Department of Medicine
Clinics of General Internal Medicine and Geriatrics
Helsinki University Central Hospital
Finland

Pitfalls in the Treatment of Persons with Dementia

Minna Raivio

Academic dissertation

*To be publicly presented by permission of
the Faculty of Medicine of the University of Helsinki
in the University Museum Arppeanum, Great Hall,
Snellmaninkatu 3, on 23 November 2007 at 12.00 noon.*

Helsinki 2007

Supervisors Kaisu H.Pitkälä, MD, PhD
Professor of General Practice and Primary Health Care
Unit of General Practice and Primary Health Care
Department of Clinical Medicine
University of Helsinki
Finland

Reijo S.Tilvis, MD, PhD
Professor of Geriatrics
University of Helsinki
Helsinki University Central Hospital
Clinics of Internal Medicine and Geriatrics
Finland

Reviewers Timo Erkinjuntti, MD, PhD, FAAN, FAHA
Professor of Neurology
Head of the University Department of Neurological Sciences
University of Helsinki
Finland

Miia Kivipelto, MD, PhD
Associate professor
Aging Research Center Karolinska Institutet Stockholm Sweden

Opponent Raimo Sulkava, MD, PhD
Professor of Geriatrics
Division of Geriatrics
Department of Public Health and General Practice
University of Kuopio
Finland

Cover Nanna Susi, Artist

“Nightly song for the sailor”, 2007
Oil on canvas, 190x105 cm

ISBN 978-952-92-2940-6 (nid.)
ISBN 978-952-10-4337-6 (pdf)

Gummerus Kirjapaino Oy, Vaajakoski 2007

This book is available at: tarina@kirjakauppatarina

To my dear children

Ronja, Tuuli, Ilpo and Heini

Journey

Make haste with care,
the never-ending sky above
embraces dreams.
To our feet
it lowers its white stars,
through which we thirstily wade,
the moon imprinted on our brow.
In the night
blue diamonds whisper,
the sounds of human dreams and longing.
Make haste with care,
the earth is full of broken songs.

Tiina Lindfors

Matka

Kiiruhda varoen,
taivas yllämme
on unelmien loputon syli.
Se on laskenut valkeat tähtensä
jalkojemme juureen
ja me kahlaamme janoisina,
kuun merkki otsallamme.
Yössä kuuluu sinisten jalokivien kuiske,
ihmisten unten ja kaipuun äänet.
Kiiruhda varoen,
maa on särkyneitä lauluja täynnä.

Tiina Lindfors

CONTENTS

LIST OF ABBREVIATIONS

AD = Alzheimer’s disease
ADL = Activities of daily living
BPSD = Behavioral and psychological symptoms of dementia
CI = Confidence interval
CDR = Clinical Dementia Rating Scale
DF = Degrees of freedom
DSM-IV = Diagnostic and Statistical Manual of Mental Disorders, fourth edition
GDS = Global Deteriorating Scale
HR = Hazard ratio
MDS = Minimum data set
MMSE = Mini Mental State Examination
N = Number
NINCDS-ADRDA = National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer’s Disease and Related Disorders Association
NPI = Neuropsychiatric Inventory
OR = Odds ratio
PID = Potentially inappropriate drug
P-value = Probability value
SD = Standard deviation

LIST OF ORIGINAL PUBLICATIONS

I Raivio M, Korkala O, Pitkälä K, Tilvis R: Rehabilitation Outcome in Hip-Fracture: Impact of Weight-Bearing Restriction – A Preliminary Investigation. Physical & Occupational Therapy in Geriatrics 2004; 22(4):1-9.

II Raivio MM, Laurila JV, Strandberg TE, Tilvis RS, Pitkälä KH: Use of Inappropriate Medications and Their Prognostic Significance among In-Hospital and Nursing Home Patients with and without Dementia in Finland. Drugs Aging 2006; 23(4):333-343.

III Raivio MM, Laurila JV, Strandberg TE, Tilvis RS, Pitkälä KH: Neither atypical nor conventional antipsychotics increase mortality or hospital admissions among elderly patients with dementia: a two-year prospective study. Am J Geriatr Psychiatry 2007 May; 15(5):416-424.

IV Raivio MM, Eloniemi-Sulkava U, Laakkonen M-L, Saarenheimo M, Pietilä M, Tilvis RS, Pitkälä KH: How do officially organized services meet the needs of elderly caregivers and their spouses with Alzheimer’s disease? Am J Alzheimers Dis Other Demen, in press.

V Raivio MM, Mäki-Petäjä-Leinonen A, Laakkonen M-L, Pitkälä KH: The use of legal guardians and financial powers of attorney among home-dwellers with Alzheimer’s disease. Alzh Dis Assoc Disord, submitted.

1 ABSTRACT

Background: Dementing diseases lead to disability, the need for help, and a greater need for institutional care, and pose a potential economical burden. Therefore, vulnerable persons with dementia require high-quality health care, rehabilitation and sufficient social services to support their autonomy and to postpone permanent institutionalization. In this way, society could offer these elderly persons better quality of life while economizing on its financial resources.

Aims: This study sought to investigate pitfalls in the care of patients with dementia. The first objective was to study the impact of weight-bearing restrictions on the rehabilitation of elderly hip fracture patients with or without dementia (I). The second objective was to study the impact of inappropriate drug (II) or atypical or conventional antipsychotic use (III) on two-year mortality or hospital admissions. The third aim was to examine the use of, the unmet needs for, and satisfaction with social services among spousal caregivers of persons with dementia (IV), as well as the use of guardianship or financial powers of attorney (V) with a large-scale questionnaire given to caregiver spouses with AD.

Methods: Study I comprised 98 elderly hip fracture patients in Lahti, 36 of whom suffered dementia. We examined the surgical method, post-operative weight-bearing restrictions, need for physiotherapy in days, and ability to learn to walk in six weeks. Studies II and III comprised 425 elderly patients in acute geriatric wards or nursing homes in Helsinki, 255 of whom suffered dementia. We investigated all the drugs used and categorized them according to the Beers 1997 and 2003 lists for potentially inappropriate drugs (PID) (II), atypical or conventional antipsychotic use, or non-use of antipsychotics (III) in order to study the impact of such drugs on two-year mortality or hospital admissions. The data for studies IV and V were collected with a postal questionnaire sent to a random sample of 1 943 Alzheimer drug users living in five areas of Finland and selected from the register of Finland's Social Insurance Institution.

Results: Mean age in these studies ranged from 78 to 86 years. In the sample of hip fracture patients, 38% received weight-bearing restrictions from their surgeon, mostly after osteosynthesis (89%), which was the most common surgical method. This restriction, especially in group of patients with dementia, was associated with a longer rehabilitation period (73.5 days vs. 45.5 days, $p=0.03$) and the inability to learn to walk after six weeks ($p<0.001$).Almost half (44%) of the pre-surgery home-dwellers with dementia in our sample required permanent hospitalization after hip fracture. Only 1 of the 12 patients with dementia and a weight-bearing restriction was able to learn to walk in six weeks.

In our sample of studies on drug treatment, 36.2% received at least one PID. Whether a patient suffered dementia showed no effect on this proportion whether. The most common PIDs in Finland were temazepam (over 15 mg), oxybutynin, and dipyridamole. However, PID use failed to predict mortality or the use of health services.

Nearly half (48.4%) of the patients with dementia used antipsychotic medication, 37.4% conventional neuroleptics (N=95), and 11% atypical antipsychotics (N=28). The two-year mortality of non-users of antipsychotics did not differ from that of users of conventional or atypical antipsychotics (49.6% vs.45.3% vs.32.1%, $p=0.195$). The mean number of hospital admissions was highest among non-users ($p=0.029$). In the Cox proportional hazard model, a high number of medications (HR 1.12, $p<0.001$) and the use of physical restraints (HR 1.72, $p=0.034$) predicted higher mortality at two years, while the use of atypical antipsychotics (HR 0.49, $p=0.047$) showed a protective effect, if any.

Spousal caregivers of persons with AD are old and many are in poor health. Disabilities and behavioral symptoms were common among the demented spouses. The services most often offered to AD families included financial support from the community (36%), technical devices (33%), physiotherapy (32%), and respite care in nursing homes (31%). Those services most often needed included physiotherapy for the spouse with dementia (56%), financial support (50%), house cleaning (41%), and home respite (40%). Only a third of the caregivers were satisfied with these services, and 69% felt unable to influence the range of services offered.

Legal guardians were used by 4.3% of our sample, while the use of financial powers of attorney was 37.8%. Almost half (47.9%) of the couples expressed an unmet need for discussion with their doctor about medico-legal issues, while only 9.9% stated that their doctor had informed them of such matters.

Conclusions: Several pitfalls can be recognized in the Finnish health care and social services systems concerning the care of patients with dementia. Although we already have many practical methods to develop the medical and social care of persons with AD, these patients and their families require better planning and tailoring of such services.

ABSTRACT IN FINNISH

Karikoita dementoituvien henkilöiden hoidossa

Taustaa: Dementoivat sairaudet johtavat aina toimintakyvyn heikentymiseen, avun ja lopulta useimmiten myös laitoshoidon tarpeeseen. Dementiaa sairastavat henkilöt tarvitsevat erityisen haavoittuvuutensa vuoksi asianmukaista terveydenhoitoa, kuntoutusta ja riittäviä sosiaalisia palveluja, jotta heidän autonomiaansa voidaan tukea ja laitoshoidon tarvetta myöhentää. Tämä voisi paitsi parantaa näiden iäkkäiden ihmisten elämänlaatua, myös tuoda taloudellisia säästöjä yhteiskunnalle.

Tutkimuksen tarkoitus: Tutkimuksen tarkoituksena oli selvittää tiettyjä kliinisiä karikoita dementiaa sairastavien henkilöiden hoidossa. Tutkimme lonkkamurtuman jälkeisen varausrajoituksen merkitystä kuntoutuksessa (I), sopimattomiksi luokiteltujen lääkkeiden (II) ja uuden polven, epätyypillisten psykoosilääkkeiden ja vanhan polven psykoosilääkkeiden käytön (III) merkitystä kahden vuoden kuolleisuuteen ja sairaalahoitoihin hyvin iäkkäillä henkilöillä, joista toisella ryhmällä oli dementia, toisella ei. Laajan Alzheimerin tautia sairastavien puoliso-omaishoitajien kirjekyselyn tarkoituksena oli selvittää sosiaalipalvelujen (IV) ja edunvalvonnan ja pankkivaltuutuksen käyttöä (V) sekä tutkia näiden perheiden palvelujen tarvetta ja tarjottujen palvelujen kohtaamista, sekä kyseisten omaishoitajien tyytyväisyyttä saamiinsa palveluihin.

