD.

This study is part of the five-year prospective Kuopio ALSOVA study, a randomised controlled AD rehabilitation study. The aim of the ALSOVA study was to elucidate the effects and cost-efficiency of psychosocial rehabilitation. A total of 241 dyads of people with AD and their caregivers were recruited and randomly assigned to one of two groups. The intervention group received 16 days of psycho-educational rehabilitation as an intervention during the first two years after diagnosis. The control group received the usual care. Both groups were followed up annually. The family caregivers wrote diaries in which they described their subjective feelings about early-stage care.

The purpose of this study is to describe spousal family caregivers' SOC and the effects of a two year psycho-educational intervention. Family caregivers' life orientation was described through their diaries, written within the first year after AD diagnosis. Furthermore, the usefulness of the qualitative diary method as a research method was evaluated.

The aim of this study is to contribute to the knowledge on person with AD care with the factors that have an impact on the promotion of family caregivers' health. Ultimately, the aim is to produce knowledge in order to improve healthcare practices for persons with AD with evidence for providing early support for family caregivers.

2 Literature review

2.1 ALZHEIMER'S DISEASE

AD is a multifactorial, progressive neurodegenerative disorder and the most common cause for progressive memory disorder. AD has a profound effect on memory, cognition, behaviour and the ability to perform daily activities. Independent living becomes progressively more difficult for people with AD, as their cognitive impairment interferes with the basic activities of daily living (ADL; e.g. Cummings, 2004).

AD is classified as a clinical disorder that starts during and encompasses both the pre-dementia and dementia phases. During the pre-dementia stage of AD, clinical symptoms including episodic memory loss of the hippocampal type are present. However, the symptoms do not severely affect the instrumental ADL, while in the dementia phase, the cognitive symptoms interfere severely with social functioning and the instrumental ADL (Dubois et al., 2010). According to NINCDS/ADRDA criteria (McKhann et al., 1984; 2011), the diagnosis of AD is classified into three categories: possible, probable and definite AD.

In total, 7.2% of the population aged over 60 has dementia in Western Europe. After the age of 65, the likelihood of dementia doubles every five years (Alzheimer's Disease International, 2009). AD prevalence increases strongly with age, from less than 1% in people aged 60 to 65 years old, to 25% of those who are 85 or older (Ferri et al., 2005). In women over 95 years of age, the prevalence of AD rises to over 50% (Alzheimer's Disease International, 2009).

In Finland in 2005, there were approximately 120,000 persons suffering from a disease with memory disorder, and there are 13,500 new cases per year (Viramo & Sulkava, 2010). Recent estimates of the prevalence of AD forecast a 40% increase in these numbers in Europe over the next 20 years (Alzheimer's Disease International, 2009). The lifetime risk of AD varies with age, sex and life expectancy (Seshadri et al., 1997). Dementia can be significantly predicted by age (≥ 47 years), low educational level (< 10 years), hypertension, hypercholesterolemia and obesity (Kivipelto et al., 2006). The duration of AD varies considerably, with values ranging from two to 16 years after the onset of the disease. The mean length of survival for patients with AD is three to seven years (Wolfson et al., 2001; Fitzpatrick et al., 2005). However, the median length of survival is estimated at 11.8 years after the retrospectively determined onset of symptoms (Roberson et al., 2005).

As the population ages, AD is causing increasing public health and financial concerns because of its progressive and devastating effects on affected individuals, as well as the substantial caregiver burden and the pressure on healthcare budgets (Jönsson & Wimo, 2009, Wimo et al., 2010).

2.1.1 Alzheimer's disease– as a challenge for caregivers

AD is clinically characterised by the progressive deterioration of memory and other cognitive functions, including a decline in cognition and memory, progressive impairment of the ability to carry out the ADL and a number of neuropsychiatric and behavioural symptoms (Cummings, 2004; Jalbert et al., 2008). A summary of the clinical features of AD is presented in Table 1. In the mild stage of AD, the significant impairment of learning and memory is the major feature. However, aphasic or visuoconstructional deficits can occur. Memory impairment usually plays a key role with difficulties in the ADL. The reduced ability to plan, judge or organise complex tasks leads to difficulty in performing household chores. Communication can suffer as a result of the patient's shrinking vocabulary, decreasing word fluency and less precise expressive language. Impaired naming and semantic difficulties are common. During the mild stage of AD, independent living is possible but support is needed in complex tasks (Förstl & Kurz, 1999). Neuropsychiatric problems also occur in the mild phase (Karttunen et al., 2011).

Moderate-stage AD is characterised by severe memory impairment. Logical reasoning, planning and organising deteriorate significantly during this stage. Language difficulties become more obvious, as the difficulty of finding the right word increases. Reading skills deteriorate, as well as writing abilities. Person with AD suffer more frequently from neuropsychiatric symptoms. In order to understand the origins of these behavioral symptoms Kolanowski & Whall (2000) emphasize the understanding the individual charasteristics of the person with AD and situational factors as origins of these behaviors. Therefore, these behaviors are need-driven and can be responded to in a manner that improves quality of life of the person with AD (Whall & Kolanowski, 2004).

Almost all cognitive functions are severely impaired during the severe stage of AD. Language is reduced to simple phrases or words. Emotional signals can serve as a form of communication with caregivers. Apathy and exhaustion typify daily life. Support is needed even for basic daily functions (Förstl & Kurz, 1999).

Table 1. Clinical symptoms of Alzheimer's disease at the mild and moderate stages, as observed in family life (Erkinjuntti, 2010; Fröstl & Kurz, 1999)

Symptom	**Symptoms in everyday life**
Memory loss	
Episodic memory	Short-term memory (of things that have happened in the last hour) loss is an early sign of AD The long-term memory (of things that occurred more than an hour ago) is not greatly affected in the early phase. Later it tend to interfere with the processing of current activities
Semantic memory	Covers the memory of what words mean: this could be affected
Procedural memory	Memory of how to carry out actions both physically and mentally. The loss of this memory can lead to difficulty in carrying out routine activities, including things that have become automatic. The procedural memory can remain intact when the semantic memory has been damaged
Apraxia-aphasia-agnosia syndrome	Apraxia: The inability to carry out voluntary and purposeful movements despite the fact that muscular power, sensibility and co-ordination are intact Aphasia: Difficulty or loss of the ability to speak or understand spoken, written or signed language Agnosia: The loss of the ability to recognise objects and their use
Communication	Usually difficulty in both the production and comprehension of language, which often relates to the loss of the ability to read and the ability to interpret signs
Personality changes	Social withdrawal, behaviour may be out of character. Mood changes are common
Behaviour	Disorientation in terms of time and place, wandering during the day and night, aggressive behaviour
Physical changes	Weight loss, muscle wasting, incontinence

2.1.2 Disclosing an Alzheimer's diagnosis

The current AD care guidelines in Finland recommend that the diagnosis of AD should be made as early as possible (Suhonen et al., 2010). The diagnostics are usually performed in memory clinics by neurologists or geriatricians. Usually, after one or two clinical visits, the follow-up is carried out by general practitioners working in primary healthcare.

Spouse caregivers in Finland reported that 93% of people with memory disorder had been told openly about their diagnosis. Approximately 80% of spouse caregivers were present when the diagnosis was given and 71% were satisfied with the amount of information they received (Laakkonen, 2008). Another point of view concerns how patients and caregivers hear and feel about the disclosure. Caregivers have reported that the diagnosis was presented too bluntly (Connell et al., 2004; Schoenmakers et al., 2009a) and under busy circumstances (Schoenmakers et al., 2009a). Caregivers valued gentleness and compassion in disclosing the diagnosis (Connell, 2004) and suggested the need to emphasise hope when faced with a difficult diagnosis (Byszewski et al., 2007). In Finnish study (Laakkonen et al, 2008) caregivers expressed feelings of disappointment because they hoped more support and better continuity of care. Half of the caregivers in their study felt that follow-up care had been inadequately arranged.

After the diagnosis of memory disorder is disclosed, feelings of regret that it had not been received earlier can emerge (Connell et al., 2004). Disclosure can increase one's awareness of memory disorder (Derksen et al., 2005, 2006) and feelings of loss and grief (Aminzadeh et al., 2007, Laakkonen et a. 2008). Regardless of the initial shock (Connell et al., 2004), the diagnosis improves caregivers' understanding of the nature of AD and later increases their adaptation to the situation (Aminzadeh et al., 2007; Derksen et al., 2006). Vernooij-Dassen et al. (2006) found adjustments to the relationship between the person with memory disorder and his or her carer. Carers gradually acknowledge the changes in their relationship with the person with memory disorder 12 weeks after the diagnosis.

2.2 FAMILY CAREGIVING

Family care has become an established practice in caring for people with memory disorders. Therefore, family caregivers constitute a healthcare resource. The number of persons in Finland who provided care in 2008 was 1.2. million, including 300,000 primary caregivers (Kattainen et al., 2008). Even though no standard definition of family caregiving exists, there is a general consensus that it involves the provision of extraordinary care, exceeding the bounds of what is normative or usual in family relationships. Caregiving typically involves significant expenditure of time, energy and money over potentially long periods of time; it involves tasks that may be unpleasant and uncomfortable and which are psychologically stressful and physically exhausting (Schulz & Martire, 2004). Family caregiving therefore exists between formal and informal care and can be separated from other ways of helping family members on a reciprocal basis (Aaltonen, 2004).

2.2.1 The situation of family caregivers in Finland

In Finland, home care for patients with memory disorder led to a public debate in the 1990s. As the population's age structure changes, healthcare strategies have to adjust to the needs of a growing number of aged people. The aim is to provide the necessary services in the home and to offer institutional care only to the neediest portion of the aged population. The trend has been towards the minimisation of institutional care. Therefore, more aged people are living at home, with a diminishing ability to cope. Municipal social and healthcare services are limited.

The National Framework for High-Quality Services for Older People (Ministry of Social Affairs and Health Association of Finnish Regional and Local Authorities, 2008) set national quantitative targets for services for aged people that municipalities and cooperation districts can use as a basis for their own targets. Based on comprehensive needs assessment, the national aim is for 91-92% of persons older than 75 to live in their own homes with social and healthcare support. Informal care remuneration will be offered at 5-6% (Ministry of Social Affairs and Health Association of Finnish Regional and Local Authorities, 2008).

The Informal Care Act (2005) entered into force in 2006. Family caregivers are entitled to care remuneration if specific demands and premises are fulfilled. Family caregivers are entitled to at least three days of leave per month. However, municipalities can allocate the money for informal care according to their economic resources and social care policy. Consequently, many family caregivers do not receive any formal support. In 2009, 25,289 people over 65 received care remuneration (Omaishoidon tuki, 2011).

The third sector, e.g. associations and congregations, also support family caregivers. Substitute care services are provided by voluntary organisations. Social activities and peer support are offered by the third sector.

Usually people with memory disorders live at home and receive support and help from their family members. Home care frequently continues into the advanced stages of the disease. As memory disorders are becoming more common, more families are becoming involved in family care. One out of five people who receive support for informal care is suffering from a memory disorder (Voutilainen et al., 2007).

2.2.2 Consequences of caregiving for family caregivers

In the literature, the psychosocial consequences of caring for caregivers of persons with memory disorder have been conceptualised in various ways. The dominant conceptual model for caregiving proposes that the onset of memory disorder and the course of caring is stressful (Pearlin et al., 1990; Schulz & Martire, 2004). Stress is usually measured in terms of psychological distress and burdens which lead to psychological and psychiatric morbidity (Schulz & Martire, 2004).

Caregiver burden was one of the first consequences of caring for family caregivers to be studied. Zarit et al. (1980) found that subjective burden was associated with the social support available. Subjective strain or burden is associated with factors relating to the caregiver and the person with AD. Caregiver-related characteristics such as kinship ties, gender and coping strategies profoundly influence caregiver burden (Torti et al., 2004). Female caregivers, and especially wives, experience heavier burdens (e.g. Almberg et al., 1997, 1998; Thomas et al., 2002).

Caregivers for persons with memory disorder report higher levels of stress, depression and distress compared with non-carers (Pinquart & Sörensen, 2003; Sörensen et al., 2006). In cross- European study on spouse caregivers Schneider et al. (1999) found that the younger the spouse carer was, the greater the carer burden was.

Female caregivers also report more health problems and depressive symptoms (Mahoney et al, 2005; Sörensen et al., 2006; Vitaliano et al., 2003). Depressive symptoms in caregivers are the most prevalent psychosocial effects of caring (Covinsky et al., 2003; Cuijpers, 2005). The prevalence of clinically-diagnosed major depression has been reported to range from 10% to 83% among carers for people with memory disorder (Sörensen et al., 2006). Furthermore, Joling et al. (2010) showed in 6-year follow up that spouse caregivers have a fourfold higher risk of a diagnosis of depression that the spouses of nondemented persons. Family caregivers’ depression is suggested to develop by same causal pathways as in other populations (Clark & Diamond 2010; Joling et al 2012). Psychological morbidity includes the manifestation of depressive symptoms and anxiety in the caregiver, which are frequently comorbid conditions. Anxiety rates vary from 10% to 35% (Cooper et al., 2007).

Family caregivers suffer from loneliness (Beeson, 2003) and social isolation (Almberg et al., 1997; Brodaty & Donkin, 2009). Families often face financial difficulties due to the complexity of applying for subsidies and reimbursements for medical care (Schneider et al., 1999). Memory disorder-related behavioural symptoms, and especially apathy (De Vugt et al., 2003), can diminish the amount and reciprocity of interactions between spouses.

Family caregivers' loss is suggested to be a relevant concept for understanding their perceptions of the changing nature of their family member with memory diorder (Noyes et al., 2010). It is further identified that caregivers' feelings of loss and grief play a significant role in their ability to cope with the stressors of caregiving (Ott et al., 2007; Sanders & Corey, 2003). The bereavement literature has recognised the distinction between depression and grief. Meuser and Marwitt (2001) suggest that anticipatory grief is equivalent in intensity and breadth to death-related grief. Family caregivers live in a relationship in which their loved one is still physically present, but cannot meet the caregiver's psychological needs.

Family caregiving is associated with an increased risk of various health problems, such as increased stress hormones, impaired metabolic functioning, cardiovascular problems and a dysregulated immune system. In addition, caregivers' health-related behaviours may suffer. Caregiving could lead to a poor diet, lack of sleep, loss of exercise and alcohol consumption (Sörensen et al., 2006; Brodaty & Donkin, 2009). Depressive symptoms in caregivers are more consistently associated with physical health complaints than the cognitive or functional capacity of the person with memory disorder. Furthermore, increased age, low socioeconomic status and lower levels of support are associated with poorer health (Pinquart & Sörensen, 2006a, 2007).

Behavioural problems associated with AD are significant factors which contribute to negative consequences for caregivers. Behaviours such as night-time wandering, aggression and agitation are strongly associated with caregiver burden (Etters et al., 2008). When these psychiatric problems are connected with a diminishing functional capacity, family caregivers tend to become exhausted (Sörensen et al., 2006).

Satisfaction in caring

Caregiving is a multifaceted situation in which caregivers can express satisfaction irrespective of the burden (Andrén & Elmståhl, 2005). Family caregivers' ability to care is a multifaceted phenomenon which is influenced by both stress and consoling factors. Motivation and meaning in caring have been studied to some extent. Finding meaning in caregiving may partially mediate the relationship between burden and mental health (McLennon et al. 2011). In Butcher et al. (2001) phenomenological study despite of the suffering and loss most caregivers found positive aspects of and meaning in caregiving process. Exasperations were turned into blessings recalling the joyful times together, living the current life intensely and focusing on life's blessings (Butcher & Buckwalter, 2002). The quality of both the previous and current relationship is associated with caregiving (Quinn et al., 2009). Caregivers' ability to finding meaning in caregiving could potentially affect whether or not they will be able to identify positive aspects of caregiving. Feelings of gratification, satisfaction and the view of caregiving as reciprocal are motivations to care. Some caregivers may not find any meaning in caregiving. The majority of caregivers are motivated by love, duty, moral obligation and guilt (Quinn et al., 2010).