Menetelmät: Tutkimus I koostui 98 iäkkäästä lahtelaisesta lonkkamurtumapotilaasta, joilla 36:lla oli dementia. Selvitimme käytetyn leikkausmenetelmän, leikkauksen jälkeisen kirurgin asettaman varausrajoitusohjeen, fysioterapian tarpeen päivissä ja sen, kykenikö potilas oppimaan kävelemään itsenäisesti tukien kanssa tai ilman kuuden viikon aikana leikkauksesta. Tutkimusten II ja III aineistona oli 425 iäkästä helsinkiläistä potilasta, joilla 255:llä dementia, akuuteilta geriatrian osastoilta tai hoivakodeista. Heidän kaikki käyttämänsä lääkkeet selvitettiin ja luokiteltiin Beers 1997 ja 2003 sopimattomien lääkkeiden listan mukaan (II), ja psykoosilääkkeiden käytön suhteen potilaat jaettiin kolmeen ryhmään: uuden polven ja vanhan polven psykoosilääkkeiden käyttäjät ja ne, jotka eivät käyttäneet mitään psykoosilääkettä (III) tarkoituksena tutkia näiden lääkkeiden käytön merkitystä kahden vuoden kuolleisuuteen ja sairaalahoitoihin. Aineisto tutkimuksia IV ja V varten kerättiin postikyselynä valikoimattomasta 1943 Kelan rekisterin mukaan Alzheimerin taudin lääkkeiden lääkekorvausta saavien ryhmästä viideltä eri alueelta Suomesta.

Tulokset: Tutkimushenkilöiden keski-ikä vaihteli välillä 78- 86 vuotta. Lonkkamurtuma-aineistossa 38%:lle potilaista kirurgi oli antanut varausrajoitusohjeen, useimmiten osteosynteesin (89%) jälkeen,

mikä oli yleisin käytetty leikkausmenetelmä. Tämä varausrajoitus liittyi erityisesti dementiaa sairastavien ryhmässä pidempään kuntoutusaikaan (73.5 pv vs. 45.5 pv, p=0.03) ja siihen, ettei potilas oppinut itsenäistä kävelyä kuuden viikon aikana (p<0.001). Melkein puolet (44%) aiemmin kotona asuneista dementiaa sairastavista potilaista joutui pysyvään laitoshoitoon lonkkamurtuman jälkeen. Vain yksi kahdestatoista dementiaa sairastavasta potilaasta, joille oli määrätty varausrajoitus, oppi itsenäisen kävelyn kuuden viikon aikana. Lääkityksiä käsittelevässä aineistossamme 36.2%:lla oli käytössä vähintään yksi sopimaton lääke, riippumatta siitä, oli potilailla dementia vai ei. Yleisin sopimaton lääke Suomessa oli tematsepaami yli 15 mg, oksybutyniin ja dipyridamoli. Kuitenkaan sopimattomien lääkkeiden käyttö ei liittynyt kuolleisuuteen tai terveyspalveluiden käyttöön. Lähes puolella (48.4%) dementiaa sairastavista potilaista oli käytössä psykoosilääke, useimmilla (37.4%) vanhan polven (N=95) ja 11.0%:lla uuden polven psykoosilääke(N=28). Kun verrattiin niitä, jotka eivät käyttäneet mitään psykoosilääkettä, sekä vanhan ja uuden polven psykoosilääkkeiden käyttäjien ryhmiä, eroa kahden vuoden kuolleisuudessa ei havaittu (49.6% vs.45.3% vs.32.1%, p=0.195). Sairaalahoitojen määrä oli suurin niillä, jotka eivät käyttäneet mitään psykoosilääkettä (p=0.029). Coxin regressiomallissa runsas lääkkeiden määrä (HR 1.12, p<0.001) ja lepositeiden käyttö(HR 1.72, p=0.034) ennustivat lisääntynyttä kuolleisuutta kahden vuoden kuluttua, kun taas uuden polven psykoosilääkkeiden käyttö oli pikemminkin suojaava tekijä (HR 0.49, p=0.047).

Alzheimerin tautia sairastavien henkilöiden, joilla oli heikko toimintakyky ja paljon käytöshäiriöitä, puoliso-omaishoitajat olivat iäkkäitä ja monella itselläänkin heikko terveydentila. Palvelut, joita näille perheille tarjottiin eniten olivat omaishoidontuki (36%), tekniset apuvälineet (33%), fysioterapia (32%) ja lyhytaikainen lomapaikka sairastuneelle laitoksessa (31%). Perheet toivoivat kuitenkin eniten fysioterapiaa Alzheimerin tautia sairastavalle (56%), omaishoidontukea (50%), kodin siivousta (41%) ja kotiin tulevaa hoitajaa pariksi tunniksi kerrallaan (40%). Vain kolmasosa omaishoitajista oli tyytyväisiä palveluihin, ja 69% koki, ettei heillä itsellään ole vaikutusmahdollisuutta siihen, mitä palveluja heille tarjotaan. Edunvalvontaa käytti 4.3%, taloudellinen valtakirja oli taas useammalla (37.8%). Lähes puolet (47.9%) pariskunnista ilmoitti tarvitsevansa keskustelua hoitavan lääkärin kanssa Alzheimerin tautia sairastavan taloudellisten asioiden hoitoon liittyvistä seikoista, mikä oli toteutunut vain 9.9%:lla perheistä.

Johtopäätökset: Suomalaisessa sosiaali- ja terveydenhuoltojärjestelmässä on tunnistettavissa useita dementiaa sairastavan henkilön hoitoon liittyviä karikoita. Siitä huolimatta, että meillä on jo olemassa monia käytännöllisiä menetelmiä kehittää dementiaa sairastavien avo- ja laitoshoitoa, me tarvitsemme uudenlaista suunnittelua ja palvelujen räätälöintiä näiden perheiden omien tarpeiden mukaisesti.

2 INTRODUCTION

During the last century, our dream has become true: we now live to very old ages. As a consequence, however, the aged population has grown exponentially. With revolutionary advancements in the treatment of cardiovascular diseases, cognitive disorders, especially AD, have taken their place as the most challenging diseases in elderly populations. About 120 000 persons in Finland suffered from dementia in 2006, with an incidence of about 13 200 new cases annually, mostly (70%) AD (Viramo and Sulkava 2006). According to the registers of Finland's Social Welfare Office, about 25 000 persons received proper diagnosis and treatment of AD in 2005 (http://www.kela.fi/in/internet/suomi.nsf/NET/131201115055HR?openDocument). Dementia is the most important disease leading to the need of long-term institutionalization, and is thus the most challenging disorder to handle, both individually and economically. According to data from the Stakes Center for Welfare and Health Research (Sosiaali- ja terveysalan tutkimus- ja kehittämiskeskus), about 90% of persons currently living in long-term care suffer cognitive impairment (Noro et al. 2005).

While the cause of AD remains unknown, recent research describes AD as a multifactorial disease for which the risk factors are largely the same as those for cardiovascular diseases, such as hypercholesterolemia, hypertension, obesity, diabetes, and a sedentary life style (Kivipelto et al. 2006). Old age and low education also increase the risk for AD. The main characteristics of AD include progressive impairment of short-term episodic memory as well as symptoms of aphasia, apraksia, agnosia, or executive domain (NINCDS-ADRDA diagnostic criteria). Behavioral disorders are also very common and may vary as the disease develops.

Most persons with dementia are home-dwellers and are cared for by those closest to them, usually relatives. About a third of them have a spousal caregiver. Persons with dementia have a strong need for health care services, and their functioning is easily threatened in by acute diseases or accidents, or inappropriate medications, care, or services. From the point of view of the family, these persons require continuous practical and emotional support, which also affects the lives of the caregivers, who are themselves at risk for mental disorders (Saarenheimo 2007). The legal capacity of persons with AD is equally impaired, thus leading to the need for new strategies for handling financial affairs in such families (Wadley et al. 2003). In this study, we focused on some pitfalls, which may lead to increased use of social and health care services or the unnecessarily early institutionalization and mortality of persons with dementia, in order to find new solutions for the treatment and service practices of such families.

3 REVIEW OF THE LITERATURE

3.1 Short historical overview of AD

In 1898, Alois Alzheimer revealed that senile dementia, cortical degeneration, and brain atrophy can develop without pathology in brain vessels (Alzheimer 1898). In a scientific meeting in 1906, Alzheimer described his 51-year-old female patient, Auguste D, who exhibited progressive cognitive impairment, neurological symptoms, delusions, hallucinations, and psychosocial disturbances, as an example of pre-senile dementia (Alzheimer 1907, Bick and Amaducci 1987, Bick et al. 1987). Plaques and neurofibrillary tangles were found in the autopsy, as well as arteriosclerotic changes (Maurer et al. 1997, Graeber et al. 1998). In 1910, Emil Kraepelin called this disease AD in the category of pre-senile dementias in his textbook (Roman 2002).

AD remained an academic rarity until the systematic neuropathologic studies of Blessed, Tomlinson, and Roth revealed toward the end of 1960s that such histopathological changes are very common in elderly patients with dementia (Blessed et al. 1968). AD proved to be the most common cause of dementive disorders among elderly patients, and nowadays accounts for 70% of dementias (Viramo and Sulkava 2006).

3.2 Definition of dementia and AD

The definition of dementia, according to widely used DSM-IV criteria, includes a state in which a patient suffers memory impairment and one or more of the following: aphasia, apraxia, agnosia, or disturbances in executive functions (American Psychiatric Association 1994; American Psychiatric Association and Finnish Psychiatric Association 1997). Cognitive deficits significantly compromise a patient’s social or occupational life, in comparison to the patient’s previous level of functioning, and are not allowed to occur only in the presence of delirium.