Spouse caregivers

Caregiving takes place in a family context, and therefore several relationships exist within the caregiving context, of which spouses have been studied the most frequently. Spouses are committed to caring regardless of their own poor subjective health (Raivio et al, 2007). The New York University (NYU) Caregiver Intervention Study (1987-2009) is currently the longest intervention study on spouse caregivers (n=406) to ever be conducted (e.g. Mittelman et al., 2006, 2007), providing information about intervention effects on caregiver burden and its impact.

Several factors influence the quality of spouse caregiving for persons with AD. The level of spouse caregivers' marital closeness influence their expressions of grief, relief and depressive symptoms (Pruchno et al, 2009). Caregivers undergo a gradual process of making sense of the memory disorder. In the initial stage, caregivers tend to deny and normalise the first observations of behavioural changes or memory problems (Betts Adams, 2006; Quinn et al., 2008). Couples face a gradual shift in responsibilities and the marital relationship (Betts Adams, 2006; Robinson et al., 2005), while caregivers also face the challenge of supporting the person with memory disorder in their need to be valued (Steeman et al., 2007). Spouses experience a sense of loss in their relationship due to the diminished quality of communication (Murray, 1999). This leads to a decline in the equality (Eloniemi-Sulkava et al., 2002) and reciprocity of the marriage (Gallagher-Thompson et al., 2001). Spouses gradually take on more and more responsibilities, providing care while, at the same time, the person with AD becomes more dependent. Quinn et al. (2009) suggest that this development creates a loss of reciprocity or mutuality.

The nature of the pre-caregiving and current marital relationship influences caregivers' well-being (Quinn et al., 2009). A positive previous relationship can have an impact on the caregiving experience and, in turn, the caregiver's health (Quinn et al., 2009). Spouse caregivers experience the deterioration of their relationship with the person with AD (De Vugt et al., 2003). Behavioural problems, and especially apathy, have a significant effect on the decline of the relationship (De Vugt et al., 2003). However, caregivers may feel that the general atmosphere in their marriage is still good. Spouses therefore regard caregiving as part of their marital duties (Conde-Sala et al., 2010). Satisfaction in marriage results from feelings of mutual affection and companionship, coupled with the fulfilment of one's sense of duty (Murray, 1999).

2.3 SENSE OF COHERENCE AND QUALITY OF LIFE

The salutogenic theory of health (Antonovsky, 1979) addresses the question of the origins of health. While all human beings are attacked by stress and demands, some people stay healthy. Salutogenic theory identifies the factors which maintain or promote human health. Antonovsky's theory was developed based upon the premise of stress as a natural part of life (Lindström & Eriksson, 2010). Health is described as a continuum between the poles of ease and disease. Thus, health is not seen as a positive or negative state, but as a movement towards health. In that process towards health, people simultaneously experience elements of health and stress or distress. Salutogenesis is a broad theory of life orientation.

Antonovsky claimed that the way in which people view their lives would have an influence on their health. Salutogenic theory focuses on three aspects. Initially, it focuses on problem-solving and finding solutions. It identifies general resistance resources (GRR) that help people to move towards health on the ease/disease continuum. Eventually, salutogenic theory identifies SOC as the ability to comprehend the entirety of a stressful situation and the capacity to use the resources available (Eriksson, 2007, p. 17). Salutogenic theory understands sense of coherence as a global orientation to life (Antonovsky, 1993).

2.3.1 Sense of coherence and general resistance resources

Antonovsky created two key concepts in his theory of salutogenesis. SOC is the mechanism which allows people to use the resources available. GRR lead to life experiences that promote a strong SOC (Antonovsky, 1979; Lindström & Eriksson, 2010). GRR help people to move towards health. GRR are characteristics of the person, group or environment that can facilitate effective tension management (Antonovsky, 1987). GRR are physical, biological and psychosocial factors. These resources can originate within people as personal resources and capacities, but may also be at one's disposal through society. They can be found in personal capacities and in the environment as material and non-material qualities (Lindström & Eriksson, 2010). Antonovsky identified GRR as prerequisites for the development of SOC.

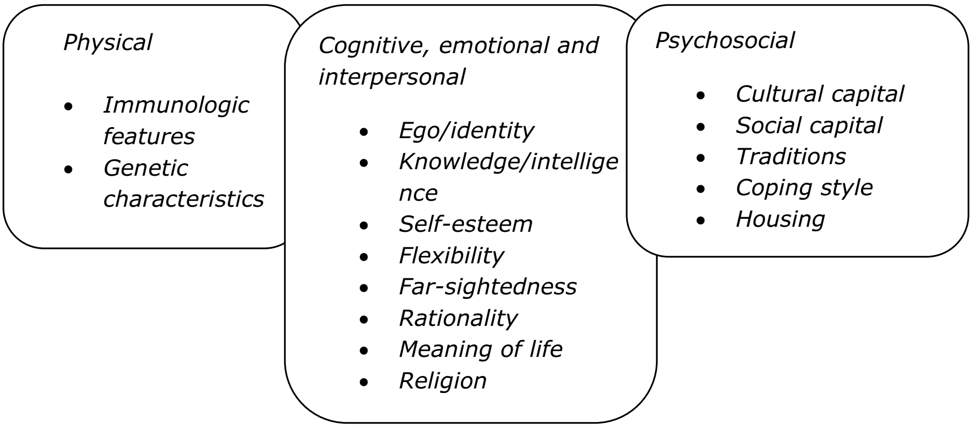

Figure 1. General resistance resources (modified based on Antonovsky, 1985, 1987; Lindström & Eriksson, 2010)

Life experiences accumulate in the interplay with one's family and in connection with one's living environment. Furthermore, Antonovsky concluded that the existence of resources is not sufficient to deal with the challenges of life. More important is the ability to use them.

Antonovsky presented SOC as a key concept for understanding life orientation. SOC is a way of being, thinking and acting (Lindström & Eriksson, 2005). Antonovsky defined three components of SOC: comprehensibility; manageability and meaningfulness. Comprehensibility refers to the extent to which one perceives comforting stimuli as deriving from internal and external environments. In order to make cognitive sense, information must be ordered, consistent, structured and clear (Antonovsky, 1987, p. 16). Manageability refers to the extent to which one perceives that resources are at one's disposal which are adequate to meet the demands. Resources may be under one's own control, or attainable from others (Antonovsky 1987, p. 17). Meaningfulness refers to areas of life which are viewed as challenges and as worthy of emotional commitment or investment. The motivational component of meaningfulness is the most fundamental element. Without it, the other aspects are likely to be temporary. With motivation, the way is open to the gaining of understanding and resources (Antonovsky, 1987, pp. 18-23). All three dimensions interact with each other, but Antonovsky (1987) pointed out that the most important is the motivational dimension, e.g. meaningfulness.

Furthermore, people with a strong SOC, who believe that they understand the problem and see it as a challenge, will select what is believed to be the most appropriate tool for the task at hand (Antonovsky, 1998). Therefore, SOC reflects a caregiver's view of life and capacity to respond to stressful situations.

2.3.2 Sense of coherence and health

SOC is strongly correlated with positive emotions and works against negative affections. In a systematic review, Eriksson (2007) concluded that SOC has a major moderating or mediating role in the explanation of health. Moreover, SOC seems to predict good health. People with a strong SOC can cope with stressful situations and maintain better health than people with a low SOC (Eriksson & Lindström, 2006). SOC seems to be a health-promoting resource (Eriksson, 2007).

SOC is strongly associated with good health, and particularly with mental health. A strong SOC protects against anxiety, depression, burnout and hopelessness. It is furthermore strongly and positively related to health resources such as optimism, hardiness, control and coping, and predicts good health (Eriksson & Lindström, 2006; Lindström & Eriksson, 2010). SOC seems to be relatively stable over time, especially within those individuals who have achieved a strong SOC. However, SOC as a dynamic orientation may fluctuate over the course of an individual's life. However, Antonovsky (1987) found that individuals with a strong SOC can withstand minor temporary changes in their average SOC. The current knowledge about originally weak SOC and the changes it undergoes is scarce.

To sum up, increased SOC results in better perceived health. However, studies have not shown enough evidence of the way in which the level of SOC could change or be influenced by interventions.

2.3.2.1 Sense of coherence in old age

SOC in the aged population seems to be closely connected with the interpersonal, affective and motivational bases of the personality system, rather than with self-reported biological reserves (Wiesmann et al., 2009). SOC tends to increase with age and men usually have higher SOC scores than women (Eriksson & Lindström, 2005;

Nilsson et al., 2010). SOC has been shown to be a good predictor of good health among active older Swedish people (Söderhamn & Holmgren, 2004) and in a study of older Italians (Ciairano et al., 2008) in connection with high levels of education, successful careers and strong SOC. In a German study of older people aged 59-89, a strong SOC was associated with subjective health, resourcefulness and self-preserving processes (Wiesmann & Hannich, 2010).

2.3.2.2 Sense of coherence in caregivers

Family caregivers' SOC in settings involving memory disorder has been explored in very few studies. High SOC is associated with a lighter burden (Andrén & Elmståhl, 2008), in addition to better subjective health (Andrén & Elmståhl, 2005). Kristensson Ekwall et al. (2007) used personal strength as a proxy for strong SOC and showed that high SOC correlated with high mental quality of life (QoL). They indicated that personal strength influences the way in which difficulties in caregiving situations are handled. In a Swedish study on older (75+) caregivers (mainly spouses), male caregivers in particular were more satisfied and used more problem-solving strategies in order to cope. However, caregivers' SOC was not associated with satisfaction in caregiving (Ekwall & Hallberg, 2007). No longitudinal studies on spouse caregivers' SOC have yet been published. Few studies have used qualitative data in mixed methods studies on family caregivers' SOC (Pogieter & Heyns, 2006; Pretorius et al, 2009). Caregivers found their loved ones cognitive and behavioral changes and erosion in their marital relationship as significant stressors (Pretorius et al, 2009). Help from professionals and family members helped caregivers to face the stressors. Future orientation and religiosity enabled caregivers to find meaning in their situation (Potgieter & Heyns, 2006). As conclusion, caregivers found their situations as comprehensible, meaningful and manageable (Potgier & Heyns, 2006; Pretorius et al., 2009).

2.3.3 Sense of coherence and quality of life associated with family caregivers

QoL has been recognised as a major element in successful home care and caregivers' well-being. (Argimon et al., 2005; Schölzel-Dorenbos et al., 2009, Takai et al., 2007; Thomas et al., 2006.) Previous conceptualisations of QoL have been disease-specific, using measurements developed for AD studies (Thomas et al., 2006; Glozman et al., 2004). Health-related QoL (HRQoL) is a broad-ranging concept which is affected in complex ways by a person's physical health, psychological state, level of independence, social relationships and relationship with salient features of his or her environment (The World Health Organization, 1995).

Strong SOC has been shown to correlate with QoL (Kristensson Ekwall et al., 2007) and satisfaction in caring (Kristensson Ekwall & Hallberg, 2007). Caregiving is associated with reduced HRQoL, especially in mental health components (e.g. Bell et al., 2001; Markowitz, 2003) and the ability to maintain interests other than caring (Kristensson Ekwall et al., 2007).

The burden of caregiving has substantial effects on HRQoL (Markowitz et al., 2003). In an Italian study (Vellone et al., 2008), caregivers attributed meaning to QoL in psychological terms, e.g. serenity and freedom. Furthermore, the elements of general well-being, good health and good financial status completed their idea of

QoL. Women have reported poorer QoL in various studies (Thomas et al., 2006). There are indications that caregivers may adapt to caregiving over time, since caregivers of AD patients who had been demented for a shorter period of time experienced a greater impact on their HRQoL (Riedijk et al., 2006).

2.4 PSYCHOSOCIAL INTERVENTIONS

Most people with AD live in their own homes with a family member acting as their caregiver. The dominant conceptual model for caregiving assumes that the onset and progression of chronic illness and functional decline is stressful for both the person with AD and the caregiver (Schulz & Martire, 2004). Therefore, interventions targeting stress, burden, anxiety and depression are commonly put into practice. Various interventions have been conducted in order to improve outcomes for caregivers and to reduce the likelihood of the institutionalisation of persons with AD. Many and varied methods and outcomes have been used in intervention studies, and have produced inconclusive results. The basic randomised approaches use protocols in which participants are assigned to treatment and control conditions.

Intervention evaluation studies are often poor in terms of their methodological validity, sample size and follow-up time (Thompson et al., 2007). However, the quality of studies is rising (Brodaty et al., 2003).

2.4.1 Reported psychosocial interventions for caregivers of persons with Alzheimer’s

Psychosocial interventions are interpersonal interventions which are concerned with the provision of information, education and emotional support (Pusey & Richards, 2001). The literature review of psychosocial interventions aimed to describe the kinds of interventions which have focused on family caregivers and persons with AD, and to evaluate the effectiveness of these interventions. The literature search focused on meta-analyses and reviews because of the vast number of individual studies. The search was limited to full-text articles in the English language, published from 2001 to the end of June 2011 in the PubMed, Cinahl, Ebsco or Scopus databases. The following search terms were used: systematic review/meta-analysis; dementia; interventions and family caregivers. The results of the literature search were assessed for relevance according to the following inclusion criteria: (1) systematic review or meta-analysis; (2) home care setting; and (3) involvement of caregivers of persons with AD. The exclusion criteria were: (1) single study; (2) caregiving situation other than AD; (3) institutional care; and (4) focus on professional care.

The study designs used included intervention studies, randomised controlled trials (RCTs) and quasi-experimental studies. The reviews included 13 to 127 studies published between 1969 and 2007. The number of studies included in the reviews varied in accordance with the strictness of the inclusion criteria used. The studies reviewed involved between four and 8095 caregivers. Follow-up times were usually less than one year, with only a few studies having a follow-up time of more than one year. The majority of the studies reviewed included patient-caregiver dyads for the interventions. A total of 32 abstracts were evaluated and 13 articles were included in the literature review (Table 2).

Table 2. Phases of the literature search for intervention reviews

	Search result (n)
Citations found in PubMed (MEDLINE), Cinahl, Ebsco, Scopus + manual search	137
Excluded based on title	105
Abstracts of articles	32
Excluded by abstract	11
Full-text articles	21
Excluded by full text	9
Articles included in the intervention literature review	13

2.4.2 Interventions and their effects

Intervention effects were assessed from the point of view of the family caregiver. The reviews assessed various intervention types. Table 3 summarises the types of interventions and outcomes, with a review of their effectiveness. The same caregiver-related outcomes were used in several studies. Psychological morbidity was used in various forms, such as burden, distress and depression. Physical health, social outcomes and QoL were evaluated less frequently. Positive outcomes such as satisfaction and personal growth were rarely evaluated.

The components of interventions seem to be similar across studies. Since the outcomes predominantly aimed to alleviate psychosocial burden, the interventions included support in various ways. Education, counselling, psychoeducation, various kinds of support programmes and even respite care were designed to reduce stress and to increase QoL. Multi-component interventions combined various components which aim to decrease caregiver burden. The indication that the time of institutionalisation can be postponed using multi-component interventions is prolific.

Prior reviews found less evidence of the benefits of interventions for caregivers (Cooke et al., 2001) or no effects at all (Pusey & Richards, 2001). The aim is usually to alleviate caregiver burden. However, the findings are inconsistent. Some interventions designed to reduce caregiver burden had no effect on burden (Acton & Kang, 2001). However, Pinquart and Sörensen (2006b) found immediate positive effects on caregiver burden. They showed that more recent studies reveal stronger effects on burden because of improved study designs. Psychoeducational (Pinquart & Sörensen, 2006b) or multi-component interventions (Acton & Kang, 2001) have been found to be the most effective. Schulz et al. (2002) infer that virtually all intervention approaches are multifaceted. They conclude that closer attention ought to be paid to the assumed links between interventions and their desired outcomes. In general in the past, psychosocial interventions have frequently been designed without clear theoretical framework (Moniz-Cook et al., 2011).