Several definition criteria for AD exist in practise, of which the most common are the NINCDS-ADRDA criteria (McKhann et al. 1984). These criteria can serve in the diagnosis of AD as clinically possible or probable. An exact and certain diagnosis of AD is possible only when the clinical criteria of AD are present and neuropathological changes have been found in an autopsy of the brain. In practice, the diagnosis of AD is primarily clinical, and autopsies of the brain are used only in certain, rare situations requiring brain surgery.

3.3 Epidemiology of dementia and AD

Dementive disorders are among the most common diseases affecting the oldest of the elderly (in position 3 to 5 according to epidemiological studies). Dementia is more common than cerebral infarction, diabetes, or breast cancer. In Europe, about 600 000 persons are diagnosed with dementia anually.

In Finland in 2005, about 120 000 persons suffered from any stage of dementia. The incidence of dementia is 13 200 of all persons over 64. Of those over 65, 1 in 12 (8%) suffers from moderate or severe dementia. Dementive disorders are rapidly becoming more common as the population ages, and their prevalence is estimated at between 22% and 35% among persons 85 and older (Viramo and Sulkava 2006).

The etiology of AD is multifactorial. Established risk factors for AD include old age, heredity, and Apolipoprotein E. Recent studies show strong evidence for other risk factors such as hypertension, hypercholesterolemia, diabetes, obesity, physical inactivity, a low level of education, and an inactive lifestyle (Kivipelto et al. 2005, Kivipelto et al. 2006a,b, Rovio et al. 2005, Rovio et al. 2007, Ngandu et al. 2007). Interestingly, most of the risk factors with strong evidence are the same as those for cardiovascular diseases (Kivipelto et al. 2005, Kivipelto et al. 2006a,b). Smoking, alcohol abuse, dietary factors (e.g. too many saturated fatty acids, lack of omega 3 fatty acids and fish oils), a high level of homocysteine, depression, female gender, head injuries, certain medications, stress and social isolation are also affiliated with potential risk factors for dementia (Anttila et al. 2004, Laitinen et al. 2006, Viramo and Sulkava 2006).

3.4 Pitfalls in the treatment of persons with dementia

The diagnosis, treatment, and care of dementia always constitute multidisciplinary work, including the work of caregivers and families. Nevertheless, several pitfalls occur in all phases of the disease. Pitfalls may occur as difficulties related to personal and family factors, the treatment of home-dwelling patients with dementia in a health care center, social services, hospital treatment and care, and the financial and legal matters of the patient with dementia.

Due to weak self-recognition of memory and other cognitive disorders, the person him/herself may ignore the first symptoms of dementia and thus delay diagnosis. Cooperation with a person suffering dementia may be difficult since s/he may forget instructions or time schedules. The caregiver may also deny the situation and require counselling (Kaye 2002; Waldorff et al. 2005). A sedentary lifestyle may lead to weak muscle function and balance, and thus to an increased risk of falls (Oleske et al. 1995). Nutrition may be insufficient (Wolf-Klein et al. 1994), especially when the person with dementia lives alone and cooks for him/herself. Long distances may lead to insuperable difficulties in obtaining required services, especially in sparsely populated countries or areas. Although many recognize the high strain caregivers experience, many caregivers fail to use available services (Brodaty et al. 2005).

The health care system in Finland presumes the patient's ability to make his/her own appointments with a doctor or other health care worker. Unfortunately, the very nature of the disease makes meeting such a demand for self-action by the patient with dementia almost impossible. Rather, the current requirement for self-action easily leads to a lack of follow-up on the patient and possibly increases the risk of hospitalization.

Certain difficulties also exist in recognizing dementive disorders in short appointments with a doctor in a health care center (Walldorff et al. 2005, Löppönen 2006). The caregiver may not accompany the patient in the doctor's office, and the lack of a detailed patient history from the caregiver may delay diagnosis and necessary referrals to a specialist. If the doctor cannot be the patient's primary care physician, the risk of polypharmacy or of prescribing inappropriate medication increases (Löppönen 2006).

From diagnosis to death, dementia takes about 10 to12 years to develop, and among females may take even longer (Viramo and Sulkava, 2006). During this period, the person with dementia depends on both the health and social service system and his/her family. Depending on several factors, the care of the person with dementia may optimally diminish possible complications and lengthen the period of home care, or, if unsuccessful, may lead to complications, disability, increased need for help, and early institutionalization.

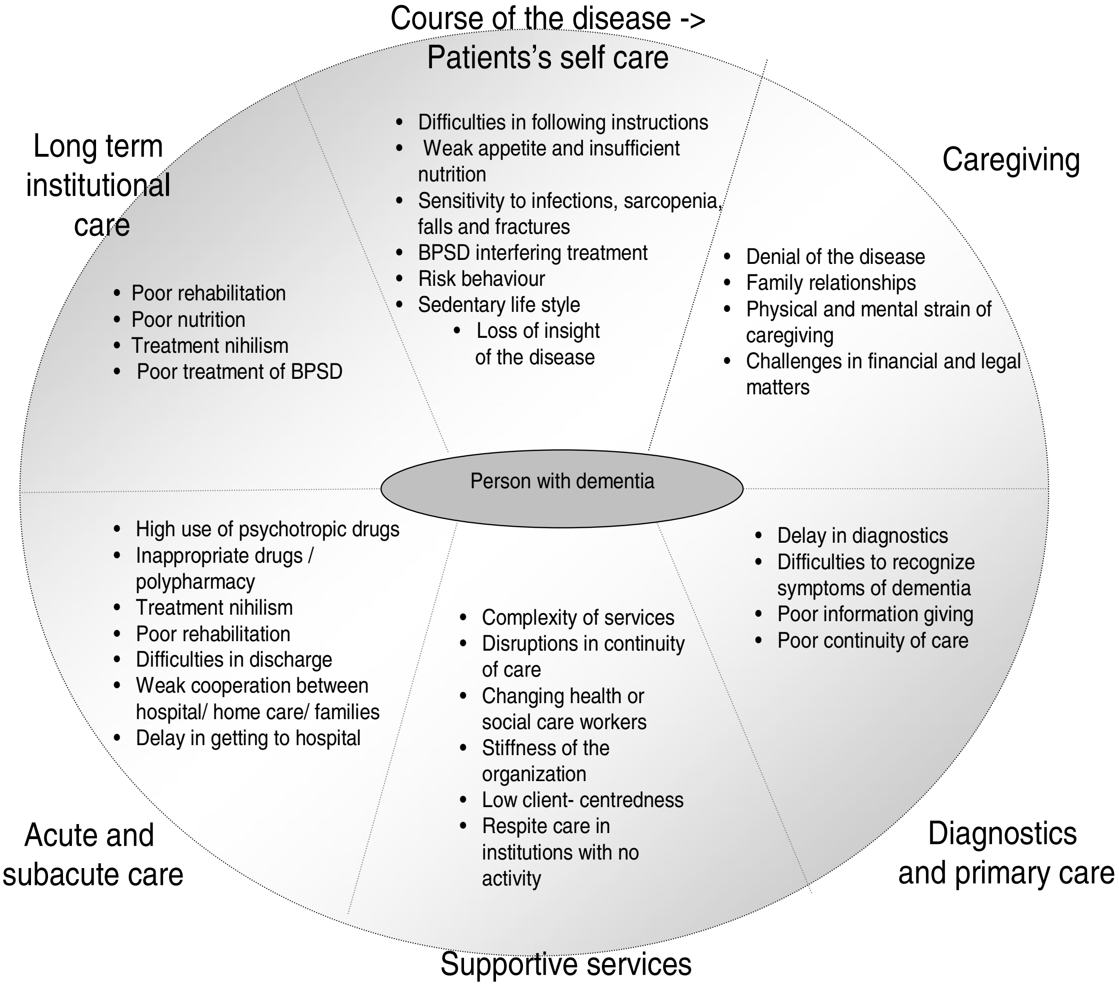
The treatment and care of persons with dementia involves a number of risks for pitfalls, which could lead to rapidly weakening functioning of these persons, and thus to the early need for permanent institutionalization. These pitfalls may originate with the patient or his/her family, environmental factors, primary care and diagnostic procedures, supportive social and health care services, or specific choices in the treatment or rehabilitation of these persons. Acute diseases and hospitalization include several potential pitfalls, and a number of potential problems also complicate the institutional care of such persons (Figure 1). The oversight of symptoms is patognomous in dementia, and often those closest to the person with dementia may also deny the cognitive impairment in the early stages of the disease (Soininen and Hänninen 2006). Thus, it is very challenging and time-consuming for the doctor to recognize dementia (Waldorff et al. 2005), especially if the patient prefers to tell about other symptoms in the health care center.

The health care system in Finland usually relies on the patient's awareness, which may lead to delays in diagnosis, especially when the patient him/herself cannot remember instructions given or time schedules and appointments. Research has shown that persons with AD decrease their nutrient intake and lose weight even in mild cases of AD (Cronin-Stubbs et al. 1997). A sedentary life style, together with depression and social isolation leads to frailty, sarcopenia, vulnerability to complications such as infections, falls and fractures. Behavioral symptoms, such as paranoia, and impaired executive functions, may lead to high-risk behavior. A caregiver's help in such situations is valued, but only if the person with AD accepts it. Family relationships, the caregiver's characteristics, interaction between the person with AD and his/her caregiver, the symptoms of the disease, and the strain and stress related to care-giving all influence the course of the disease.

In the past decade, the health care system in Finland has made progress in the diagnostics and care of AD. However, over half of patients with dementia in Finland are under-diagnosed, their comorbid diseases remain improperly treated, and inappropriate anticholiergic medication is widely used (Löppönen 2006). Nowadays, with AD medication, diagnoses should be performed as early as possible. Nevertheless, delays in getting to the memory clinics still occur, families still receive poor information, and the continuity of care when the patient is discharged to open care remains poor. Special challenges at the time of diagnosis are daunting: patient and caregiver anxiety and depression, the capacity to continue working despite mild AD, retaining a driving license, and other issues. The official system of support services is very complex and adjusts only rigidly to the needs of these families (Eloniemi-Sulkava et al. 2006). Health care and social workers often change, and the flow of information between various services is poor, and disruptions in the continuity of care are common.

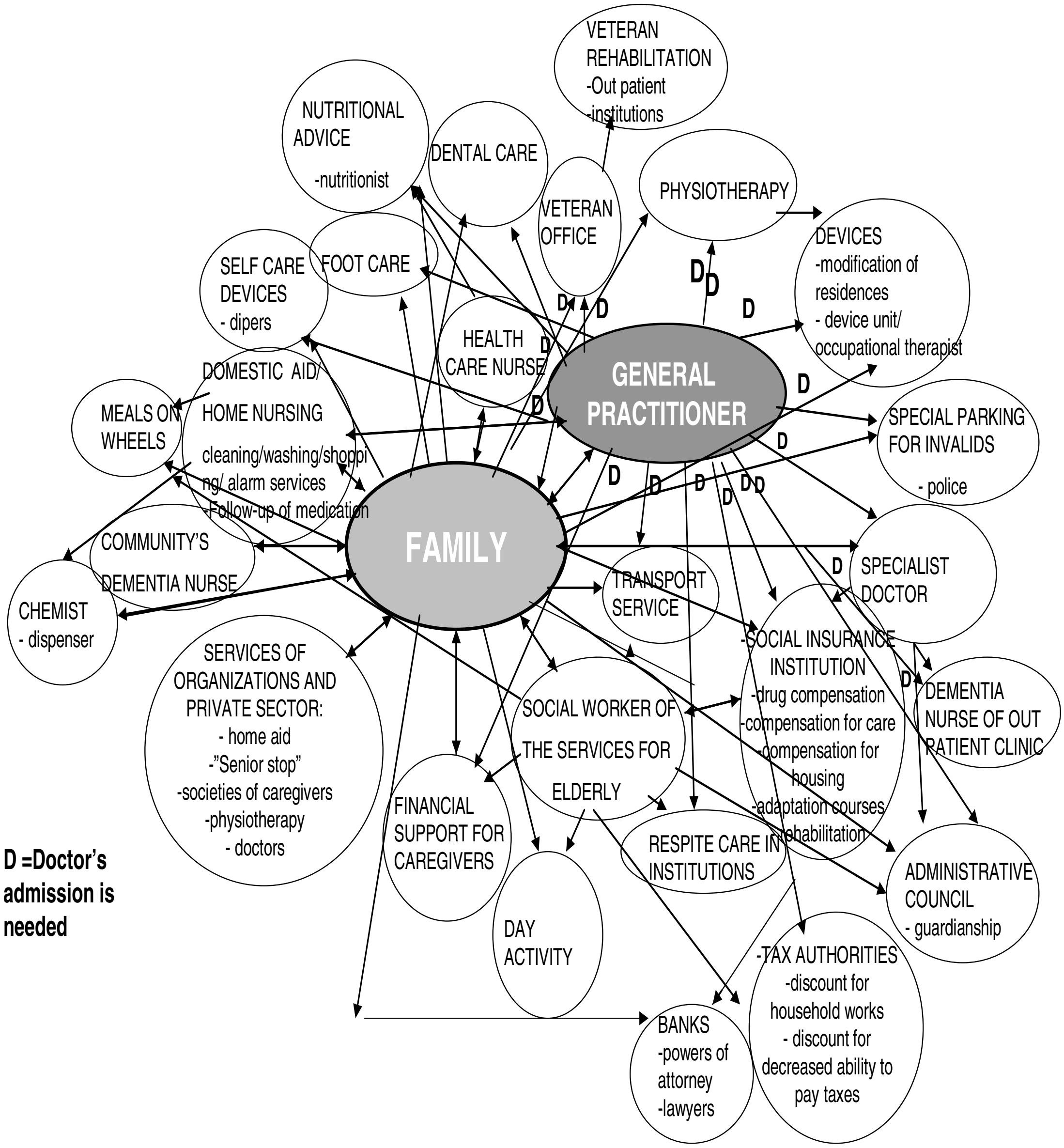
The care of acute diseases may encounter delays in getting to the hospital, thus leading to complications. The diagnosis of dementia may awaken nihilistic attitudes among professionals with regard to treatment and the need for rehabilitation. Friction may exist between hospital and home care services, thus leading to difficulties in discharging the patient as well as extended hospital stays. Several studies have suggested that patients with AD in institutional care are prone to polypharmacy and the use of a high number of psychotropic and inappropriate drugs (Avorn and Gurwitz 1995; Pitkälä et al. 2004; Löppönen 2006). Such patients also suffer from malnutrition and poor rehabilitation services, as nonpharmacological treatments for behavioral and psychological symptoms of dementia remain scarce (Cronin-Stubb 1997, Pitkälä et al. 2004, Suominen et al. 2004). The continuity of care is important to persons who experience difficulty in recognizing his/her own symptoms and who are unable to provide proper anamnesis (Figure 1).

Figure 1. Pitfalls in the treatment of persons with dementia



Finland's system of social services is very complex and fragmented. Consequently, persons with dementia may find it especially difficult to understand and to seek help. Each service provides different social or health care workers and the necessary application forms for these services vary and may be complicated (Eloniemi-Sulkava et al. 2006) (Figure 2). Navigating these services and submitting the application requests to several different offices often requires the assistance of a caregiver. However, those living alone are in a much weaker position if assistance with such bureaucracy is unavailable.

Figure 2. The Finnish social service system for caregiving families with dementia sufferers (Eloniemi-Sulkava et al. 2006)



When patients require hospital treatment and care, dementive diseases should be taken into account when choosing treatments. Delay in getting to the emergency unit is common due to AD-related loss of insight. Drug-related problems include polypharmacy, the use of psychotropics, and inappropriate medications and drug interactions. A low level of physical activity while bed-ridden due to acute disease may result in poor appetite as well as eating and drinking difficulties. These complications may then lead to increased risk for permanent institutionalization and death. Frail elderly patients are prone to infections (Qizilbash and Arrieta 2002), cognitive disorders lead to poor cooperation in hospital, and difficulties may exist when organizing their discharge. Consequently, rehabilitation is necessary as early as possible.

Most persons with mild or moderate dementia are home-dwellers, about one third of whom have a spousal caregiver. Others live alone and are cared for by those closest to them. Financial and legal affairs are often matters of considerable concern in families, and even more so for persons with dementia living alone. Trustworthy family relationships enable family members to arrange medico-legal matters, such as financial powers of attorney or guardianship. Unfortunately, the swindling of elderly persons is also possible. On the other hand, persons with dementia frequently harbor paranoid suspicions, regarded as one symptom of the disease (Knopman 2002). The most challenging situations involve persons with dementia who lack living family members or friends capable of helping them in their daily living.

This thesis focuses on certain clinical pitfalls in the treatment of persons with dementia which may lead to complications, and thus increasing early hospitalization or mortality with time, taking into account the heavy strain suffered by their caregivers, who carry the greatest responsibility for the care of these frailest of home-dwellers. In particular, this thesis focuses on the following issues: rehabilitation according to weight-bearing restrictions after hip fracture, the use of potentially inappropriate medication, the use of antipsychotics and their prognostic significance, the subjective need for support services for AD families and how the official service system responds to their needs, and the use of guardianship and financial powers of attorney among care-giving families of persons with AD and their need for information about these issues.

3.4.1 Hip fracture and dementia

The incidence of hip fractures increases with old age, with estimates of 8 700 hip fractures annually in Finland by 2010. Most patients with hip fractures are females over 80 (Huusko et al. 2006).

Risk factors for hip fractures can be divided into two categories: those factors which increase falls and those that affect bone density. Both of these factors increase with old age and lack of sufficient physical activity. Accordingly, persons with dementia are particularly prone to fractures, of which hip fractures are the most dangerous. The front paw walking position, weak balance, low step height, weakening of sensomotor functions and sight all impact the risk for fracture. The incidence of osteoporosis increases up to 13-fold between the ages of 60 and 80 (Huusko et al. 2006), although the incidence of hip fractures is now decreasing nationwide (Couris et al. 2007). While the exact reasons for this are unknown, a healthier aging population, increased average body weight, and the improved functional ability of the elderly population are of particular interest (Kannus 2006).

3.4.1.1 Treatment of hip fractures

The treatment of hip fractures usually requires two surgical techniques: osteosynthesis or arthroplasty of the hip. Osteosynthesis, which enables early rehabilitation with normal postoperative walking, is recommended when treating undisplaced hip fractures (Parker and Blundell 1998, Huusko et al. 2006). Patients with hip fractures are usually allowed postoperatively to stand and walk normally after total arthroplasty or hemiarthroplasty of the hip. This normal weight-bearing with full weight of the leg is also usually possible when the surgeon considers the fracture fixation stable (i.e. in undisplaced femoral neck fractures fixed with screws). In all other cases involving osteosynthesis with metallic screws and plates, only restricted weight-bearing is usually permitted. This practise is international. Estimating the stability of osteosynthesis may be difficult, and in certain cases re-operation is necessary, especially when the osteosynthesis of femoral neck fractures involves screws (Vajanto et al. 1998). The augmentation of osteoporotic fracture osteosynthesis by banked bone or bone substitutes should be considered more often in order to increase fracture stability (Kuokkanen et al. 2001).

3.4.1.2 Rehabilitation after hip fractures

Rehabilitation after hip fracture usually begins in the surgical ward immediately after surgery, provided no complications preclude it. While the length of hospitalization in surgical wards has been reduced to only a few days, postoperative hip fracture rehabilitation in primary care hospitals or specific rehabilitation wards usually continues. Few randomized studies have examined the impact of specialized rehabilitation on patient recovery and the rehabilitation time needed prior to discharge from the hospital. Some studies have shown beneficial effects (Kennie et al. 1988; Cameron et al. 1993; Huusko et al. 2000), while others only moderate effects (Jette et al. 1987; Gilchrist et al. 1988; Galvard and Samuelsson 1995). All concur that individually-planned rehabilitation designed by a multidisciplinary team comprising a nurse, physical therapist, geriatrician, and orthopaedist yields the best results (Young et al. 1996; Saarela and Valvanne1999; Wade et al. 2000). In Finland, however, this is possible only in big cities with access to various specialist services. The first Current Guidelines for the Treatment of Hip Fractures have been published in Finnish to serve physicians planning the rehabilitation of their hip fracture patients (Huusko et al. 2006).