2.4.2.1 Interventions combining education and support

Usually, these interventions combine both education and support for caregivers in groups or individually (Acton & Kang, 2001). Support could be individualised or conducted in groups.

Caregivers' depressive symptoms are the most prevalent psychosocial effects of caring (Covinsky et al., 2003; Cuijpers, 2005) and are hence the most frequently-studied outcomes (Schulz et al., 2002). Group interventions have been found to be more effective than individual programmes (Thompson et al., 2007). Schulz et al. (2002) found clinically-relevant outcomes in terms of improving depressive symptoms, but interventions need to be sufficiently long-term to have a positive effect on depression (Brodaty et al., 2003; Pinquart & Sörensen, 2006b). Individual behavioural management techniques for six or more sessions were effective in the alleviation of caregiver depression (Selwood et al., 2007).

Anxiety is one of the psychological effects on caregivers, in addition to burden (Cooper et al., 2007), especially in female caregivers (Mahoney et al., 2005). However, reducing depression may not necessarily reduce anxiety, e.g. Cooper et al. (2007), in their review, did not find any evidence of a reduction in anxiety in interventions that were found to have a positive effect on depression. In fact, they established that behavioural management, exercise therapies and respite are ineffective. In contrast to these results, Schulz et al. (2002) showed clinically-significant outcomes in terms of improving depressive symptoms, reducing anxiety and possibly anger and hostility.

2.4.2.2 Multi-component interventions

Multi-component interventions combine various forms of interventions, such as education, support, counselling, respite and the coordination of care (Pinquart & Sörensen, 2006b).

Delaying the institutionalisation of persons with memory disorder is one of the key agendas in healthcare. Family caregivers' psychosocial distress and lack of competence are strong determinants of institutionalisation (Gaugler et al., 2009). Therefore, contemporary interventions and public healthcare aim to create support programmes which can contribute to family care (Spijker et al., 2008). Recent multi-component interventions have succeeded in postponing the institutionalisation of persons with AD. Support has been multifactorial, providing a multi-component intervention programme with a family coordinator, support groups for caregivers and individual services. After 1.6 years, a larger proportion of the control group than the intervention group was in long-term institutional care. The range of time for postponing the institutionalisation was 52-233 days (Eloniemi-Sulkava et al., 2009). In the NYU caregiver intervention study, the median time before nursing home placement was 329 days longer in the intervention group versus the control group. The intervention effects were greater among male caregivers (551 days) than female caregivers (244 days) (Mittelman et al., 1996).

2.4.2.3 Other interventions

Educational interventions are designed to provide standardised information about the AD process, neuropsychiatric symptoms and information about care support in order to enhance the caregiver's ability to manage problematic situations. Caregiver education has been found to be effective when knowledge of the illness is considered as the outcome (Cooke et al., 2001). Education has been found to have an effect on most outcomes which have been assessed (Pinquart & Sörensen, 2006). However, Selwood et al. (2007) summarise that education alone is not effective. Counselling by trained professionals may be included in various educational interventions in order to meet the individual needs of the caregiver (Acton & Kang, 2001). Some of these interventions have been conducted using telephones or the Internet. The target has been to provide easy access to information in a caregiver support network (Thompson et al., 2007). One particular research program (REACH and REACH II) has significantly improved caregivers quality of life measured by psychosocial factors in six months follow-up. (Belle et al., 2006; Elliot et al., 2010).

Respite care as an intervention is a planned form of temporary relief for the caregiver. It seems to provide modest but significant benefits in terms of knowledge and psychological morbidity (Brodaty et al., 2003). Respite care has been found to have a small but significant effect on burden, depression and subjective well-being (Pinquart & Sörensen, 2006b). Previously, respite care had not been found to have a positive effect on burden (Acton & Kang, 2001). The most recent review (Selwood et al., 2007) found that respite care was responsible for an increase in burden.

In a comparison of different interventions, the findings give conflicting results.

Table 3. Summary of intervention effects

Intervention	Content	Effectiveness
Interventions combing education and support	Educational and supportive components, e.g. information about the disease, resources and services. Provision of support on an individual or group basis Problem-based training,	Minor effect on depression (Schoenmakers et al., 2010). Modest but significant benefits in terms of psychological morbidity, knowledge, coping skills and social support (Brodaty et al., 2003). Possible reduction in hostility and anger (Schulz et al., 2002) Effective in reducing psychological morbidity (Thompson et al., 2007) when conducted as a group intervention. Significant effects on burden, well-being and ability/knowledge (Sörensen et al., 2002)
Individual counselling, behavioural techniques	Individualised information based on needs, training	Reduction in depression (Mittelman et al., 2007). No statistically significant effect on depression (Thompson et al, 2007). Teaching coping strategies provides short-term psychological benefits (Selwood et al., 2007)
Group-based intervention	Information and support based on the needs of the group	Reduction in depression, clinical significance unclear (Thompson et al., 2007). Minor effect on burden and knowledge/ability (Sörensen et al., 2002). Low effectiveness (Pusey & Richards, 2001). Effectiveness alone poor (Pusey & Richards, 2001)
Multi-component interventions		
Multi-component intervention with flexible, intensive counselling	Combination of various components, e.g. education, case management, support and respite	Delayed institutionalisation in three trials (Eloniemi-Sulkava, 2009; Mittelman, 2006; Brodaty et al., 1997). The most effective type of intervention for reducing burden (Acton & Kang, 2001)
Other interventions		
Educational intervention	Standardised information	Education alone is not effective (Pinquart & Sörensen, 2006b; Selwood, 2007) Children of dementia patients are more likely to benefit from education than spouses (Sörensen et al., 2002). Effective when knowledge of the illness is an outcome (Cooke et al., 2001)
Techology-based intervention	Provide a network or support line for caregivers	No evidence of effectiveness (Pusey & Richards, 2001). No statistically significant effect on depression (Thompson et al., 2007)
Respite care	Services to give caregivers a temporary break from caregiving	Some effect on burden, depression and well-being (Sörensen et al., 2002). Not effective in reducing anxiety (Cooper et al., 2007). No effect (Acton & Kang, 2001). Increase in burden (Selwood, 2007)

2.5 FAMILY CAREGIVERS' LIFE ORIENTATION BASED ON CAREGIVERS' DIARIES

In the past, family caregivers' diaries have rarely been used as research data. Diaries describe the interaction between the person with memory disorder and the caregiver. In particular, they illustrate how to establish a stable phase in the interaction between the person with memory disorder and the caregiver (Vernooij-Dassen et al., 2006). Caregivers experience QoL in phases, e.g. though discordance at the beginning, and then in finding a balance through normalising, interfacing and interacting. This process may lead to the emergence of QoL (Clarke, 1999; Quayhagen & Quayhagen, 1996). Individual narratives can describe individual caregivers' experience of becoming a caregiver (e.g. Swenson, 2004; Salmon, 2006). Thus far, family caregivers' life orientation has not been studied using diaries.

2.6 SUMMARY OF THE THEORETICAL BACKGROUND

Many families are facing issues concerning the responsibility of care. Aged spouses, adult children or other relatives usually take care of a family member with AD. Family care will become more common in our society and has already become an integral part of the healthcare system in caring for people with memory disorder (Kattainen et al., 2008; Voutilainen et al., 2007). AD is a progressive neurodegenerative illness which leads to memory and functional decline as well as behavioral symptoms. Family caregivers taking care of persons with AD often experience a great deal of psychological stress which can threaten their physical health, which may ultimately compromise their own wellbeing and lead to early institutionalisation. Family caregivers are typically aged spouses with health problems of their own. (Gold et al., 1995.)

Salutogenic theory recognises caregivers' resources for coping with the task of caregiving. It further identifies the cognitive, instrumental and motivational dimensions of SOC. To sum up, it is a global orientation towards the view of life as structured, manageable and meaningful, and the world as more or less coherent (Antonovsky, 1993; Eriksson, 2007).

Having a strong SOC enables family caregivers to view their life as coherent, comprehensible, manageable and meaningful. It allows the caregivers to trust that they can identify resources within themselves and within their environment, and to use those resources. A strong SOC is related to good subjective and mental health. Aged people usually enjoy stronger SOC than younger people.

In conclusion, many characteristics lead to the negative consequences of caring, such as female gender, being a spouse caregiver, additional stressful life events, physical health complaints, a family history of mental health issues, the quality of the caregiving relationship, life satisfaction, low levels of self-efficacy and mastery, high neuroticism and the behavioural and psychological symptoms of the person with memory disorder (e.g. Brodaty & Donkin, 2009; Dunkin & Anderson-Hanley, 1998; Sörensen et al., 2006). However, while there is a vast amount of literature about family caregiving, very few studies have clarified the stage of AD in question. The current body of knowledge is based mainly on research conducted with patients with moderate AD. It is difficult to interpret these findings in the absence of contextual data regarding the time of diagnosis and the severity of the illness.

Non-pharmacological interventions combining various components may reduce caregivers' psychological stress and increase their knowledge of AD and its manifestation. Postponing the institutionalisation of the person with AD is one of the key targets of interventions. However, the evidence for the reduction of caregivers' psychological and physical morbidity is mixed.

To sum up, Schulz et al. (2002) concluded that there is no single, easily implemented and consistently effective method of achieving clinically significant effects across caregivers. This conclusion is corroborated by Thompson et al.'s (2007) review with the observation that the idea of the universal effectiveness of interventions in improving the lives of caregivers is not based on evidence. However, caregivers are usually satisfied with interventions (Brodaty et al., 2003). Multifactorial psychoeducational interventions reduce caregivers' feelings of subjective depression, burden and anxiety immediately (Acton & Kang, 2001; Pinquart & Sörensen, 2006b), but overall, their effectiveness is modest. It has been assumed that the outcomes of interventions will be revealed later (Cooke et al., 2001). The follow-up time in intervention studies thus far has usually been too short to elicit long-term effectiveness.

The use of family caregivers' diaries as research data is rare. Diaries describe the interaction between the person with memory disorder and the caregiver or can be used to illustrate individual cases (e.g. Clarke, 1999; Salmon, 2006). In particular, they have been used to illustrate how to establish a stable phase in the interaction between the person with memory disorder and the caregiver (Vernooij-Dassen et al., 2006). Thus far, family caregivers' life orientation has not been studied using diaries.

3 Aims of the study

The aims of this study are to describe the SOC of family caregivers of persons with very mild or mild AD and to explore possible changes in their SOC during the three year follow-up time from the AD diagnosis. Furthermore, the aim is to gather evidence based knowledge of family caregivers' experiences of the early phase of caregiving in order to develop support strategies for caregivers. Based on these findings, interventions targeting family caregivers and persons with AD will be improved and made more effective. In addition, the use of an SOC instrument to set follow-up efficacy parameters provides information about its usefulness in the caregiver population.

The specific research objectives in this thesis are as follows:

1. To study spouse caregivers' SOC and factors related to SOC at the baseline (Article II);
2. To describe the change in SOC at the three-year follow-up and to explore which factors are related to SOC in spouse caregivers (Article IV);
3. To evaluate the effect of a psychosocial intervention on SOC (Article IV);
4. To evaluate the methodological aspects of the use of diaries as primary data (Article I);
5. To describe family caregivers' life orientation during the first year after diagnosis (Article III).

4 Materials and methods

4.1 Study design

This study is part of the ALSOVA study which was conducted by the Neurology Unit of the School of Clinical Medicine in collaboration with the Department of Nursing Science, the Department of Health and Social Management at the University of Eastern Finland, the Neuron Research and Rehabilitation Centre, the Social Insurance Institute of Finland (Kela) and the Alzheimer Society of Finland during the period 2002-2011. The ALSOVA study was conducted as a prospective RCT (e.g. Burns & Grove, 2009). The aim of ALSOVA study was to evaluate whether early psychosocial rehabilitation combining education and support can postpone institutionalisation of the persons with AD. Further aim was to evaluate intervention effects on caregivers' SOC and quality of life as well as persons' with AD quality of life.

Participants were recruited from memory clinics serving three healthcare districts (Northern Savo, Northern Carelia and Central Finland) during their diagnosis visit. The recruitment process was voluntary. The inclusion criteria for person with dementia were a diagnosis of very mild or mild AD (CDR 0.5-1) (O'Bryant et al., 2008; Morris 1997), older than 65 and family caregivers in intense, preferably daily, contact. The exclusion criteria were other dementias, no caregiver, permanent institutional care, alcoholism, clinical depression and some other malignant life-threatening disease.

Potential participants were given oral and written information about the study. After they had agreed to participate, contact information was passed to the researchers, who arranged the baseline visit for as soon as possible (< a year after the diagnosis). At the baseline visit, the study protocol was discussed. Both the person with AD and the family caregiver gave their written consent. The family caregiver also gave proxy consent on behalf of the person with AD. Follow-up visits were conducted annually on a voluntary basis.

Recently-diagnosed AD patient-caregiver pairs (n=241) were randomly assigned to one of two groups: (a) the intervention group received intensive psychosocial courses during the first two years after diagnosis and traditional care while (b) the control group received traditional care. Follow-up visits were conducted annually (Figure 2). Randomisation was performed after the initial visit by study nurses who were not participating in the ALSOVA study. The participants drew lots, in accordance with previous statistical randomisation. One third of the group was allocated to the intervention group and two thirds to the control group. The researchers who collected the data were blinded to the group segmentation.

The criteria for dropping out of the study were defined as permanent instutionalisation or the death of the study patient. In the event that participants dropped out for other reasons, they were asked for the primary reason for their discontinuation in the study. This information was included in the drop-out analysis.

There were some protocol violations, i.e. participants younger than 65 (n=14) and with moderate dementia (CDR 2, n=1). One exclusion was made from the follow-up analyses because the patient's diagnosis changed during the follow-up.

The psychosocial intervention took the form of rehabilitation courses in the Neuron Rehabilitation Centre. The courses were conducted during the first two years after diagnosis and took up a total of 16 days (Figure 2).

The psychosocial intervention included lectures about AD by neurologists, information about social services for persons with AD, group discussions for both the person with AD and caregivers separately, physical exercise, creative activities and individual discussions with personnel from the rehabilitation centre. The families in each rehabilitation group remained the same for the two years. Altogether, 11 course groups were arranged. A maximum of 10 families were invited to each course. The control group was followed up annually but did not receive the psychosocial intervention organised by the ALSOVA study.

In this study mixed methods approach was used. Quantitative and qualitative methods were used sequentially and the rationale is to provide a more complete and comprehensive picture of family caregivers' SOC (see Song et al., 2010). Mixed methods are defined as research in which investigator combine in one study both qualitative and quantitative approaches and methods. (Tashakkori & Teddlie, 2003, pp.1.) As Creswell and Plano Clarke (2011) argue, mixed methods help to answer research questions that cannot be answered using qualitative or quantitative methods alone. Therefore, mixed methods provide a greater means to meet the aims and objectives of this study. Family caregiving is a complex phenomenon and a range of perspectives is required.

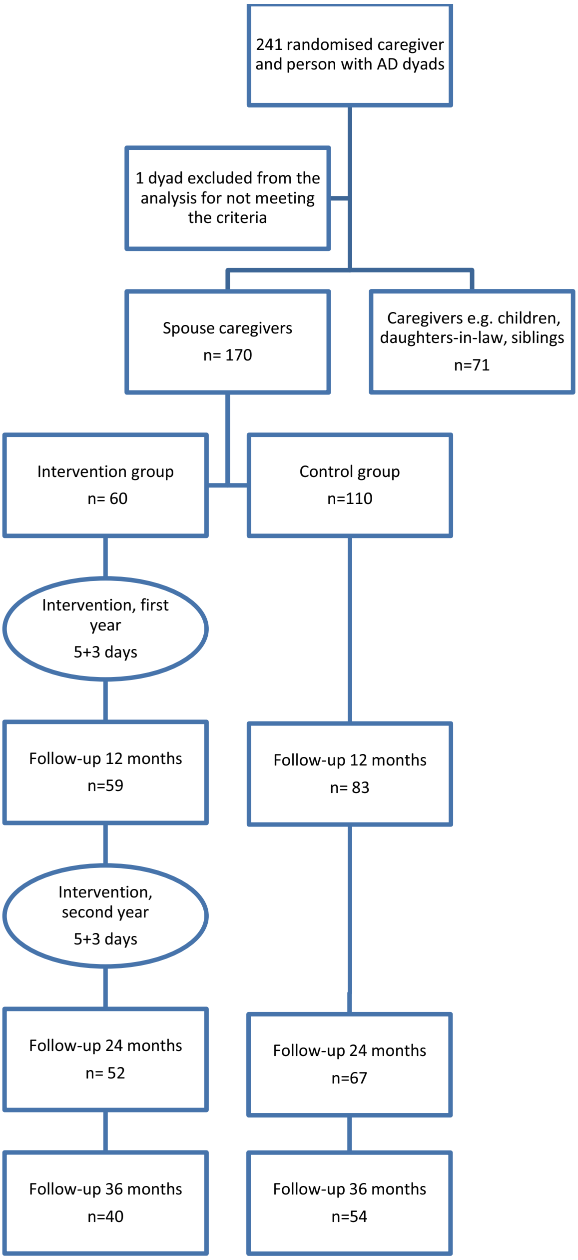

Figure 2. The study design and creation of the study population, focusing on spouse caregivers

4.2 SAMPLES AND DATA COLLECTION

In this study, both quantitative and qualitative material was collected (Table 4). Data collected included socio-demographic details (age, sex, education, living arrangements, income and activities) and general health (other diseases, use of the drugs). In quantitative part of the study, data were collected using several scales: SOC (Antonovsky 1987), BDI (Beck 1961), VAS, 15D (Sintonen 2001), GHQ (Goldberg & Hillier 1979), MMSE (Folstein et al. 1975), CDR Hughes et al. 1982, Morris 1993), NPI (Cummings et al. 1994), ADCS-ALD (Galasko 1997); see Table 5 for details.

A study nurse and a psychologist interviewed the participants and made psychometric analyses on an annual basis. The two practitioners were blind to each other's work. Each visit took three to four hours. Persons with AD were studied using standard neuropsychological examination procedures. If the person with AD could not answer the questions, a note of this was made. Some of them could not respond to the questions at the three-year follow-up. The diaries were collected from those caregivers who agreed to write one on their first visit to the memory clinic.

Table 4. Research materials, data collection times and analyses of the study and the related articles

Material and time	Analyses	Articles (I-IV)
Questionnaire n=170, spouse caregivers 2002-2006	Frequency, t-tests, explanatory factor analysis, linear regression analysis	Artice II
Questionnaire n=94, spouse caregivers 2005-2009	Frequency, t-tests, Mann-Whitney U-test, paired t-tests, Wicoxon test, linear regression analysis	Artice IV
Diaries n=83 2002-2004	Qualitative content analysis	Articles I, III

4.2.1 Quantitative methods and data collection

The quantitative data collection was conducted at two points; baseline and three-year follow up. A total of 241 caregiver-person with AD dyads were recruited to the ALSOVA study. The data collection for the present study was conducted in two phases: first, at the baseline in 2002-2007 with 170 spouse caregiver-person with AD dyads who were living at home. Only spouse caregivers were included. Second, three-year follow-up visits were conducted between 2005-2009. Data collection for the follow-up evaluation was restricted to the same spouse caregivers (n=94) who had remained with the study for three years. The scales used to assess the caregivers and people with AD are presented in Table 5.

4.2.1.1 Caregiver assessment

The data collected include socio-demographic data, i.e. age, sex, educational level, living arrangements and household composition, as well as resource utilisation, time spent caring in hours and caring subsidy. SOC was assessed using a scale (Antonovsky, 1987) with 29 items. The items measure perceived comprehensibility

(11 items), manageability (10 items) and meaningfulness (eight items). Each item on the scale is answered by choosing the number on a scale from 1 to 7 which best represents the caregiver's point of view at that moment. Thirteen of the items were formulated negatively and reversed in the scoring process, so that a high total score indicates a strong SOC. Depression was assessed using the 21-item Beck Depression Inventory (BDI; Beck et al., 1961). HRQoL was measured using the 15D questionnaire and a visual analogue scale (VAS). The 15D is a generic, multidimensional, standardised, self-administered instrument, which has both profile and single index score properties (Sintonen, 2001). The dimensions of the 15D are mobility, vision, hearing, breathing, sleeping, eating, speech, elimination, usual activities, mental function, discomfort, symptoms, depression, distress, vitality and sexual activity. Overall HRQoL was assessed using a 10 cm VAS scale. A 12-item version of the General Health Questionnaire (GHQ; Goldberg & Hillier 1979) was used to measure the extent of distress.

4.2.1.2 Assessment of persons with Alzheimer’s disease

Cognition was evaluated using the Mini Mental State Examination (MMSE; Folstein et al., 1975). The severity of the disease was rated using a Clinical Dementia Rating (CDR; Hughes et al., 1982; Morris, 1993). The Neuropsychiatric Inventory assess behavioral symptoms including delusions, hallucinations, agitation, depression, anxiety, euphoria, apathy, disinhibition, irritability, aberrant motor behavior, sleep and eating (NPI; Cummings et al., 1994). The Alzheimer’s Disease Cooperative Study-Activities of Daily living (ADCS-ADL) was used to evaluate activities in daily living (Galasko et al., 1997).

Table 5. Scales used to assess caregivers and persons with Alzheimer's in the ALSOVA study

Caregiver		**Person with AD**		**Reference**
Baseline	*3-year follow-up*	*Baseline*	*3-year follow-up*	
SOC- 29 (Sense of coherence)	SOC-29			Antonovsky, 1987
BDI (Beck Depression Inventory)	BDI			Beck, 1961
VAS (Visual Analogue Scale)	VAS			
15D (General HRQoL)	15D			Sintonen, 2001
GHQ (General Health Questionnaire)	GHQ			Goldberg & Hillier, 1979
		MMSE (Mini Mental State Examination)	MMSE	Folstein et al., 1975
		CDR, CDR sum of boxes (Clinical Dementia Rating, sum of boxes)	CDR sum of boxes CDR total score	Hughes et al., 1982; Morris, 1993
		NPI (Neuropsychiatric Inventory)	NPI	Cummings et al., 1994
		ADCS-ADL (Alzheimer's Disease Cooperative Study-Activities of Daily Living)	ADCS-ADL	Galasko, 1997

4.2.2 Qualitative methods and data collection

The qualitative data included in this study were collected using caregivers' unstructured diaries. In the pretest of diaries as a data collection method, three diaries were written by family caregivers. Two spouses, one female and one male, in addition to one daughter pretested the diary method. Based on the analysis of these diaries, no changes were made to the instructions. Diaries were written according to the instructions. Family caregivers who pretested the method did not find diary-writing to be too stressful or difficult. Thus, the diary data collection method was included in the data collection.

The analysis was limited to those diaries which were written by those caregivers whom I had met personally at the baseline visit (n=132).

On their first visit to the memory clinic between 2002 and 2004, I asked the family caregivers to write a diary over a two-week period. I discussed writing a diary with the family caregivers and emphasised the voluntary nature of their participation. The family caregivers were also given written instructions on how to write diaries. The basic question was: "What is your life like now that a member of your family has AD?" The written instructions suggested possible themes to write about, which covered a wide range of topics of daily life, the impact of AD and events experienced in different phases of the disease, ways of solving problems and moments of contentment. The family caregivers' life orientation during the first year after AD diagnosis was described by analysing their diaries, written soon after the diagnosis. The aim was to describe the meaning of the onset of AD to family caregivers' life orientation in the early stage of their loved ones' AD before possible intervention. Furthermore, the aim was to describe family caregivers' life orientation and changes in it during the first year after the diagnosis of AD. The caregivers were given an A5-sized notebook containing 40 pages and a prepaid envelope. My contact details were included in case they had any questions.

4.3 DATA ANALYSIS

4.3.1 Quantitative analysis

4.3.1.1 Baseline evaluation (Article II)

Descriptive statistics were used to summarise the variables studied and the characteristics of the persons with AD and their spouse caregivers. T-tests were used to compare SOC, depressive symptoms, HRQoL and distress between men and women. The statistical analyses were carried out with the SPSS for Windows version 14.0 software package. A p-value of less than 0.05 was regarded as significant.

An explanatory factor analysis was conducted with the SOC instrument in order to identify underlying structures. The factor analysis was carried out with principal component axis factoring with promax rotation. One item (number 9) loaded as one factor in itself and was excluded from the final analysis. A cut-off point of eigenvalues over 1.0 was used. Items with communalities over 0.3 were used in further analysis. The five-factor solution was the most meaningful. Sum variables were formed based on compound factors and were later used as continuous variables. In the first linear regression model, the dependent variables were the total SOC score, the five-factor sum variables and the second analysis involving the HRQoL. The HRQoL variable was first transformed so that it was normally distributed using power transformation. The independent variables in the analyses reflected patients' characteristics (MMSE, NPI, CDS sum of boxes, patient's age, ADCS-ADL) or the caregivers' characteristics (age, total amount of drugs used, depressive symptoms, distress, income, gender). Statistical significance was assumed if $p<0.05$. Statistical analyses were carried out using SPSS for Windows version 14.0.

4.3.1.2 Three-year follow-up evaluation (Article IV)

Descriptive analyses were used to summarise the variables studied and the characteristics of the caregivers and the persons with AD. The caregivers were divided into two groups according to the median baseline SOC score (145.0). The weak SOC group included 53 caregivers and the strong SOC group comprised 41 caregivers. Comparisons between groups were determined using the x^2 test, t-tests and the Mann-Whitney U-test. Comparisons within groups were determined using paired t-tests or Wilcoxon matched pairs test. Statistical significance was assumed if $p<0.05$. Statistical analyses were carried out using SPSS for Windows version 17.0.

4.3.2 Qualitative analysis (Articles I and III)

The diaries were analysed using qualitative content analysis (Sandelowski, 1995). I chose to use inductive content analysis in order to discover the caregivers' perceptions of their life in the early stage of caring. In the preparation phase of the analysis, it was found that the analysis should focus on the latent content of the diaries. Field notes served to aid the recall of the families. The purpose of the preparation phase was to make sense of the data and to determine the content of the diaries (Elo & Kyngäs, 2008). First, I read each diary through, followed by a detailed reading with field notes. Second, I described the content of the diary, e.g. the identity of the writer, relationship to the care recipient, age and living conditions. The purpose was to understand each diary as a whole in its individual context. In the second phase, I wrote a brief abstract and list of themes of each diary. The analysis continued through a closer examination of the themes explored by the caregivers. Similar categories were classified together. The standpoint (person with memory disorder or caregiver) from which the caregivers had chosen to write was noted. Few diaries were actually written from the standpoint of the person with AD. In addition, the caregivers' comments on writing were gathered together.

A unit of meaning, which is a constellation of words or statements that relate to the same central meaning (Graneheim & Lundman, 2004), proved to be an appropriate unit of analysis in the diaries. Using ATLAS.ti helped to keep the large amount of data in check. The inductive analysis included open coding, the creation of categories and abstraction (Elo & Kyngäs, 2008).

In the first content analysis, family caregivers' perspectives on daily life were derived from the diaries. In the second content analysis, diary entities were analysed. Furthermore, categories were assigned names that describe the content and meaning of life orientation.

4.4 ETHICAL CONSIDERATIONS

The ethics committee of Kuopio University Hospital reviewed the ethical issues involved in this study (64/00) and approved the ALSOVA project. The study was approved by the Finnish Supervisory Authority for Welfare and Health and the Finnish Ministry of Social Affairs and Health.

The study was carried out in accordance with the Helsinki Declaration. Willing participants were recruited on a voluntary basis in three hospital districts in Eastern and Central Finland. Potential participants were given written and oral information about the study and an initial visit was arranged soon after the diagnosis for those who consented. The voluntary nature of participation and the confidentiality of the data collected were emphasised. A consent form was signed by both the caregiver and the person with AD. The caregiver also provided proxy consent on behalf of the individual with AD.

Consent is understood as a process. In each follow-up visit, the study questions were discussed with the participants if they so desired. Usually, the caregivers were eager to know how the study was progressing. The caregivers were generally highly motivated to participate in this study. However, the decision-making process concerning participation may have caused conflict between the person with AD and the caregiver. Most commonly, however, in this study, the caregivers actively wanted to participate, and the persons with AD did not object, although they showed no enthusiasm either.

5 Results

5.1 CHARACTERISTICS OF THE STUDY PARTICIPANTS (ARTICLES II AND IV)

5.1.1 Characteristics of the spouse caregivers at the baseline and three-year follow-up

The characteristics of the spouse caregivers and persons with AD are given in Table 6. At the baseline, most of the spouses were female (n=107, 62.9%, p= .001). They were usually in long-standing marriages, with the mean number of years spent cohabiting varying from 0-61 (mean=44 years). There were couples married in old age as well some participants were cohabiting without being married. The mean age was 71.6 (range 48.2-84.5). Due to the spouse caregivers' age range, 16 of them were working full time outside of the home. At the baseline, nearly a third of the spouses were receiving help from at least one child (n=52, 30.6%). Some were also receiving help from someone else, i.e. another relative, friend or neighbour (n=12, 7.1%). The total number of drugs being used can provide an estimate of their general health; the mean was 4.3 for women and 3.8 for men.

The same spouse caregivers were assessed at the baseline and at the three-year follow-up (n=94, 55.3%). Most of the spouses were female 54 (57.4%, p=.149), while 40 of them were men (42.6%). The mean age of the caregivers was 73.2. Couples had been living together for 46.8 years. Spouse caregivers' depressive symptoms had increased (BDI mean=11.7), as had QoL (VAS mean=67.7, 15D mean=.8608).

5.1.2 Characteristics of the persons with Alzheimer's at the baseline and three-year follow-up

The characteristics of the persons with AD at the baseline are given in Table 6. The mean age of the persons with AD was 74.2 years old (range 53.8-87.4). Most of them were men 107 (62.9%), while 63 were female (37.1%). The majority had very mild (n=77, 45.3%) or mild AD (n=92, 54, 1%), and one person had moderate AD (0.6%) at the baseline. The mean MMSE was 21.7, reflecting mild AD. Almost all (95.3%) of the persons with AD were having anticholeinesterase treatment or antiglutamateric treatment. The mean ADCS-ADL for male patients was 62.7 and for female patients it was 68.9. There were no other gender differences in AD-related symptoms.

During the three years, AD had progressed to the mild or moderate stage in most patients (MMSE mean=16.5). AD was still in a very mild stage for four persons (4.3%), mild in 53 persons (56.4%) and moderate in 30 persons (31.9%). In five persons (5.3%), the disease had reached the severe stage. Neuropsychiatric symptoms had become more frequent (NPI mean=15.1). In addition, ADL had deteriorated, as measured by the ADCS-ADL score (mean=44.2).