While most hip fractures occur among the oldest of the elderly, the number of persons with dementia is also considerable. Weakening cognition hampers rehabilitation, and persons with dementia having hip fractures require special care in order to benefit from rehabilitation. A patient whose surgeon has issued a weight-bearing restriction for his/her leg should be capable of understanding and remembering the meaning of it: to stand on only one leg and to walk with crutches or a walker in such a way as to avoid bearing weight on the injured leg. If the patient has difficulty learning this, the rehabilitation possible in such a situation is limited to muscle strengthening and general conditioning while the person remains in a wheelchair or lies in bed for the first six weeks after surgery. This more or less leads to the immobilization of such persons during the most important period of rehabilitation.

Huusko and her colleaques have studied hip fracture rehabilitation in patients with mild or moderate dementia (N=243), and concluded that rehabilitation could be successful in spite of cognitive disorders when carried out with a specialized geriatric team (Huusko et al. 2000). In the intervention group, which received referrals to the geriatric wards, the length of hospital stay shortened and the risk for readmissions decreased, compared to the control group, which received treatment in local hospitals (Huusko et al. 2000). In their sample, however, by exceptional order of the head of the surgery department, all the patients could begin walking normally after surgery, so no weight-bearing restrictions were necessary.

The potential for the successful rehabilitation of each patient could benefit from a surgeon's preoperative evaluation before choosing the surgical method (Kuokkanen and Korkala1992; Luethje et al. 1995). While several studies have examined the impact of various surgical methods on mortality, time in surgery, wound infection, mobility, thrombosis, and pulmonary embolism (Gillespie 2001; Bhandari et al. 2003), no previous studies have as yet focused on the impact of weight-bearing restrictions.

3.4.1.3 Prognosis of hip fractures

The increased need for permanent institutional care and long rehabilitation periods has had a considerable impact not only on the quality of life of these individuals, but also on the costs of care. Mortality among hip fracture patients is particularly high: 21% to 33% in Finland during first year. Neither mild dementia among home-dwelling elderly patients with hip fracture nor age over 85 showed any impact on mortality.

The weak general condition – especially the weak functioning, comorbidity, anemia, delay of surgery for more than two days, delay of early rehabilitation, and different postoperative complications – of the patient was the most important factor behind the increasing mortality (Huusko et al. 2006).

3.4.2 Potentially inappropriate medication and dementia

3.4.2.1 Drug use among patients with dementia

Persons with dementia usually suffer from many diseases, thus taking a very wide variety of medication. Home-dwelling patients with dementia suffer not only from more comorbidity, but also from more undiagnosed diseases than do non-demented patients (Löppönen 2006). According to studies by Löppönen et al., persons with and without dementia had 8.3 and 6.0 previously diagnosed comorbid conditions, and 66% and 45% suffered from at least one undiagnosed, and therefore untreated, disease, respectively. Medication use was more common among persons with dementia than among those without: 5.7 and 3.8 medications, respectively. The use of anticholinergic drugs was especially common among home-dwelling persons with dementia in a Lieto study: 45% of persons with mild dementia used such drugs, which are considered inappropriate for elderly persons (Löppönen 2006). In Finland, home-dwelling patients with dementia use more of various kinds of medication, especially psychotropic drugs, than do patients without dementia (Hartikainen et al. 2003). A high risk for polypharmacy, adverse effects, and drug interactions exists, especially among the frailest patients with dementia, in nursing homes and hospitals (Avorn et al. 1995, Gurwitz et al. 2000).

3.4.2.2 Various criteria for potentially inappropriate medication

To improve the quality of medical care for the elderly, various criteria and national guidelines for PID use have been created. Zhan et al. (2001) have defined PIDs in two categories: “always avoid” and “rarely appropriate”. In Sweden, the Socialstyrelsen of Sweden have published recommendations for doctors about the medication of the elderly (Socialstyrelsen 2003). The most widely used and updated criteria are the Beers criteria (Beers et al. 1991; Beers et al. 1997; Fick et al. 2003). These criteria were created in Canada using Delphi techniques involving a panel of nationally recognized experts. The Beers criteria take into account evidence of the efficacy of the medication for the elderly, possible side effects, the availability of safer alternative medication, and factors related to certain diagnoses or conditions. The Beers criteria categorize a number of drugs with anticholinergic properties as inappropriate. Cognitive decline is one of the most harmful side effects of these drugs, which understandably renders persons with dementia especially vulnerable (Ancelin et al. 2006).

3.4.2.3 Prevalence of inappropriate medication use among the elderly

The use of PIDs has been the focus of considerable study. Depending on the study sample and cultural context, the administration of PIDs among home-dwelling patients has ranged from 12.5% to 41.1% (Stuck et al. 1994; Willcox et al. 1994; Golden et al. 1999; Piecoro et al. 2000; Zhan et al. 2001; Pitkälä et al. 2002; Stuart et al. 2003; Curtis et al. 2004; Fialova et al. 2005). In nursing homes, the respective values have ranged from 12% to 50% (Beers et al. 1992; Williams et al. 1995; Spore et al. 1997; Aparasu et al. 2000; Dhalla et al. 2002; Gray et al. 2003; Lau et al. 2004). Among elderly in-hospital patients, PID use has varied between 15% and 29% (Onder et al. 2003; Onder et al. 2005), and among emergency units, between 11% and 13% (Chin et al. 1999; Caterino et al. 2004). Most of these investigators have modified the Beers criteria, which makes comparison of these studies difficult.

3.4.2.4 Prognosis of inappropriate medication use among the elderly

While several studies have examined the associations and predictors of PID use (Stuck et al. 1994; Piecoro et al. 2000; Beers et al. 1992;Williams et al. 1995;Dhalla et al. 2002; Gray et al. 2003; Lau et al. 2004; Aparasu et al. 2000; Onder et al. 2003; Onder et al. 2005; Chin et al. 1999; Caterino et al. 2004; Fu et al. 2004; Hanlon et al. 2000; Lane et al. 2004; Simon et al. 2005), few studies have explored the prognosis of PID use (Onder et al. 2005; Fu et al. 2004; Hanlon et al. 2002; Fillenbaum et al. 2004; Perri et al. 2005; Klarin et al. 2005). Only one study has shown an increase in mortality attributable to PID use (Lau et al. 2005), while others have reported no such impact (Onder et al. 2005; Hanlon et al. 2002; Klarin et al. 2005). Three studies have examined the impact of PID use among in-hospital patients (Onder et al. 2005; Perri et al. 2005; Lau et al. 2005), showing controversial results: hospitalization and mortality increased in the US study (Lau et al. 2005), whereas an Italian study showed no differences in mortality, adverse reactions or length of hospital stay (Onder et al. 2005), and yet another study from the US showed an increase in one of the three adverse health outcomes: hospitalization, visits to the emergency room, or death (Perri et al. 2005) (Table 1). To date, no studies have examined the prognosis of PID use among persons with dementia.

Table 1. Prognostic studies examining PID use, according to previous studies

Author	Country N	Follow-up months	Criteria	PID %	Prognostic outcomes
Home-dwelling patients					
Hanlon et al. 2002	USA 3234	36	Beers 1997 modified	21.0	Mortality +- Functional status -
Fu et al. 2004	USA 2305	4- 24	Beers 1997	13.3	Self-perceived health status -
Fillenbaum et al. 2004	USA 3165	36	Beers 1997	27.9	Use of outpatient services + Hospitalization + Nursing home entry +
Klarin et al. 2005	Sweden 785	36	Beers 1997 modified, Canadian criteria, and clinical indicators of drug-related morbidity	18.6	Hospitalization + Mortality +
Nursing home and in-hospital patients					
Perri et al. 2005	USA 1117	5	Beers 1997	46.5	One of the adverse health outcomes (hospitalization, emergency department visits or death) +
Onder et al. 2005	Italy 5152	10 years	Beers 2003, not fully applied	28.6	Mortality +- Adverse reactions +- Length of hospital stay +-
Lau et al. 2005	USA 3372	3	Beers criteria, combined version	51.3	Hospitalization + Mortality +

+ = significant increase

+- = no significant changes

- = significant decrease

$p < 0.05$

3.4.3 Antipsychotic drugs and dementia

3.4.3.1 Use of antipsychotics in the treatment of persons with dementia

Persons with dementia often exhibit behavioral symptoms, which can vary as the disease progresses (Sink et al. 2005). Such disorders are an important cause of permanent institutionalization (Koponen and Saarela, 2006). Antipsychotic medication is widely used among elderly long-term care patients, mainly to manage the behavioral disorders of dementia (Phillips et al. 2003; Pitkälä et al. 2004). The antipsychotic drug use has varied from 15% to 42% among nursing home patients (Avorn et al. 1995;Gurwitz et al. 2000; Llorente et al. 1998; Lasser et al. 1998; Liperoti et al. 2003; McGrath et al. 1996; Oborne et al. 2002; Ford et al. 2002; vanDijk et al. 2000; Ruths et al. 2001; Sorensen et al. 2001; Holmquist et al. 2003; Hosia-Randell et al. 2005; Snowdon et al. 1999; Draper et al. 2001) (Table 2). This has been considered enough of a problem that the US government passed the Omnibus Reconciliation Act (OBRA-87), legislation designed to restrict the over-prescription of these drugs to the elderly (Snowden et al. 1998). When researchers estimated the current practice in the UK from 1997 to 1998, only 17.8% of antipsychotic prescriptions were considered appropriate (Oborne et al. 2002). Studies of the incidence of antipsychotic use among patients with dementia are scarce. In institutions in Finland, the use of antipsychotic medication among patients with dementia is high: up to 55% (Pitkälä et al. 2004).The corresponding value in Singapore is 45% (Mamun et al. 2003), and in the US, 52% (Lasser and Sunderland 1998).