Table 6. Patient and spouse caregivers' demographic characteristics, patient disease severity and caregiver experience at the baseline* and at the three-year follow-up°

CHARACTERISTICS	**CAREGIVERS* N=170 Baseline**	**PATIENTS* N=170 Baseline**	**CAREGIVERS° N= 94 Baseline**	**Follow-up**	***P*-VALUE**	**PATIENTS° N=94 Baseline**	**Follow-up**	***P*-VALUE**
Gender								
Male	63 (37.1%)	107 (62.9%)	40 (42.6%)	40 (42.6%)		54 (57.4%)	54 (57.4%)	
Female	107 (62.9%) *	63 (37.1%)	54 (57.4%) **	54 (57.4%)		40 (42.6%)	40 (42.6%)	
Age	71.6 ± 7.2 (48–85)	74.2 ± 6.6 (54–87)	70.2 ± 7.6 (48-84)	73.2 ± 7.6 (51-87)		73.0 ± 6.5 (53-85)	76.0 ± 6.6 (56-88)	
Years of education	8.8 ± 3.5	8.1 ± 3.6	8.9 ± 3.2	8.9 ± 3.2				
Years of co-habiting	44.2 ±12.5		44.1 ± 11.9	46.8 ± 12.3				
Employment/working full time	16 (9.4%)							
SOC	148.48 ± 22.83		149.2 ± 23.6	145.0 ± 23.6	.008*			
BDI	10.32 ± 6.6		9.5 ± 6.2	11.7 ± 7.9	.053			
HRQOL /15D	0.8714 ± 0.08783		.8743 ± .08527	.8608 ± .09388	.081			
GHQ	24.88 ± 4.8		25.1 ± 5.3	26.1 ± 5.2	.204			
VAS	72.9 ± 17.5		74.9 ± 17.5	67. 5 ± 20.3	.001*			
ADCS		65.0 ± 9.7				65.4 ± 8.7	44.2 ± 18.9	.000*
MMSE		21.7 ± 3.4				21.9 ± 3.4	16.5 ± 5.3	.000*
CDR sum of boxes		4.08 ± 1.6				4.0 ± 1.5	8.4 ± 3.5	.000
CDR								
Very mild		77 (45.3%)				43 (45.7%)	4 (4.3%)	
Mild		92 (54.11%)				50 (53.2%)	53 (56.4%)	
Moderate		1 (0.6%)				1 (1.1%)	30 (31.9%)	
Severe							5 (5.3%)	
NPI total score		9.2 ± 10.0				9.1 ± 9.3	15.1 ± 13.4	.000

The results are expressed as mean ± standard deviation (range) or frequency (percentage of total). SOC = Sense of Coherence Scale; HRQoL = Health Related Quality of Life; BDI = Beck Depression Scale; VAS = Visual Analogue Scale; GHQ = General Health Questionnaire; CDR = Clinical Dementia Rating; MMSE = Mini Mental State Examination; ADCS-ADL = Activities of daily living; NPI = The Neuropsychiatric Inventory; Reliability = Cronbach's alpha. *Analysed at the baseline for Article II. °Analysed for the follow-up study.

* =.001; **=.149

5.2 SPOUSE CAREGIVERS' SENSE OF COHERENCE AND RELATED FACTORS (ARTICLES II AND IV)

5.2.1 Sense of coherence at the baseline

Women's SOC was significantly weaker than men's (144.2 ± 23.1 vs. 155.7 ± 20.6, *p*=<.001). SOC score was negatively correlated to depressive symptoms and distress and therefore moderately correlated to the values of the 15D. There was no significant association between SOC and patients' neuropsychiatric symptoms or the severity of AD. Years of education was not associated with SOC, but income displayed a weak association with SOC in male caregivers (*r*=.260, *p*=.039). Cronbach's α for the scale as a whole was 0. 9. In the factor analysis of SOC, the first factor (consistency of life) accounted for the largest proportion of the explained variance (27%). The other four factors altogether accounted for 19% of the explained variance. The five-factor model fitted well with the data, as confirmed by KMO=869 and Bartlett's test (x^2=1832, 624, *p*=.000). The item content of the compounded five factors was labelled: Consistency of life (factor 1); Contentment (factor 2); Purpose (factor 3); Disappointments (factor 4) and Interest in life (factor 5). A further examination of the factors revealed that women experienced lower consistency of life (factor 1) and interest in life (factor 5) than men.

The stepwise (backwards) linear regression analysis was conducted with five SOC factors as the dependent variables and years of education, MMSE, NPI, CDR sum of boxes, total amount of drugs used, the caregiver's age, the patient's age, depressive symptoms, distress, income and ADCS-ADL as the independent variables. The analysis was controlled for gender. In this analysis, depressive symptoms and distress were the main predictors of caregivers' low SOC.

5.2.2 Sense of coherence at the three-year follow-up

The mean SOC decreased by 4.17 points after three years, after a small rise at the follow-up after the first year. Spouse caregivers were divided into weak and strong SOC groups at the baseline, according to the median SOC score of 145.0 (Table 7). The diminishing trend was similar in both groups, but more evident in the spouse caregivers who had initially had a stronger SOC, with no significant gender differences. Spouse caregivers in both SOC groups reported significant weakening in the patients' ADCL-ADL (*p*=.000) and cognition (*p*=.000). At the baseline, caregivers with a weak SOC reported more burden and patients' cognition was poorer.

During the follow-up period, caregivers with a strong SOC reported a significant increase in depressive symptoms (BDI, *p*= .050) and distress (GHQ, *p*=.002). The trend in the weak SOC group was similar, but not statistically significant. There was a tendency for depressive symptoms to increase in all caregivers, but not to rise to the cut-off point of 12 for depression. The SOC score was negatively correlated with distress (*r*=-.672, *p*=.000) and depressive symptoms (r=.617, *p*=.000). SOC was also correlated with HRQoL (*r*=.486, *p*=.000). However, we did not find any significant predictors of change in SOC.

5.2.3 Factors relating to sense of coherence at the baseline

Women reported more depressive symptoms than men (BDI scores 11.6 ± 6.9 vs. 8.1 ± 5.3, *p*=<.001). Consequently, more than one third (37.6%) of spouse caregivers could be considered to be depressed (BDI > 12), and one of them (35.3%) were receiving no medication for depression. Women caregivers reported more distress than men

(GHQ scores 25.5 ± 5 vs. 23.8 ± 4.3, *p*=.016). The severity of their depressive symptoms correlated with distress, the total amount of medication and also low income (Table 2). Male caregivers' depressive symptoms correlated relatively strongly with the patient's neuropsychiatric symptoms (*r*=.498, *p*=<.001), whereas female caregivers' depressive symptoms correlated only weakly with these symptoms (*r*=.213, p=.027).

There were no gender differences in reported QoL. The participants’ 15D scores were negatively correlated with depression (*r*=-.572, *p*=<.001), distress (*r*=-.568, *p*=<.001) and the total amount of drugs used (*r*=-.450, *p*=<.001). A comparison of 15D profiles (the mean scores of the dimensions) revealed that there were statistically significant differences between men and women in the dimensions of sleeping and distress, with women feeling worse. Years of education and income were not significantly associated with HRQoL. The stepwise (backwards) regression analysis was undertaken with 15D scores as the dependent variable and years of education, MMSE, NPI, CDR sum of boxes, total amount of drugs used, the caregiver’s age, the patient's age, depressive symptoms, distress, income and ADCS-ADL as independent variables. This analysis indicated that the total amount of drugs used, severe depressive symptoms and distress were statistically significant predictors of HRQoL (adjusted R^2=.46).

5.2.4 Factors relating to sense of coherence at the three-year follow-up

The participants’ SOC scores were negatively correlated with distress (*r*=-.672, *p*=.000) and depressive symptoms (*r*=.617, *p*=.000). SOC was also correlated with HRQoL (*r*=.486, *p*=.000). However, we did not find any significant predictors of change in SOC.

Table 7. Comparison of caregivers in the weak and strong sense of coherence groups

Characteristics	**Strong SOC (n=41)**		***p*-value**	**Low SOC (n=53)**		***p*-value**	***Comparison of follow-up between groups***
	Baseline	Follow-up		Baseline	Follow-up		
CAREGIVER							
Gender							
Male	19 (46.3%)	19 (46.3%)		21 (39.6%)	21 (39.6%)		
Female	22 (53.7%)	22 (53.7%)		32 (60.4%)	32 (60.4%)		
			.329			.149	
Age	70.3 ± 7.1	73.4 ± 7.2		70.1 ± 7.9	73.1 ± 7.9		.976
Years of education	8.8 ± 3.2			8.9 ± 3.2			.796
Years of co-habiting	41.8 ± 12.3	44.8 ± 12.2		45.9 ± 11.6	48.3 ± 12.2		.057
SOC	150.6 ± 19.4	146.0 ± 22.6	.054	148.0 ± 26.5	144.2 ± 24.4	.073	.713
BDI	8.9 ± 6.8	11.5 ± 7.4	.050	10.0 ± 5.5	11.9 ± 8.4	.242	.473
HRQoL/15D	.8795 ± .08743	.8648 ± .09895	.248	0.8702 ± .08418	.8577 ± .09061	.199	.557
GHQ	21.9 ± 3.2	25.5 ± 5.0	.002	27.5 ± 5.4	26.4 ± 5.4	.395	.291
VAS	77.3 ± 14.7	72.9 ± 15.6	.141	73.2 ± 19.4	63.2 ± 22.5	.001	.042
PATIENT							
Age	72.9 ± 6.3	75.9 ± 6.3	.000	73.1 ± 6.6	76.1 ± 6.8	.000	
ADCS	65.4 ± 9.4	42.6 ± 19.9	.000	65.3 ± 8.2	45.5 ± 18.4	.000	.497
MMSE	20.7 ± 3.2	15.4 ± 5.6	.000	22.9 ± 3.2	17.2 ± 5.0	.000	.326
CDR							
Very mild	20 (48.8%)	1 (2.4%)		23 (43.4%)	3 (5.7%)		
Mild	20 (48.8%)	24 (58.5%)		30 (56.6%)	29 (54.7%)		
Moderate	1 (2.4%)	9 (22.0%)			21 (39.6%)		
Severe		3 (7.3%)					
CRD sum of boxes	4.1 ± 1.6	8.6 ± 4.0		4.0 ± 1.4	8.2 ± 3.0		.721
NPI total score	9.1 ± 9.8	15.2 ± 14.9	.025	9.1 ± 8.9	14.9 ± 12.4	.002	.649

The results are expressed as mean ± standard deviation (range) or frequency (percentage of total). SOC = Sense of Coherence Scale; HRQoL = Health Related Quality of Life; BDI = Beck Depression Scale; VAS = Visual Analogue Scale; GHQ = General Health Questionnaire; CDR = Clinical Dementia Rating; MMSE = Mini Mental State Examination; ADCS-ADL = Activities of daily living; NPI = The Neuropsychiatric Inventory

5.3. INTERVENTION EFFECTS AT THE THREE-YEAR FOLLOW-UP (Article IV)

5.3.1 Intervention effect on SOC

The intervention and control groups were statistically equal at the baseline. At the three-year follow-up, we did not find any positive intervention effect in the studied efficacy parameters. The intervention was unable to maintain the SOC level during the follow-up period. In fact, in the intervention group, the caregivers' SOC (mean + SD, baseline 155.2 ± 22.1 *vs*. follow-up 148.1 ± 23.5, *p*=.000) and HRQoL (mean + SD, baseline .8878 ± .07969 *vs.* follow-up .8829 ± .07611, *p*=.000) were significantly lower than they were at the baseline.

5.3.2 Intervention effect on continuation in the study

In the drop-out analysis, we found that there were several reasons for discontinuation with the study. A total of five spouse caregivers and 20 patients died. Furthermore, 58 dyads dropped out due to various other reasons.

In the rehabilitation group, 15 dyads ended their participation in the study versus 43 in the control group. With the exception of death, the reasons for dropping out in the rehabilitation group were the patient's institutionalisation (n=8, 53.3%) and other health problems (n=7, 46.7%).

In the control group, more patients were institutionalised (n=11, 25.6%), but the most common reason for withdrawal from the study was the caregiver's health (n=19, 44.2%) or fatigue (n=12, 27.9%). One (2.3%) moved to another city. It was found that there were no discontinuations in the intervention group due to the caregiver's psychosocial fatigue.

In a comparison between the spouse caregivers who dropped out of the study and those who continued to the three-year follow-up, no statistical differences in the studied efficacy parameters were found (Table 8). However, the spouse caregivers who dropped out were slightly more depressed and burdened, and their QoL was poorer. The cognition of people with AD was similar, but in the drop-out group, they were more likely to suffer from neuropsychiatric symptoms, according to the caregivers' ratings.

Table 8. Comparison of spouse caregivers who dropped out of the study for reasons other than death (n=58) to the study population

Characteristics	Dropouts	Study population	*p*-value
Gender			
Male	21	40	
Female	37	54	.457
Age	73.0 ± 6.7	70.2 ± 7.6	.130
Years of education	8.5 ± 3.9	8.9 ± 3.2	.200
Years of co-habiting	44.7 ± 13.1	44.1 ± 11.9	.673
SOC	147.9 ± 23.0	149.2 ± 23.6	.654
BDI	11.9 ± 6.7	9.7 ± 6.2	.531
HRQoL/15D	.85851 ± .09076	.8743 ± .08527	.284
GHQ	24.2 ± 4.5	25.1 ± 5.3	.629
ADCS-ADL	62.2 ± 9.7	65.4 ± 8.7	.071
MMSE	21.2 ± 3.1	21.9 ± 3.4	.195
CRD			
Very mild	26 (44.8%)	77 (45.3%)	
Mild	32 (55.2%)	92 (54.1%)	
Moderate		1 (0.6%)	
NPI total score	10.2 ± 11.5	9.0 ± 9.3	.916
VAS	67.7 ± 21.3	75.7 ± 17.4	.115

SOC = Sense of Coherence Scale; BDI = Beck Depression Scale; HRQoL = Health Related Quality of Life; GHQ = General Health Questionnaire; ADCS-ADL = Activities of daily living; GHQ = General Health Questionnaire; CDR Clinical Dementia Rating; MMSE = Mini Mental State Examination; NPI = The Neuropsychiatric Inventory; VAS = Visual Analogue Scale.

5.4 FINDINGS FROM CAREGIVERS' DIARIES AT THE BASELINE (Article I AND III)

5.4.1 Background information on the diary writers

A total of 83 caregivers consented to write a diary. The majority them were spouses: 47 female and 17 male spouse caregivers agreed to write a diary. Daughters (n=12), sons (n=3), daughters-in-law (n=3) and one sibling also returned diaries. The age range was 41-85. The length of the diaries varied from one to 19 pages, the mean length being five pages, making a total of 446 pages of text.

5.4.2 Perspectives on caregiving from the diaries

The use of diaries as a data collection method in nursing science was evaluated in the context of caregiving. The research questions were: what kind of data can unstructured diaries produce in a study of family caregivers of persons with AD? What are the benefits and limitations relating to the use of diaries in nursing research?

The contents of the diaries were analysed in relation to the purpose of the study. Four different perspectives were revealed: *scarce diaries; reporting diaries; descriptive diaries* and *reflective diaries* (Figure 3).

Scarce diaries (n=3) were brief, containing only a few lines in which the caregivers characterised family life in general with an emphasis on the problems of daily life. These writers did not want to share their personal thoughts any more openly.

> *"There have been no changes for good or bad during this period, everything has stayed the same".*

Reporting diaries (n=4) were written like reports of daily timetables. These reports mainly concerned health and the frequency of physical symptoms. Reporting diaries were characterised by the caregivers' distance from the AD. This distance was manifest in their addressing the patient as "patient" or using only the initial "P".

> *"P took care of his own breakfast. Wanted to go plant saplings even though the job was finished and all the saplings planted yesterday. Nothing more to add today."*

In descriptive diaries (n=22), family caregivers described their daily tasks. Some of these diaries were detailed and intimate accounts of daily duties. The level of intimacy in the diaries varied, and some caregivers placed more emphasis on describing the memory functions and mood of the family member with AD. They were highly personal accounts of what the family caregivers thought and felt. The writers had been made aware that the diaries would be used for research purposes, but they were nevertheless able to produce personal accounts. This was made clear by a group of diaries that were reminiscent of letters in their form. The diaries had clearly been written for research use and addressed to the researcher. Therefore, the diaries served to maintain a personal relationship between the caregiver and the researcher.