Table 2. Use of antipsychotic drugs among nursing home and hospital patients with or without dementia, according to earlier studies

Authors	N	Country	Antipsychotic use
Avorn et al, 1995	1106	USA	25%
McGrath and Jackson, 1996	909	UK	24%
Llorente et al, 1998	1573	USA	18%
Lasser and Sunderland, 1998	298	USA	42%
Snowdon, 1999	1975	Australia	23%
Gurwitz et al, 2000	2916	USA	17%
van Dijk et al, 2000	2355	Netherlands	35%
Ruths et al, 2001	1552	Norway	23%
Sorensen et al, 2001	288	Denmark	21%
Draper et al, 2001	647	Australia	21%
Ford et al, 2002	125 (1999) 119 (2001)	UK	38% 37%
Oborne et al, 2002	934	UK	25%
Liperoti et al, 2003	139714	USA	15%
Mamun et al., 2003	384	Singapore	24%
Holmquist et al , 2003	175	Sweden	16%
Raivio et al, 2005	425	Finland	48%
Hosia-Randell et al, 2005	1987	Finland	43%

3.4.3.2 Risks of the use of atypical antipsychotics

Since 2002, a lively discussion of the risks of atypical antipsychotic drugs in patients with dementia has taken place as several studies have shown increased stroke and death risks related to such drugs (Wooltorton et al. 2002; Wooltorton et al. 2004; Singh and Wooltorton 2005; Schneider et al. 2005). Odd ratios concerning the risks for adverse cardiovascular events range from 2 to 4, based on partly unpublished data from pooled analyses of clinical nursing home and outpatient trials (11 nursing home, 4 outpatient trials) of risperidone and olanzapine for residents with dementia (Medicines and Healthcare Products Regulatory Agency 2004; Racoosin et al. 2004). Becauce of these risks, Health Canada, the US Food and Drug Administration, and UK Committee on the Safety of Medicines have warned clinicians about the stroke risks related to the use of atypical antipsychotics (Schneider et al. 2005; Gill et al. 2005).

According to a meta-analysis of 15 trials, 9 of which remain unpublished, death occurred more often among patients using atypical antipsychotic medication than among non-users (3.5% vs. 2.3%, respectively, OR 1.54, 95% CI 1.06-2.23; p=0.02). All of these studies lasted only 10 to 12 weeks. In conclusion, the meta-analysis showed the association of a slightly higher risk for death among users of atypical antipsychotics than among those with placebo (Schneider et al. 2005). These findings lead to the possibility of an increase in the use of older, conventional antipsychotics instead of newer, atypical drugs in the treatment of behavioral symptoms of persons with dementia.

In a one-year prospective follow-up design, Suh and Shah (2005) compared the mortality risk of 273 nursing home patients with dementia using any kind of antipsychotic to that of non-users; their results showed a surprisingly higher risk of mortality among non-users (RR 1.3, 95 %CI 1.1-1.4).

Comparing the risks of users of atypical or conventional antipsychotics has yielded mixed results. Three large-scale retrospective studies have examined stroke risk; all of them concluded that users of conventional antipsychotics showed no higher risk for stroke than did users of atypical ones (Gill et al. 2005; Herrmann et al. 2004; Finkel et al. 2005). Two studies lasting from 180 days to two years examined mortality risk as a whole among elderly patients (Nasrallah et al. 2004; Wang et al. 2005); both studies found higher mortality rates among users of older, conventional antipsychotics. However, these studies did not examine persons with dementia as a special subgroup nor did they compare users to non-users.

3.4.3.3 Effectiveness of antipsychotics in the treatment of behavioral symptoms of dementia

Until now, the benefits of atypical antipsychotics to treat psychosis, agitation, or aggression in patients with AD, have remained uncertain. According to a review by Sink et al. (2005), most drug therapies lack evidence of effectiveness in the care of behavioral symptoms, whereas atypical antipsychotics show the strongest evidence (Sink et al. 2005). In a recent multi-center, double-blind, placebo-controlled US trial by Schneider et al. (2005), 421 home-dwelling patients with AD were examined while undergoing treatment for psychosis, aggression, or agitation with olanzapine, quetiapine, risperidone, or placebo. The follow-up period lasted up to 36 weeks, and the main outcomes showed that the most influential factors were time from initial treatment to the discontinuation of it for any reason and the number of patients showing at least minimal improvement on the Clinical Global Impression of Change scale at 12 weeks. This study found no advantage in the efficacy of atypical antipsychotics for the treatment of outpatients with AD exhibiting psychosis, aggression or agitation, which could offset the adverse effects of these drugs (Schneider et al. 2005).

In conclusion, clinicians treating elderly persons with dementia express controversy over the hazards and efficacy of medication treatment for behavioral disorders, which are the most challenging symptoms to manage, and which are among the most important reasons for institutionalization. The warnings given to clinicians cannot properly be taken into account in practice, and some have questioned whether the agitation itself, rather than the use of atypical antipsychotics, leads to increased mortality (Schneiderman 2005; Karlawish 2006).

3.4.4 Use of and need for services among AD families

3.4.4.1 Use of the social services among care-giving families of persons with AD

Spousal caregivers of persons with AD are usually very committed to their care-giving and feel that they have a lifelong duty to care for their spouse rather than to entrust his/her care to a nursing home (Ganzer and England 1994; Saarenheimo 2007). Earlier population-based studies indicate that neuropsychiatric symptoms such as depression, agitation, paranoid thoughts, hallucinations, and wandering, occur frequently in patients with AD: 75% of patients with dementia and 43% of patients with mild cognitive impairment suffer from such symptoms (Lyketsos et al. 2002). Many studies have identified the caregiver's heavy burden, stress, and mental strain as well as his/her need for support and services (Mittelman et al. 1996; Dello Buono et al. 1999; Eloniemi-Sulkava et al. 2002). Nevertheless, the families of dementia patients are often reluctant to use services offered (Toseland 2002; Zarit and Leitsch 2001; Ganzer and England 1994; Dello Buono et al. 1999; Nankervis et al. 1997).

Officially organized services are typically taken into consideration when informal services, usually provided by the closest, are no longer available or only in crisis situations (Nankervis 1997). Families may have insufficient information about services available (Dello Buono et al. 1999; Toseland et al. 2002), and may previously have experienced disappointment with, for example, health care workers inadequately trained to cope with patients with AD; such health care workers are equally puzzled such families' failure to accept the services offered them (Dello Buono 1999; Zarit and Leitsch 2001). Such families, who very highly value autonomy, privacy, and dignity in their very stressful situations, seek a more flexible service system with the potential to influence the services offered them (Malone Beach et al. 1992; Nankervis 1997; Saarenheimo 2007).

3.4.4.2 The Finnish social service system

In Finland, both local and state authorities officially offer different social services to such families. Local authorities offer financial support to caregivers on the basis of the application submitted. Skilled home nursing and other practical daily services fall under the responsibility of the local authorities. Support from the state is administered by the Social Insurance Institution under the authority of the Ministry of Social Care and Health. This support is provided on the basis of an application for reimbursement of AD medication (donepezil, galantamine, rivastigmine, and memantine) from a special caring pension for the person with AD who requires extra help, guidance, or supervision, and who may also incur high costs because of the disease. In addition to these, various organizations, such as chemists, tax authorities, police, private medical centers, and administrative councils, handle a range of other services (Eloniemi-Sulkava et al. 2006) (Figure 2).

Because the long-term use of medication for AD is costly for the family, most individuals exercise their legal right to receive compensation for drug costs from the state. To apply for such compensation, every patient must submit a statement from a specialist doctor (neurologist, geriatrician, or psychogeriatrician) to the Social Insurance Institution. Reimbursement of drug costs is approved only if AD has been properly diagnosed. Thus, each patient must undergo proper diagnostics, which include neuropsychological tests or at least the Mini Mental State Examination, laboratory tests, and a CT or MRI scan of the brain in addition to proper anamnesis of the patient and of someone close to him/her as well as a physical examination by a doctor.

3.4.4.3 Impact of the unmet needs of care-giving families on persons with AD

Unmet needs and dissatisfaction with services are common (Dello Buono et al. 1999; Nankervis et al. 1997), more so among families caring for dementia patients than among caregivers of non-demented patients (Philp et al. 1995). In the EUROCARE cross-national survey (N = 280), formal home care received or financial support had no impact on caregivers' burden (Schneider et al. 1999). Only a few large-scale studies have examined the impact of unmet needs on families with Alzheimer patients. A US study of 4 761 families with dementia sufferers suggested that early utilization of community-based services was cost-effective and delayed institutionalization (Gaugler et al. 2005a). An 18-month longitudinal study of 5 831 families with dementia sufferers found that unmet needs were associated with an increase in nursing home placements, deaths and lack of follow-up visits (Gaugler et al. 2005b). To date, no large-scale epidemiological studies have investigated the unmet needs of specific services among care-giving families of persons with AD.

3.4.5 Guardianship and use of financial powers of attorney among persons with AD

3.4.5.1 Legal capacity and AD

Dementive disorders lead to a decline in cognitive capacity. Caregivers and those closest to the dementia sufferer – usually inadvertently – assume responsibility for financial and other legal affairs even before diagnosis. The patient's weakening cognitive capacity is not an all-or-nothing situation. In the mild stages of dementia, a person is usually able to understand the meaning and consequences of legal matters. In the moderate stages, however, the decline begins such that most persons in the severe stages of dementia are considered incapable of decision-making in legal matters (Mäki-Petäjä-Leinonen 2003).

Legislation varies among the different European countries. According to Alzheimer Europe, a European association of AD, Austria, Germany, Denmark, and Finland are regarded as having sufficient legislative flexibility to accommodate changes in patients' needs. Guardianship laws in Finland and Denmark emphasize self-determination and the need to respect the wishes of the incapable person, a view which Alzheimer Europe also recommends (Gove and Georges 2001).

Incapacity in decision-making has received relatively little empirical study as lawyers mostly concentrate on interpretations of law. One US study examined this issue among nursing home patients and found that incapacity in decision-making is quite high (44-69%) (Kim et al. 2002). Most care-giving families lack sufficient information on how to appraise these problems in their everyday life (Wadley et al. 2003). Families expect the doctor to take the initiative (Markson et al. 1997). Guidelines for such medico-legal situations currently exist in the US (Overman and Stoudemire 1988) and UK (Lord Chancellor's Department 2003; British Medical Association and Law Society 2004). Finland, however, as yet has no specific guidelines for such matters.

3.4.5.2 Guardianship and AD

AD is the most common reason for guardianship orders (Wattis et al. 1990). Guardianship is usually needed to handle financial arrangements, but sometimes decisions concerning a patient's place of residence while the disease develops as well as specific treatment decisions, such as end-of-life care, can be notable (Caralis 1994; Kane 2001; Wattis et al. 1990). Guardianship is often necessary when a patient loses cognitive capacity and refuses help (Wattis et al. 1990).