Reflective diaries (n=56) contained information about family caregivers' daily events and emotions. Like descriptive diaries, reflective diaries also contained detailed information on the caregivers' tasks. Although reflective diaries contained information about daily tasks, the descriptions differed from other types of diary. Caregivers were less likely to write chronologically and focused on meaningful events. The viewpoint was very subjective. In addition to describing their daily responsibilities, caregivers also elaborated on their emotions and the meanings they associated with caregiving.

The diaries also contained the caregivers' reflections on the meaning of the disease.

> *"Being a family caregiver means to me that Kauko's well-being comes first and everything else after that... This is not a normal relationship between spouses but rather a care relationship. I think of this as a project and hope to have a life after this".*

Reflective diaries contained information spanning several years. The caregivers' considerations were focused mainly on the present, but they also occasionally reflected on the past, especially on how the manifestation of AD first began. Reflective diary writers also considered the future more than caregivers who wrote their diaries in different forms.

> *"I just can't help thinking how I'm going to cope when all the strength runs out and the illness gets worse... Who is going to help us then? I haven't needed outside help as yet, but that time will soon be at hand."*

> *"I keep having this state of mind as we're approaching the twilight of our life, wondering how this will end."*

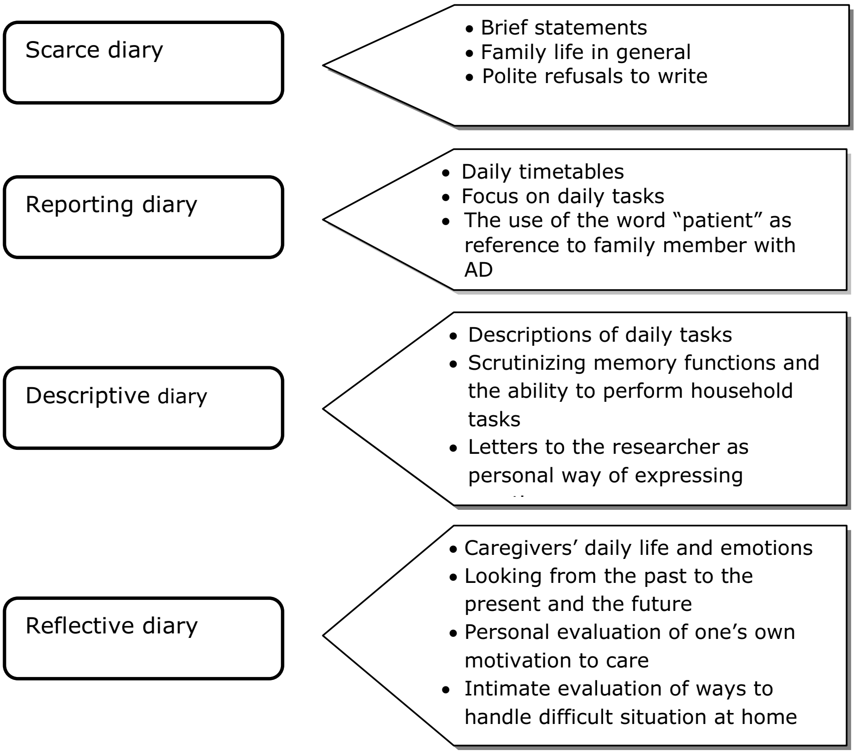

Figure 3. Perspectives on caregiving presented in the diaries

5.4.3 Caregivers' life orientation during the first year after Alzheimer's diagnosis

The meaning of the onset of Alzheimer's for the lives of family caregivers

The meaning of the onset of AD for the lives of family caregivers can be categorised according to three themes: *time of doubt; inner conflict* and *a conception is set* (Figure 4). Family caregivers described how they had gradually become aware of the changes in their family member's behaviour, memory and personality. Family caregivers took the initiative to get a diagnosis. This period of time was characterised by observations and disbelief of those observations. The diagnosis caused family caregivers to experience inner conflict. Hearing the diagnosis was upsetting: *"the blunt diagnosis of the disease felt terrible."*

This experience was also hard to comprehend: *"inside is a feeling that cannot be described with words."* After the initial shock, the family caregivers were anxious to get information about AD. New information about AD and ways to deal with it in everyday life were found to be useful. The emotional consequences of information were contradictory: *"I'm always getting more information and guidance in matters… I just can't think."* They found that information provided relief: *"it helps me go forward in this life situation."*

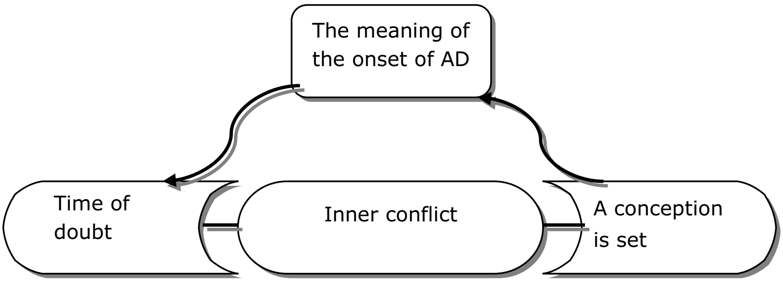

Figure 4. The onset of Alzheimer's in the context of family caregivers' lives

Restructuring life in its entirety

Family caregivers' life orientation changed during the first year after diagnosis. These changes were manifest in three areas of life: *changes in the family caregivers' personal milieu*; *familial cohesion* and *creating a new future* (Figure 5).

Changes in the family caregivers' milieu included caregivers' personal chance to become a caregiver. This process included a shift in family responsibilities to family caregivers. Family caregivers took responsibility for the daily care of the person with AD. They also took responsibility for instrumental tasks outside the home. In addition to these prolific tasks, the family caregivers' inner feelings changed. They felt that the foundation of their life was wobbling and that the usual rules no longer applied. They described the feeling of diminishing from a person to a caregiver and no more. Life seemed to shrink to a tunnel. This feeling was interconnected with physical stain, exhaustion and social isolation: *"I'm extremely tired."*

Family caregivers wrote frankly about their frustration in their relationship with the family member with AD. Feelings of pity, shame and anger about their diminishing skills in daily activities led family caregivers to a process of self-evaluation. Bereavement plays a part in anticipating the progress of AD: *"The shadow of death is approaching… strangely… a living person becomes unrecognisable."*

Gradually, the family caregivers found harmonising elements in their life. Altruistic motives seemed to be strong at the beginning of caregiving. Motivations to care were found in reciprocity and one's obligation as a spouse or a child. *"These daily events and making food and cleaning are minimum payment afterwards… now I'll pay back for as long as possible."* Caregivers' time alone without the person with AD became essential in recovering from the daily strain: *"At the same time, I can be home alone… it's hard to believe, having once been fiercely in love and lonesome for the other [person]… that it's also nice to be alone."*

Family cohesion was challenged from the caregivers' point of view. Relationships in the family changed. Children, even adult ones, needed support in this new situation. Family caregivers were concerned about the emotional distance which seemed to appear within the family. They also found that changes in loved ones behavior was unsetting. Family caregivers struggled to understand the cause of these changes. In parallel with threats to family cohesion, positive aspects of life and feelings of interconnectedness were strengthened.

The creation of a new future became important in the family caregivers' lives. The course of life which they had previously anticipated was now changing. In understanding that they were responsible for their family, the family caregivers were concerned about whether they would have sufficient strength in the future. They reflected that life with the person with AD would become more complicated in the following years. Family caregivers reflected that their personal life was subsidiary in contrast to caring. Aged caregivers in particular settled on the future in a confident way. Life had been satisfactory, and AD did not pose any threat. In sum, the family caregivers hoped for *"a good year"* in the future, and simultaneously hoped that the difficulties they anticipated would pass. *"One can get used to anything, even get numb to Alzheimer's… it has become a family member."*

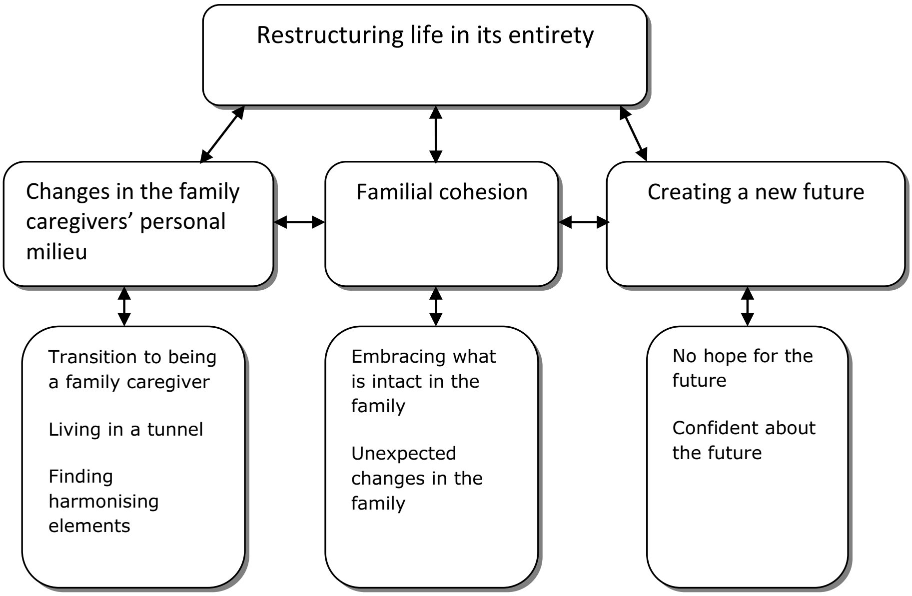

Figure 5. Family caregivers' restructuring of their life in its entirety

5.5 SUMMARY OF THE RESULTS

1. Caregivers' SOC was associated with depressive symptoms and burden at the baseline. Low HRQoL was associated with weak SOC**.** During the follow-up, caregivers' SOC was found to have diminished, and the intervention could not maintain the level of SOC;

2. The psychosocial intervention did not have a discernable effect on the studied parameters in spouse caregivers;

3. Family caregivers who dropped out of the study during the three years were slightly more depressed and distressed. Their care recipients' daily activities were more severely impaired and they suffered from more neuropsychiatric symptoms. Caregivers in the intervention group were more likely to continue with the study to the follow-up;

4. The family caregivers faced profound life changes in the early phase of caregiving. The time of diagnosis and the following year are characterised by shock and emotional distress, which were verified by spouse caregivers' high rates of depressed feelings and distress. Subjective feelings of QoL remained strong in some participants in the early phase;

5. Family caregivers' SOC is characterised by a threat to their consistency of life and contentment in life. Family caregivers face changes in their personal life as well as in terms of familial cohesion. However, this creates a motivation to care and helps them to build a new orientation towards life;

6. Diaries can be used as a primary data collection method. Diaries produce detailed information on everyday life without delay. Diaries may help caregivers to reflect on their lives in a meaningful way, as the diaries serve as a trusted way to reflect on the manifestation of AD.

6 Discussion

This is the first prospective follow-up study on caregivers' SOC with early rehabilitation as an intervention. The main findings of this study show that family caregivers' SOC deteriorates over the three years after the AD diagnosis of the care recipient. Strong SOC at the baseline does not prevent feelings of distress and a diminishing QoL. However, a strong initial level of SOC mitigates this negative trend in family caregivers' health. The psychosocial intervention could not maintain or improve family caregivers' SOC. However, intervention may support caregivers' ability to cope with caregiving, reducing subjective health complaints and fatigue. The diaries proved to be a useful research method of eliciting family caregivers' subjective feelings about caregiving. Family caregiving had started and caregivers' roles and responsibilities had already changed in the pre-diagnostic phase. It was also shown that family caregivers' basic responsibility for daily life had already been established (Betts Adams, 2006; Pinqart & Sörensen, 2003), along with the associated feelings of burden. However, they also felt the basic responsibility for familial cohesion. The onset of AD results in an in-depth change in family life. The closer the relationship, the more profound the consequences are. Progressive disease influences family caregivers' expectations for the future.

6.1 SENSE OF COHERENCE

SOC as a life orientation refers to caregivers' ability to feel that they can cope with different life situations. A strong SOC will allow caregivers to take better advantage of the resources available. In this study, spouse caregivers' SOC was evaluated soon after the diagnosis of AD and followed for three years. Family caregivers' SOC has never before been followed in this kind of homogenous sample.

Family caregivers' SOC might be increased or maintained by psychosocial intervention. When family caregivers' level of SOC is identified and support program is tailored to meet the needs, intervention effects might be positive. Wiemann & Hannich (2010) found that aged persons SOC could be mainly strengthened by high self-efficacy, high self-esteem, low depressive mood and low fatalistic locus of control. Therefore interventions supporting aspects of mental health, social relations and knowledge of AD as well as resources available might be helpful.

The results at the baseline show that depression and distress are significantly associated with HRQoL and SOC. Age was not related to total SOC or SOC factors, probably due to the limited age range of this cohort. However, female caregivers had a significantly lower SOC. These results confirm previous findings that depression and feelings of distress are significantly associated with caregivers' SOC (Andrén & Elmståhl, 2008).

At the three-year follow-up, the mean SOC decreased for all caregivers, and even more so in the originally strong SOC group. This result corroborates previous findings in a working-age population that SOC is unstable and that the level clearly decreases, even in people with strong SOC, after a negative life event, health problems or adverse life events (Kivimäki et al., 2002; Nilsson et al., 2003). Negative life events affect strong SOC, and strong SOC was shown to be no more stable than initially weak SOC in a Finnish five-year follow-up study on the working-age population (Volanen, 2011). In contrast to some previous findings, SOC was not found to be stable in those with initially strong SOC (Nilsson et al., 2003) and did not improve with age (Nilsson et al., 2010). Furthermore, caregivers in the weakest SOC group reported the highest burden, which is in line with two Swedish studies on caregivers (Andrén & Elmståhl, 2005).

This study showed the trend in the originally strong SOC group that spouse caregivers' depressive symptoms and distress increased while their HRQoL diminished. In three years, the caregivers' situation in the high SOC group became much more similar to that of the caregivers in the low SOC group at the baseline. This finding may be explained by the fact that those caregivers whose SOC was strong could realise and assess in a very realistic way the consequences of AD in their life. It seems that progressive diseases, such as AD, pose a special threat to family caregivers' SOC at various levels of life. These caregivers suffer the loss of their previous independence and experience social isolation due to caring. The findings from the caregivers' diaries corroborate this explanation, since the loss of their personal life through becoming a family caregiver was devastating. As established at the baseline, certain spouse caregivers are already vulnerable at the early stage of caregiving. Their starting point at the beginning of caregiving is fragile. Their distress continues during their years as a caregiver. It could be concluded that those caregivers whose own health was poorer found the obligation to care very stressful.

6.2 QUALITY OF LIFE AND DEPRESSION

The results indicate that HRQoL in caregivers remains strong at the time of diagnosis, but there is a complex relationship between depressive symptoms, distress and SOC. Depressive symptoms are strongly associated with low HRQoL. Previous studies have also detected an association between depression and HRQoL (Thomas, 2006). This study also indicated that good HRQoL was correlated with strong SOC in the sample of family caregivers. This connection has previously been shown in other populations (Eriksson, 2007). Depression and a heavy burden of care pose a threat to the continuation of home care (Mittelman et al., 2006). The results of this study show that the prevalence of depressive symptoms (BDI over 12 points) in the caregivers was higher than was previously found in the general population (Covinsky et al., 2003). The prevalence of clinically diagnosed major depression has been reported to range from 10% to 83% among carers of people with memory disorder (Sörensen et al., 2006). Depressive symptoms and low QoL were strongly related to burnout experience in Japanese sample of caregivers (Takai et al., 1009) in congruence findings in this thesis . In agreement with previous studies, depressive symptoms were more frequent in women than in men (Cuijpers, 2005). These results suggest that depression may remain unnoticed in caregivers during the early stages of AD.