One US study has examined the use of guardianship by interviewing caregivers of nursing home patients. The researchers concluded that most of the caregivers were familiar with the term guardianship, and nearly a quarter (23.6%) of nursing home residents had a court-appointed guardian (Janowsky et al. 1993). The largest and to date the only empirical study on the use of guardianship among home-dwellers with AD is an Italian study of a sample of 100 patients. In this sample, none of the patients with mild-stage dementia had a guardian, while 11.5% of those with moderate-stage, and 10.4% of those with severe-stage dementia did. The researchers recommended national guidelines and emphasized the importance of discussions with a doctor as soon as possible after the diagnosis of dementia (Ruggieri et al. 2003). No other earlier large-scale studies exist on the prevalence of guardianship use or on factors related to the need for guardianship.

3.4.5.3 Financial powers of attorney and AD

One of the most sophisticated way to handle financial matters for a person with AD is with a financial power of attorney, when made by the person him/herself prior to the decline in his/her legal competency. This method is also often recommended among lawyers because guardianship is a much more comprehensive form of control and is difficult to revoke (Mäki-Petäjä-Leinonen 2003). Nevertheless, enacting financial powers of attorney is difficult arrangement with related conflicts inside the family or when the person with dementia distrusts those close to her/him. Although paranoia may sometimes arise, the financial exploitation of elderly persons with dementia does occur, which should be taken into account when considering the sufficiency of powers of attorney. In such situations, including when a person lives alone with no close ones to care for her/him anyhow, financial powers of attorney may not be a good alternative and such a person may require a court-appointed guardian. In the literature contains no empirical clinical studies on the use of financial powers of attorney among persons with dementia.

In Finland, the economic affairs of a person with dementia can in the future be handled with Enduring Powers of Attorney. Then, a person with dementia can arrange his/her financial or other affairs beforehand and, in addition to designating a trusted person, decide on how his/her affairs should be handled when s/he is no longer capable of handling them her/himself. Act of Enduring Powers off Attorney comes into force at 1st November 2007 in Finland.

In conclusion, a decline in decision-making capacity is one symptom of AD, and most guardianship arrangements are made for persons with dementia. Empirical studies on this topic are rare, however, and to date only one rather small Italian study (Ruggieri et al. 2003) has examined the prevalence of guardianship use among home-dwelling person with AD.

4 AIMS OF THE PRESENT STUDY

The primary aim of this study was to explore pitfalls in the treatment and care of persons with dementia in order to identify possible new solutions or ways to approach these clinically important matters.

The specific aims were:

1. To study the impact of weight-bearing restrictions on the rehabilitation outcome of elderly hip fracture patients with and without dementia. (Study I)
2. To examine the use of inappropriate drugs (according to the Beers criteria) among institutionalized elderly patients with and without dementia, and their impact on two-year mortality and the use of health services. (Study II)
3. To investigate the impact of atypical and conventional antipsychotics on mortality and on hospital admissions among elderly institutionalized patients with dementia over a two-year follow-up period, and to compare their prognosis to that of non-users. (Study III)
4. To explore how the spousal caregivers of home-dwelling dementia patients receive support and services and how these services meet the caregivers' needs. (Study IV)
5. To examine the prevalence of court-appointed guardians or financial powers of attorney among persons with AD or both, and the factors associated with them as well as whether such persons with AD and their spousal caregivers discussed or felt the need to discuss such issues with a doctor or both. (Study V)

5 THE PRESENT STUDY

5.1 Subjects and methods

5.1.1 Hip fracture patient sample in the Päijät-Häme area (Study I)

The data for Study I, which explores the impact of weight-bearing restrictions on hip fracture patients, were collected in the Päijät- Häme area of Southern Finland. All the patients (N = 98) underwent surgery at the Päijät-Häme Central Hospital and were transferred to the local Lahti City Hospital for rehabilitation between 1998 and 1999. Patients from long-term care, provided they had a hip fracture and underwent rehabilitation in the same hospital, were also included. Totally bedridden patients were excluded. All patients were able to walk independently with or without aids prior to the hip fracture.

Medical records were used in collecting information on patient characteristics and their outcome data. Those with dementia (N = 36) were sub-analyzed. Dementia was defined as performing poorly (≤ 24/30 points) on the Mini Mental State Examination (Folstein et al. 1975, Tombaug et al. 1992). We excluded those lacking an MMSE test score and those with delirium or other serious, acute illnesses causing acute cognitive disorders. Independent walking ability with or without aids within six weeks and the mean number of active rehabilitation days with a consulting physiotherapist served as the main outcome measures.

5.1.2 Sample of institutionalized elderly patients in Helsinki (Studies II and III)

5.1.2.1 Participants

Study II, which examined the prevalence and prognostic significance of inappropriate medication use (according to the Beers criteria) in Finland, and Study III, which examined the prognostic significance of antipsychotics, both comprised a sample of patients from seven acute wards of two geriatric hospitals (Laakso hospital and Kivelä hospital, N = 230) and from thirteen wards of seven nursing homes (Apollo, Lilla Apollo, Mariankoti, Pikku-Maria, Minervakoti, Villa Näset, and Villa Kälkestad, N = 195) in Helsinki (total N = 425). The mean age of the patients was 86 years. Detailed interviews and observations of the patients were carried out in this two-year longitudinal study, which was originally designed to investigate symptoms of delirium in long-term care among the elderly (Laurila et al. 2003). All consecutively admitted patients in acute geriatric hospitals (November 1999 to March 2000) and all residents of nursing homes (November 1999 to October 2000) during the study period underwent assessment. Coma and age < 70 years were the only exclusion criteria.

5.1.2.2 Examinations

Examination comprised an extensive patient interview, various mental tests, and data were collected from medical records and nurses' notes as well as from caregivers' and nurses' interviews conducted by two geriatricians (Jouko Laurila and Kaisu Pitkälä) in acute geriatric wards and by ward nurses in nursing homes (Laurila et al. 2003). The assessment included the patient's history, a physical examination, and a determination of mental status with MMSE (Folstein et al. 1975), the digit span test, and parts of the Wechsler adult intelligence scale (Wechsler 1958) suitable for assessing abstract thinking, comprehension, judgment, and problem-solving, the Clinical Dementia Rating Scale (CDR) (Charlson et al. 1987), and DSM-IV criteria for delirium and dementia (American Psychiatric Association 1994). To confirm the patients' pre-assessment cognitive status, comorbidities, symptoms, and signs, all of the patients' caregivers were interviewed. Medical records provided data on demographic variables, place of residence, and comorbidities. We also used the Charlson comorbidity index, a weighted index that takes into account the number and severity of comorbid conditions (Hughes et al. 1982) and assessed dependence in activities of daily living (ADL) with the CDR class "Personal care": CDR class 1 or higher ("Requiring at least prompting or assistance in dressing, hygiene, managing personal effects, or requiring much help with personal care, often involving incontinence") was defined as dependence in ADL (Charlson et al. 1987). The caregivers of all of the patients were interviewed in order to estimate the patients' status according to the CDR.

5.1.2.3 Definition of dementia

Global assessment of dementia (definite or highly probable) among patients in acute geriatric wards and in nursing homes was based on consensus among three geriatricians (Jouko Laurila, Kaisu Pitkälä, Timo Strandberg) with the aid of all the information gathered. Prior diagnoses of dementia and the adequacy of their diagnostics were assessed from medical records. The CDR and the operationalized dementia criteria (according to the DSM-IV) served to support the diagnoses of dementia. The nurses or caregivers or both were interviewed with regard to the patients' previous cognitive performance and physical functioning. Results of the brain CT/MRI scan (36% of the patients), EEG (3% of the patients), and previous MMSE scores (32.5% of the patients) – if any of these three tests were performed – were registered.

5.1.2.4 Diagnosis of delirium and use of restraints

Delirium was explored in detailed examinations of all present symptoms and signs at the time of the investigation, and was operationalized using the delirium criteria of the Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV) (American Psychiatric Asssociation 1994). Medical records provided data on the use of restraints, meaning whether a patient had been physically restrained in a bed or geriatric chair during the two weeks prior to assessment.

5.1.2.5 Mortality and hospital admissions

Central registers were used for gathering the mortality and death dates at the end of 2002 such that each subject had a two-year follow-up period. Medical records from all area hospitals provided data on admissions to acute geriatric hospitals based on the index hospitalization and the days spent there after the assessment. The acute geriatric hospitals in this study serve a population of about 200 000 inhabitants, and mainly treat elderly subjects with acute illnesses and in need of rehabilitation. Residents from nursing homes may also receive temporarily treatment in these hospitals for various acute illnesses.

5.1.2.6 Study II

Medical records were used to estimate the use of medication (Pitkälä et al. 2004). We used the Beers criteria 1997 for coding medications because these criteria were available and familiar to clinicians at the time, but used the criteria 2003 for examination; we examined only those medications in regular daily use, and used only diagnosis-independent Beers criteria rather than criteria that included drug-disease interactions. For safety reasons, several drugs in the Beers criteria were unavailable in Finland between 1999 and 2000, namely because more effective drugs were available. Those drugs included phenylbutazone, pentazocine, trimethobenzamide, methocarbamol, carisoprodol, chlorzoxazone, metaxalone, cyclobenzaprine, flurazepam, chlorpropamide, dicyclomine, hyoscyamine, propantheline, belladonna alkaloids, chlorpheniramine, difenhydramine, cyproheptadine, promethazine, tripelennamine, dexchlorpheniramine, meperidine, and ticlopidine. Treatment with difenhydramine requires special permission, which makes its use in Finland quite rare. Tioridazine, which the Beers criteria (2003) list as a PID, is no longer available in Finland.

5.1.2.7 Study III

Data on medication use were collected from medical records at baseline between 1999 and 2000 (Pitkälä et al. 2004). The baseline examination of drugs was cross-sectional, and no data were available on the withdrawal or subsequent re-administration of medications during the two-year follow-up period. In Study III, we examined only those antipsychotics that were in regular use. Antipsychotics were coded and classified as follows: atypical antipsychotics included risperidone and olanzapine. None of these elderly patients used quetiapine, aripiprazole, ziprasidone, or clozapine between 1999 and 2000. Haloperidol, levomepromazine, melperone, sulpiride, zuclopenthixol, flupentixole, perphenazine, pericyazine, promazine, chlorpromazine, and chlorprothixene were classified as conventional antipsychotics. One patient taking both atypical and conventional antipsychotic medication was excluded from the analyses. Our sample then comprised 424 subjects, 254 of whom had dementia.