6.3 PSYCHOSOCIAL INTERVENTION

Statistically significant intervention outcomes could not be established in the spouse caregivers. This may be due to the small sample size at the three-year follow-up. However, dyads who attended the intervention programme did not drop out of the study as frequently as dyads in the control group. The drop-out rate was twice as high in the control group. It was further shown that in the control group, persons with AD were institutionalised more frequently during the three years. Spouses were more likely to give their own health problems and fatigue as their reason for withdrawing from the study. This finding is in agreement with the conclusion of Brodaty et al. (2003), that caregivers are satisfied with interventions. In addition, follow-up visits may serve as supportive interventions and may bias the findings. However, both groups were followed up equally.

The drop-out analysis revealed a trend that spouse caregivers who withdrew from the study were slightly more depressed and distressed when they began to care. The severity of the AD was similar in both groups, but the persons with AD required more assistance in their daily activities from caregivers. This finding is in accordance with the previous observation that more depressed (Buckwalter et al., 1999) and burdened (Schoenmakers et al., 2009b) caregivers drop out of intervention studies earlier than non-depressed caregivers. Furthermore, in a study of the effectiveness of psychoeducational nursing interventions, it was found that persons cared for by these caregivers were more likely to be institutionalised (Buckwalter et al., 1999.)

It may be that interventions targeted at all caregivers regardless of their psychological morbidity cannot gain effective results. It is possible that conducting a similar intervention for all caregivers could not support the vulnerable caregivers in the study. Therefore, in the future, more specialised and individualised interventions may be more effective when conducted at an appropriate time. Zarit and Femia (2008) pointed out that a better approach would be to design interventions which are specific to selected groups of caregivers, such as those with depression. Gallagher-Thompson & Coon (2007) further point out that it is not really know yet exactly who would benefit and at what level of AD the most from an intervention. In addition different subgroups of caregivers (e.g. spouses, adult children, siblings) may gain help from varied interventions. Thus more effective results in target-orientated outcomes could be gained.

In this study, spouse caregivers underwent the same intervention programme, regardless of their initial situation. The important limitation in the ASOVA study was the lack of family-focused tailoring of services. Tailored support intervention have been shown to be effective way to improve caregivers' well-being and quality of life as well as postpone the institutionalisation of persons with AD (Eloniemi-Sulkava et al., 2009). The use of combination of individual and group interventions based on family needs may support home care more effectively (Elonimi-Sulkava et al., 2009; Mittelman et al., 2007).

The expected outcomes may not be measurable using these parameters for all caregivers. Furthermore, positive intervention outcomes may not be measurable by the parameters used, due to the small sample size. However, there is a possibility that the efficacy parameters used in clinical practice and in this study will not reveal the outcome or efficacy of psychosocial interventions.

6.4 CAREGIVER DIARY STUDY

6.4.1 Diaries as research data

Based on the findings of the present study, unstructured diaries can be used as a primary data collection method to produce unique information on family caregivers' lives. The diaries produced by the family caregivers contained detailed and precise accounts of daily life.

An important benefit of using diaries in research is the ability to achieve a fresh and personal insight into the informants' lives. In the present study, the caregivers used the diary as a means to reflect on their emotions and motivations for caring for an ill family member. In the light of these observations, diaries appear to be a comprehensive technique and useful method of data collection, enabling one to capture a subjective picture of the life of a caregiver. As a research method, diaries provide a good opportunity to elicit actions and emotions experienced in everyday life immediately or very soon after the evocative events. Hence, diaries produce detailed and reliable information about the events of daily life. The diaries provided family caregivers with a personal space in which they could freely express their own thoughts. They were motivated to write by the idea that they could contribute to improving the treatment of AD by keeping a diary and sharing their feelings and thoughts. The reflective diaries in particular were reported to be beneficial to the caregivers themselves. The experience had been pleasant, even therapeutic, in some families, helping them to think through their personal situation. Some caregivers described the diary as the only forum in which they could openly reveal their thoughts, frustrations and fears. It emerged during the meetings that the family caregivers felt that they could not freely discuss their own life in the presence of the ill family member.

During a telephone conversation and a follow-up visit a year later, the informants were asked to give feedback about their writing. Some of the caregivers had found the diary writing to be difficult at first, but once they got over the initial difficulties, they found it to be a positive experience. The feedback revealed no negative effects on the family caregivers, and they felt that the writing had been confidential interaction.

6.4.2 Limitations of diaries used as research data

The use of diaries as a data collection method involves some limitations. These limitations concern the writers' motivation, efforts to confirm the quality of the data and the researcher's high dependency on written data. The method is extremely dependent on the writers, which means that a high level of motivation improves the quality of the data and diminishes the risk of the informants dropping out. It was found to be important that the participating family caregivers understood that the diary-writing was voluntary. At the initial meeting, an effort was made to guarantee good-quality data by underlining that it was important for the family caregivers to express their subjective views and experiences. The researcher's personal contact with the family caregivers enhanced their motivation and gave the caregivers a chance to ask specific questions for clarification about diary writing.

Actual diary data were found to be different from what was expected with some of the caregivers. When this is the case, the writer has understood the aim of diary-writing differently or has not found the writing to be personally rewarding. This study contained two diary types which did not produce information as expected. The existence of scarce diaries can be explained by considering them as polite refusals to write. Reporting diaries contained valuable information, although the point of view in these diaries was not exclusively the caregivers' own. Writers should apparently be intrinsically motivated to write a diary or feel that they can help to develop treatment by writing. Possible reasons for a direct refusal to write include a lack of motivation, the feeling that diary-writing would be an extra source of stress and a critical attitude towards one's own writing skills.

Another issue relating to the limitations of this method is the caregivers' possible concerns about the adequacy of their own writing skills. Many of the family caregivers had not written much since their school days, and some doubted whether they could write in the correct way. This is why they were assured that no school-like criteria would be applied and that they would not need to worry about spelling or grammar. This proved to be a good solution, because many family caregivers agreed to write a diary, and it later emerged that they were able to describe their life even without much experience of writing. There was only one diary which it was difficult to understand due to the writer's lack of skills. Some of the more aged caregivers had been in the habit of writing letters earlier in their life. On the whole, however, there was a lot of variation in the family caregivers' writing skills.

The caregivers kept a diary for two weeks at a time. Some previous studies (Burman, 1995) consider this a long enough period to provide a good view of the family caregiver's life without being too long and causing the informant to become tired of writing. The caregiver's personal method of writing a diary seemed to be related to his/her level of motivation. The caregivers who used the diary to reflect on their lives and life situations found the period of writing suitable or even said they could have continued writing, while some of those who merely recorded the events of their everyday life felt two weeks to be too long a period.

6.4.3 Diaries as reflections of caregivers' life orientation

The findings support the idea that caregivers' life orientation reflects the components of SOC. Based on the analyses, family caregivers used the diary-writing exercise as a means to comprehend their life in relation to the person with AD. The comprehension of their life with AD was evident. Their methods of managing as a caregiver unfolded in their reflections on their role as caregivers. The tasks and responsibilities of the family caregivers' daily life were described as a story that was both accurate and emotional, as found in a study by Clarke (1999). The most important element of SOC, according to Antonovsky (1987), is meaningfulness. The present study shows that caregivers restructure their lives in their entirety at three levels. There are similarities to the findings of Kelly et al. (2002), who found that the most important theme in the home caregiving process is making meaning of the caregiving experience. Writing about one's own thoughts and feelings may facilitate the meaning-making process (Butcher & Buckwalter, 2002) and consequently support caregivers' health.

Caregivers have also been found to use diaries to analyse everyday events and their significance for themselves (cf. Burns & Grove, 2009). Furthermore, diaries reflect the caregivers' frustration and anger towards the disease and its consequences for their life. These emotions were discernible because the events were recorded on a daily basis and they were still fresh and unprocessed in the caregivers' minds at the time of writing. Caregivers used the diaries to describe difficulties that they encountered in everyday caring situations and also to reflect on alternative ways to deal with them.

6.5 VALIDITY AND RELIABILITY OF THE STUDY

This study was conducted using qualitative and quantitative approaches. The use of concepts to describe trustworthiness differs between the qualitative and quantitative research traditions (Graneheim & Lundman, 2004). In both approaches, validity serves the purpose of checking the quality of the data, results and their interpretation (Creswell & Plano Clarke, 2011, pp. 210-212).

6.5.1 The validity and reliability of quantitative studies

Validity in the quantitative part of the study was tested through an evaluation of internal and external validity. Internal validity describes the extent to which the effects detected in the study are a true reflection of reality (Burns & Grove, 2009) and whether there is a cause and effect relationship between the variables (Creswell & Plano Clarke, 2011). The research process was conducted as designed in the research plan. As the recruitment criteria were tight, the study process was postponed for a few years. However, the blinded randomisation as well as the annual evaluations were made according to the study protocol. The follow-up analysis was limited by the sample size, because the drop-out rate was higher than expected. The deaths of persons with AD and caregivers were foreseeable due to the aged study population. The high drop-out rate due to caregivers' physical or psychological complaints was not anticipated beforehand. The use of a care coordinator may have prevented these drop-outs.

The reliability of the quantitative part of any study depends on the consistency with which the instrument used measures the attribute it is designed to measure. In this study, all of the measures used were previously validated. SOC was measured using the original scale, which has been noted to be reliable, valid and cross-culturally applicable (Eriksson, 2007). Cronbach's alpha test for scale reliability was used at the baseline to assess the internal consistency of the questionnaires used (Burns & Grove, 2009), as reported in the publication. The external validity is the extent to which the study findings can be generalised beyond the sample (Burns & Grove, 2009). Due to the descriptive nature of this sample, the generalisability of the findings is limited. However, previous studies corroborate the findings of this study, and some recommendations can be made.

6.5.2 The validity and reliability of diary studies

The qualitative part of the study was evaluated considering the trustworthiness of the research process using credibility, dependability and reflexivity (Lincoln & Guba, 1985, pp. 289-331; Malterud, 2001). The diary method was piloted with five writers and, based on their feedback, served the purpose of this study.

Reflexivity as a critical awareness of the preconceptions of the caregivers as well as the researcher was taken into account during the research process. Reflexivity starts by identifying preconceptions brought to the research by the researcher (Malterud, 2001). The field notes served as a means to explore my own preconceptions as well as to observe the interaction during each visit. Credibility deals with the focus of the research and refers to the level of confidence in how well the data and the analysis process address the intended focus (Polit & Hungler, 1999). The credibility of the results depends on the researcher's commitment to the study and the confidential interpersonal relationship between the researcher and the informants (Lincoln & Guba, 1985, pp. 289-331). When analysing the diary data, the researcher is dependent on the written text. Unlike an interview, it is not possible to pose further questions to a diary if a certain topic remains unclear or is particularly interesting. Diaries may also contain contradictory comments on a given topic. If this is the case, researchers must make their conclusions based on the text as a whole and their field notes. Based on my experience of analysis, a researcher using unstructured diaries as a primary method of data collection should meet with the informants personally beforehand. Field notes made during meetings and telephone conversations will help to produce an adequate analysis of the data.

The analysis of the diary data has been described in publications (Articles I and III). Bergman (2010) states that content analysis is the most suitable for pursuing a complementary mixed-methods design. In order to address the issue of dependability, I analysed the diaries by comparing and validating them against themes and categories (Elo & Kyngäs, 2008). Agreement was not sought from the caregivers, because I validated the analysis with co-researchers at the category and theme levels (Graneheim & Lundman, 2004). In order to achieve credibility, the most suitable unit of meaning was chosen to make it possible to perceive multiple expressions that the caregivers used in their personal ways. Furthermore, in-depth descriptions of authentic quotations were used without compromising the caregivers' anonymity.

Verbrugge (1980) points out that the writers may become more sensitive to symptoms or events when they have undertaken to write a diary. Although there is the risk of increased sensitivity, the diaries mostly contained the family caregivers' reflections on the manifestations of the disease. The caregivers tried to understand the new situation and sought out optimal ways to act. There is a need to take into account the effects of diary writing on family caregivers. The caregivers pointed out that it was easy to write about things that they would not have considered or expressed in an interview. The privacy of the participating family caregivers and their families was guaranteed by changing the names that occur in the authentic quotations and by not giving out their address. It is possible to generalise the results (Lincoln & Guba, 1985, pp. 289-331) to the similar situations of other family caregivers of AD patients. It would, however, be necessary to take into account each person's individual situation in life and the subjectivity of the family caregivers' experiences.

6.7 STRENGTHS OF THE STUDY

This study has several strengths. Three years of follow-up time is long enough to verify the long-term changes in the spouse caregivers' situation. The majority of previous studies have followed up participants after only 12 months (Thompson et al., 2007), and therefore long-lasting intervention effects have rarely been found in previous studies. Furthermore, the study group was homogeneous. All the study patients were recently diagnosed with AD by a geriatrician or neurologist using the NINCDS-ADRDA criteria (McKhann et al., 1984 and DSM IV (APA) (APA; 1994) criteria (O'Byant et al., 2008; Morris, 1997). All of the persons with AD had very mild or mild AD (CDR 05. or 1.0), and only spouse caregivers were included in the quantitative analysis of this study. This study started in 2002 when DSM IV and NINCDS-ADRDA criteria for AD were used. However, in comparison of old and current diagnostic criteria, the persons with AD fulfilled the mild AD dementia criteria (Dubois, 2010; McKhann, 2011) at the baseline. The baseline visit was made soon after the diagnosis, and the mean time after which the therapy started was five months. Evaluations were conducted once a year with the persons with AD and caregivers by a neuropsychologist and a study nurse who were blind to the randomisation and each other's results. The persons with AD were treated according to current guidelines which focus on early diagnosis and AD medication.

This study answers to the challenge to develop methods to study family caregivers' subjective views of caregiving (Funk & Stajduhar, 2009; Gibson et al., 2004; Nolan, 2001). Mixed method study design was used to describe the family caregivers' sense of coherence and evaluate the changes in sense of coherenece. As Creswell & Plano Clarke (2011, pp.1-18) argue, mixed methods have helped to answer the research questions that were not possible to answer by qualitative or quantitative methods alone.

In general, qualitative studies may give novel knowledge of positive aspects of caregiving (e.g. Farran, 1997; Farran et al, 1991). It is suggested that both meanings and motivations can impact on caregivers' well-being. More qualitative research is needed to widen the aspects of caregiving. (Quinn et al., 2010.) Deeper understanding of caregivers' life in its variations will help to target support to those caregivers who are the most vulnerable (Shim et al., 2012). In this study descriptive and reflective diaries contained significant descriptions and analyses of emotions and atmospheres. Their writers pointed out that it was easy to write about things that they would not have thought of or expressed in an interview. Diary writing can be therapeutic and could be utilizable in clinical practice.

6.8 SUGGESTIONS FOR FUTURE RESEARCH

1. There is a need to identify vulnerable caregivers at the time of diagnosis. Therefore, subsequent research needs to develop procedures for the identification of these caregivers;

2. Interventions which aim to alleviate the negative consequences of caregiving could benefit from a more specific sample selection. It seems that family caregivers are a heterogeneous group of people who face the caregiving situation from an individual starting point;

3. There is a need to study both caregivers and persons with AD together. The next step in intervention studies could be the development of methods which facilitate the study of the interplay in caring relationships, e.g. video recording, interactive interviews and writing or painting;

4. The evaluation and future development of diaries as a research method.

6.9. IMPLICATIONS FOR HEALTHCARE

The emphasis of care of persons with Alzheimer's disease and related disorders in Finland has thus far been on early diagnosis and the provision of support for home care, primarily through financial support for families. Family caregivers have been treated as resources by the healthcare system. They are usually offered similar support during the various stages of AD. However, as AD progresses, the need for support changes and family caregivers need constant counselling. In addition, family caregivers are a heterogeneous group of people with individual needs with regard to support. The findings in this thesis emphasise the need to recognise vulnerable groups of caregivers, as they may need and benefit from continuous counselling, psychological support and even drug treatment.

More attention should be paid to caregivers' health at the time of diagnosis. Many negative aspects of well-being accumulate in caregivers during the very early phases of the caregiving process. Therefore identifying those caregivers who suffer from depressive symptoms, sleeping problems and social isolation could help to focus support for these caregivers at the early stage of caregiving.

In the future the whole family of persons with AD should be able to have counseling when needed. Based on findings of this thesis family relations change and negative changes pose threads to family cohesion and well-being of family members.

Counselling should also be offered to family caregivers at the time of diagnostic procedures. As caregiving has already started in the pre-diagnostic phase, caregivers' physical and psychological morbidity can exist at this time. It is recommended that family caregivers' physical and psychological health, as well as their social support resources, should be evaluated at the time of the diagnosis of AD.

Family caregivers ought to receive counseling given by a nurse who specialises in Alzheimer's disease and related disorders and AD about maintaining their identity as a spouse, child and individual, and not solely as a family caregiver. Other roles besides primary caregiver should be maintained and supported.

In the future, we need to arrange more specialised and individualised intervention programmes for caregivers in order to provide effective support.

7 Conclusions

1. Spouse caregivers' complex experience of SOC, depressive symptoms, HRQoL and distress during the early phase of caring suggests that some caregivers may benefit from counselling and individual support at the time of AD diagnosis. Healthcare practices should recognise that caregiving starts at the pre-diagnostic phase;

2. Spouse caregivers' SOC had weakened by the three-year follow-up. A strong SOC can act as a buffer to the negative consequences of caring. A weak SOC may predict poor management in caregiving. Female spouse caregivers had lower SOC than males. Age was not related to the level of SOC, nor did SOC not improve with age, as SOC was not stable within caregivers;

3. The psychosocial intervention combining education and support could not increase or maintain the level of spouse caregivers' SOC. However, the study participants in the intervention group stayed with the study for longer and continued caregiving at home for longer. Therefore, it seems that the caregivers who participated in the psychosocial intervention were supported by it. There is no feasible measurement with which to capture parameters which influence family caregivers' health;

4. Diaries are a feasible method of eliciting caregivers' life orientation and capturing its development. Diaries produce subjective knowledge of the emotions, experiences and meanings associated with caregiving.

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Appendix 1. Articles included in the review of psychosocial caregiver interventions.

Authors	**Aims/ research questions**	**Sample and follow-up time**	**Sample sizes in reviewed studies**	**Inclusion criteria**	**Years**	**Exclusions**	**Outcome measures**	**Main findings**	**Limitations**
Acton & Kang, 2001	To evaluate intervention strategies designed to help caregivers (CGs) of adults with dementia to cope with the burden of caregiving	24 studies. Follow-up not mentioned	Total: 1254, experimental: n=866, control: n=388, range: 11–180, mean 51.08	Intervention studies	1982-1999	Insufficient statistical data for burden, low number of participants	Burden	Interventions designed to reduce CG burden had no effect on burden. Multi-component interventions (n=3) reduced subjective burden	Burden may not be the best outcome to measure in intervention studies
Brodaty et al., 2003	To review published reports of interventions for CGs of persons with dementia	30 studies, 34 interventions. Follow-up times classified for the review, range not mentioned	Total: 2040, range: 16–206, median 53	RCT or quasi-experimental trials. Informal CG	1985-2000	Respite care. Double publication	Psychological morbidity, burden, psychological distress	Interventions provide a small but significant benefit in terms of knowledge, psychological morbidity, coping skills and social support. CGs satisfied or very satisfied with the interventions	Positive ES (random effect size) is based on small numbers, should interpret with caution
Cooke et al., 2001	1. What are the components of psychosocial/psycho educational interventions for dementia CGs? 2. How successful are the different combinations of components in producing positive outcomes for CGs?	40 studies. Follow-up time: 6-11 months, three studies had a follow-up 12 months or longer	Range: 5-5307	Quantitative descption of intervention effectiveness. Focus on improving CGs' psychological /social well-being.	1970-2000	Interventions directed towards care recipient, respite care, illnesses other than dementia or not mentioned. Lack of analysis of outcome using standardised measures. CG reports, case studies and non-English studies	Knowledge, psychosocial well-being, CG burden, social outcomes and general outcome	Possible improvement in CGs' knowledge of the illness, but the knowledge appears to be unrelated to psychological or social outcomes. Social components of interventions or combinations of social and cognitive components are relatively effective in improving psychological well-being	Wide variety of outcomes used in studies, small sample sizes and a lack of control groups dilute the quality of this review. No statistical analysis of studies.

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Authors	**Aims/ research questions**	**Sample and follow-up time**	**Sample sizes in reviewed studies**	**Inclusion criteria**	**Years**	**Exclusions**	**Outcome measures**	**Main findings**	**Limitations**
Cooper et al., 2007	To synthesise evidence regarding interventions that reduce anxiety	24 studies. Follow-up time: 1 week to max. 6 months	Intervention: 4-180, control: 3-61.	Primary research reporting the effects of an intervention on anxiety, quantitative outcome measures of anxiety	Not mentioned	Qualitative studies, single case studies and dissertation abstracts	Anxiety	Little evidence of the efficacy of any intervention. One RCT targeted at anxiety was effective. Grade B evidence that behavioural management, exercise therapies and respite care were ineffective. Preliminary evidence that interventions including yoga and relaxation may be helpful	Heterogeneous interventions therefore overlap between groups
Pinquart & Sörensen, 2006	To assess the average effects of interventions. To compare the effects of different forms of intervention. To analyse the impact of study characteristics on intervention effects	127 intervention studies. Average follow-up time: 11 months	Intervention: 4-4151, median: 23, control: 4–3944, median 22	Dementia, intervention control design, one outcome reported, possible to convert statistics into ES, English, German or a translation	1982-2005		CG burden, depression, indicators of positive subjective well-being, ability/ knowledge, care recipients' symptoms, risk of institutionalisation	Positive immediate effects on CG burden, depression, subjective well-being, ability/knowledge and care recipients' symptoms. Only structured, multi-component interventions decrease the risk of institutionalisation	
Pusey & Richards, 2001	To assess which psychosocial interventions have an effect on CGs	30 RCTs. Follow-up time: max. two years, most less than 6 months	Sample size: 12-206	Informal CGs, community setting, psychosocial intervention.	1969-1999	391 studies from search, exclusion criteria not mentioned but all but 30 studies were excluded based on not meeting the criteria	Psychological and physical health, QoL	No evidence to support the use of technology-based interventions in psychosocial interventions. Effectiveness of the group-based interventions and service configurations was weak. Some evidence of individual-based interventions reducing depression	

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Authors	**Aims/ research questions**	**Sample and follow-up time**	**Sample sizes in reviewed studies**	**Inclusion criteria**	**Years**	**Exclusions**	**Outcome measures**	**Main findings**	**Limitations**
Schoenmakers et al., 2010	To analyse the effect of the different types of professional dementia home care interventions	26 studies. 12 months data was used for analysis in long term-follow-up studies. range not mentioned	Range 36–5307	RCTs, quasi-experimental trial, home care	1980-2007	Qualitative studies	Depression, burden	Only weak evidence that supporting family CGs could be beneficial. Minor decrease in depression. Respite care increased burden	Recruitment bias, small sample sizes, confounding factors and weak designs are common in the studies reviewed
Schulz et al., 2002	To focus on clinical significance in CG intervention research	27 studies. Follow-up time not mentioned	Not mentioned	Family CG, non institutionalised care recipient, intervention with CGs and/or care recipients, quantitative data, at least one clinically relevant outcome, comparative statistics, between-and/or within-group differences	1996-2001	Pharmacological interventions, case studies, reports of quantitative or descriptive data	Symptomatology, QoL, social significance, social validity. The magnitude of the effect of outcomes which had statistical significance in the study was examined	Clinically significant outcomes in improving depressive symptoms, reducing anxiety, possibly anger and hostility by multifaceted interventions. Overall QoL is only slightly improved, but burden, mood and perceived stress respond to multidimensional interventions. Effects of social significance were inconsistent. Delaying institutionalisation requires intense multidimensional interventions with a heavy dose of counselling, support and education. Social validity: 80-100% of participants rated the intervention as helpful, beneficial or valuable	Sample sizes are too small to detect large effects, RCT method used infrequently and implemented incompletely, and the number of studies is still small
Selwood et al., 2007	To compare the efficacy of different kinds of interventions using standardised criteria	62 studies. Follow up-time: max. 9 months	Intervention: 11-58, control; 0-31	Primary research studies with quantitative outcome measures of CG psychological health	Until 2003	Outcomes regarding the patient. Non-dementia CGs. Interventions other than psychological interventions		Individual behavioural management techniques are effective in reducing CG depression in 6 or more intervention sessions. Group and individual CG coping strategies alleviate depression for some months. Education alone is ineffective	Only 10 level 1 studies. Subjective well-being and knowledge are not evaluated

Appendix 1. Articles included in the review of psychosocial caregiver interventions.

Authors	**Aims/ research questions**	**Sample and follow-up time**	**Sample sizes in reviewed studies**	**Inclusion criteria**	**Years**	**Exclusions**	**Outcome measures**	**Main findings**	**Limitations**
Smiths et al., 2007	To review the evidence for the effects of combined programmes for both the informal CG and the person with dementia	25 reports, relating to 22 programs. Follow-up time: max. 8 years, usually less than 12 months	Range: programme group: 15-4140, control group: 15-3944	Intervention aimed at both CG and patient, living in their own homes, dementia and reports of study effects	1992-2005	Not mentioned	CG: mental health, burden, competence. Patient: mental health, cognitive functioning, behavioural problems, physical functioning, delayed admission to long-term care, mortality	CG: clear positive effects of combined programmes on mental health, burden and competence are difficult to establish. Patient: positive effect on depressive symptoms. Programmes delay admission to long-term care	Review of stated results of 25 studies
Sörensen et al., 2002	To determine the effectiveness of interventions for family CGs of older adults	78 studies. Follow up time: average 7 months (SD 5.1 months)	Intervention groups: 4-2268	Care recipient ≥60 years old, intervention-control design, statistics could be converted into effect sizes (at least for listed outcome measures), peer-reviewed publication of studies	1986-2000	Insufficient information to calculate ES, no comparative data on the non-treatment group, publication not in peer-reviewed journals	CGs: CG burden, self-related depression, subjective well-being, uplifts in caregiving, ability and knowledge. Care recipient outcomes: memory and behaviour problem checklist, ADL, IADL	The combined interventions produced a significant improvement of 0.14 to 0.41 SD units for burden, depression, subjective well-being, perceived satisfaction, ability/knowledge and care recipient symptoms. Intervention effects were larger for increasing CGs' ability/knowledge than for burden or depression	Only 61% of the studies focused on care for dementia patients only, heterogonous samples and many studies had missing data and non-relevant variables

Appendix 1. Articles included in the review of psychosocial caregiver interventions. 5/5

Authors	**Aims/ research questions**	**Sample and follow-up time**	**Sample sizes in reviewed studies**	**Inclusion criteria**	**Years**	**Exclusions**	**Outcome measures**	**Main findings**	**Limitations**
Spijker et al., 2008	To estimate the overall effectiveness of non-pharmacological support programmes for CGs and patients aimed to delay institutionalisation	13 studies. Follow-up time: 3-102 months	Range: 60-8095	Dementia patients and CGs, home care, controlled, non pharmacological studies, English language	1990-2006	Not mentioned	Institutionalisation	Patients involved in interventions were significantly less likely to be institutionalised. The mean time before institutionalisation was 4.9 months longer in the intervention groups. High-quality studies could not demonstrate a longer mean time in home care patients. Intensive, multi-component support programmes were effective	Multi-component programmes decrease the odds of institutionalisation, and significantly increase the time to institutionalisation
Thompson et al., 2007	To assess the effectiveness of interventions based around the provision of information and support for informal CGs of people with dementia	44 RCTs. Follow up-time: max. 12 months	Range: 9-93	Study design: RCT, principally with informal CG and care recipient dyads living in the community. Intervention: information and/or support	Search performed: 11/2003-10/2005		CG: QoL, physical and mental health, burden or satisfaction. Patient: ADL or behaviour. Health service utilisation: number of in-patient, outpatient or primary health contacts. Economic outcomes: time spent on caring activities	The overall quality of the studies included was poor. Group interventions appear to have a positive impact on depression in CGs. Clinical significance is unclear	Only RCTs were included. Need for systematically reviewed qualitative findings

HYVÄ OMAISHOITAJA!

Lievää Alzheimerin tautia sairastavia potilaita ja heidän omaishoitajia koskevaan tutkimushankkeeseen liittyen pyydän Teitä pitämään päiväkirjaa kokemuksistanne Alzheimerin tautia sairastavan läheisenä. Päiväkirjat tulevat ainoastaan tutkimuskäyttöön ja päiväkirjoissa esiin tulevat tiedot eivät mitenkään vaikuta saamaanne hoitoon tai sopeutumisvalmennukseen. Tutkimus raportoidaan siten, että yksittäisiä kirjoittajia ei ole mahdollista tunnistaa. Väitöskirjatyötäni ohjaavat professori, THT Katri Vehviläinen-Julkunen ja professori, THT Anna-Maija Pietilä Kuopion yliopiston hoitotieteen laitokselta sekä ma. professori, LT Tuula Pirttilä Kuopion yliopistollisen sairaalan neurologian klinikalta.

Pyydän Teitä kirjoittamaan oheiseen vihkoon kahden viikon aikana elämästänne omaishoitajana. Toivon, että kirjoitatte päiväkirjan ennen mahdollisen sopeutumisvalmennuskurssin alkua. Tulen soittamaan Teille yhden kerran kirjoittamisaikana ja tiedustelemaan kokemuksianne päiväkirjan kirjoittamisesta. Päiväkirja palautetaan tutkijalle oheisessa kirjekuoressa, jonka postimaksu on maksettu.

Voitte kirjoittaa vapaasti arjestanne ja läheisenne Alzheimerin taudin vaikutuksesta elämäänne, myös vaikutuksista Teidän henkilökohtaiseen elämään. Toivon, että kirjoitatte kokemuksistanne ja ajatuksistanne niin kuin Te itse niistä ajattelette. Voitte kuvata päivienne tapahtumia, yhteydenpitoa muihin ihmisiin, pulmatilanteita ja niistä selviytymistä sekä myöskin niitä tyytyväisyyden hetkiä, joita koette. Halutessanne voitte kertoa kaikista niistä tunteista ja tapahtumista, joita teillä on ollut läheisenne sairauden eri vaiheissa myöskin mietteistä Teidän ja läheisenne tulevaisuudesta. Voitte kirjoittaa sen verran kuin itse haluatte.

Kaikki mitä haluatte kirjoittaa, on arvokasta omaishoitajien elämää käsittelevässä tutkimuksessani, koska omaishoitajien kokemuksista ja näkökulmasta on vasta vähän tietoa.

Vastaan mielelläni tutkimusta koskeviin kysymyksiin.

LÄMPIMÄSTI YHTEISTYÖSTÄ KIITTÄEN

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Family Caregivers of Persons with Alzheimer´s Disease: Focusing on the Sense of Coherence and Adaptation to Caregiving

An ALSOVA Follow-up Study

Family caregivers are responsible for the homecare of the persons with Alzheimer's disease. Family caregivers' transformation to caregivers starts in pre-diagnostic phase. Family caregivers' SOC was associated with depressive symptoms, distress and health-related quality of life. Additionally, during three year follow-up caregiver' SOC declined. The psychosocial intervention could not prevent increase in depressive symptoms and burdens or the decline in quality of life. Based on caregivers diaries their personal milieu, familial cohesion changed and a new future was created for them.

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