5.1.3 Sample of the caregivers of patients with AD in Finland (Studies IV and V)

5.1.3.1 Participants

The Social Insurance Institution of Finland maintains a register of Alzheimer drug users from which we collected our random sample (N = 1 943). Each person with AD in that register had been approved for compensation of AD drugs and had a spouse living at the same address. A postal questionnaire was sent to such spouses living in five urban and non-urban regions (Helsinki, Tampere, Central Finland, Northern Karelia, and Lapland and Northern Osthrobothnia) representative of various parts of Finland. Our study used no age criteria.

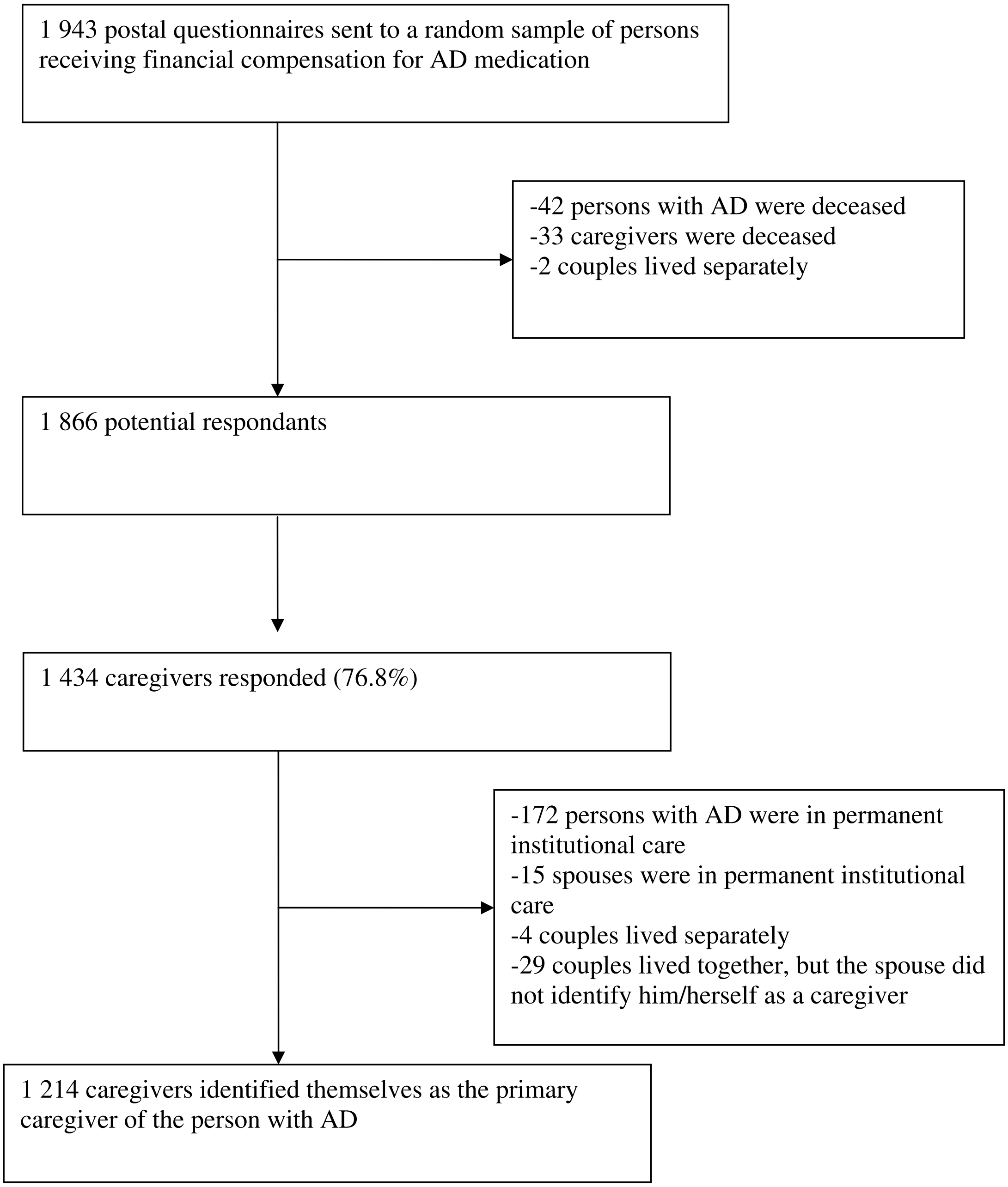
5.1.3.2 The Finnish drug compensation strategy for persons with AD

The Ministry of Social Care and Health in Finland has obligated the Social Insurance Institution to consider all grounds for AD drug (donepezil, galantamine, rivastigmine, and memantine) compensation. Most individuals apply for compensation from the state to cover the high costs of these drugs. Each application must include a statement from a specialist doctor (a neurologist, geriatrician, or psychogeriatrician), and financial reimbursement is approved only if AD has been properly diagnosed. Thus, each patient must undergo diagnostics, which include neuropsychological tests or at least the Mini Mental State Examination, laboratory tests and a CT or MRI scan of the brain.

5.1.3.3 Sample of the spousal caregivers of persons with AD

Mortality registers served to remove participants no longer living (N = 77), and two couples who, according to current address information, lived separately (Figure 3). Questionnaires were sent in September 2005 (Appendix 1) and were resent in November 2005 to those spouses who had not responded. In all, 77% (N = 1 434/1 866) returned the questionnaire. Of these, 1 214 spouses identified themselves as the primary caregiver of the spouse with AD. Of those who did not consider themselves caregivers (N = 220), a majority had already admitted their spouse to permanent institutional care (N = 172) (Figure 4). Because the caregivers were also old and sick, 15 potential caregivers had themselves

Figure 3. Data collection from the postal survey of Finnish spousal caregivers of persons with Alzheimer's Disease, autumn 2005



been admitted to permanent institutional care. Four couples announced that they lived separately. Only a minority of possible caregivers having a spouse with AD at home (N = 29) failed to identify themselves in such a role; most of these (N = 27) were in even poorer health than the person with AD.

5.1.3.4 The questionnaire

Our questionnaire inquired about demographic variables, the physical and psychological symptoms of the spouse with dementia, the support and services received by the family from the official service system, and the caregivers' subjective needs and satisfaction with these services (Appendix 1). To ensure that our questions were easy to understand, the questionnaire was piloted with ten elderly spousal caregivers. Several large scale epidemiological surveys of the elderly had previously validated many of the questions in our questionnaire (Pitkälä et al. 2001; Routasalo et al. 2006; Savikko et al. 2005). A lawyer specializing in matters relating to people with dementia examined those questions inquiring about the use of and need for legal advice. All the spouses were offered the possibility to phone one geriatrician (MR) if they had a question or concern about the questionnaire. This phone call service was available from September to December 2005, the end of the data collection period.

The demographic variables consisted of questions concerning both the caregiver and his/her spouse: their age, gender, duration of their marriage, education, and income. Answers to questions about the subjective health of the caregiver were divided into two categories: 1) good (subjective health good or fairly good) or 2) poor (subjective health poor or fairly poor). The time from the first symptoms of impaired memory of the spouse with AD was inquired with the question "In your opinion, when did your spouse's first symptoms of memory impairment or dementia begin to appear?" with the following alternatives: 1) under one year, 2) one to two years ago, 3) three to four years ago, and 4) five or more years ago. These responses were then categorized into two groups: less than two years ago (responses 1-2) and more than two years ago (responses 3-4). Physical functioning was inquired with "What is your spouse's capability in daily activities?" with the following response choices: 1) very good, 2) good, 3) moderate, 4) poor, 5) very poor. These responses were then categorized into the following two groups: good to moderate (responses 1-3) and poor (responses 4-5).

The mobility of the spouse with AD was inquired by asking whether he/she was able to walk indoors without difficulty; the answers were categorized as "able to walk indoors without aid" (1 = yes) and "requires aid when walking indoors" (2 = no, requires a stick or walking aid; 3 = no, requires the aid of another person, and 4 = no, cannot walk at all). The incontinence of the spouse with AD was inquired with the question "Does your spouse experience urinary or bowel incontinence?" with a yes/no option. The need for a caregiver's assistance and continuous presence was inquired with the question "Does the care of your spouse require your continuous presence?" with a yes/no option. Questions about hallucinations, depression, and the agitation of the spouse with AD were drawn from the Neuropsychiatric Inventory (NPI) (Cummings et al. 1994) with yes/no answers.

The need for a caregiver's assistance and continuous presence was inquired with the question "Does the care of your spouse require your continuous presence?" with a yes/no option. Difficulties with cooperation were inquired with "Do you encounter situations when your spouse refuses to cooperate or does not accept help?" with answers yes/no. Strain in care-giving was inquired with two questions "Do you consider care-giving mentally/physically demanding work?" with a yes/no answer. Medico-legal issues, such as financial powers of attorney and the use of legal guardians and discussions, or need for them, with a doctor, were inquired with a question requiring a yes/no answer. The use of various official services in Finland and the subjective need for them were inquired with yes/no questions. We also asked whether the caregivers found it easy to obtain information about available services. Finally, the caregivers' satisfaction with available services and their ability to influence what services they received were inquired with yes/no questions.

5.1.3.5 Official services for caregiving families

In Finland, caregivers who devote several hours of work to daily care-giving are legally entitled to financial support from the community. Families must apply for this support, however, but after submitting an application, a social nurse carries out a home-visit and evaluation. Before any official services are provided for the family, a social or health care worker must approve their need beforehand. The communal service system offers a wide range of services (skilled home nursing, domestic help, meals on wheels, physiotherapy, day care, respite care, etc.). Communities also offer transport services if using public transportation is impossible or too difficult for the disabled person. Of course, communal services carry a charge, which depends on the income of the care recipient. Various technical devices are free of charge. Finnish World War II veterans, for example, are eligible for state-funded (free of charge) physiotherapy.

5.1.3.6 Study IV

This cross-sectional survey of a random sample of 1 214 spouses identifying themselves as the primary caregiver of their spouse with AD inquired about the symptoms and care needs of the spouse with dementia, official services received, remaining unmet needs, and the satisfaction of the caregivers with regard to the services offered.

5.1.3.7 Study V

This study consisted of a cross-sectional examination of 1 214 caregivers of persons with AD, the prevalence of their use of court-appointed legal guardians or financial powers of attorney, or both, factors related to these, and discussions held with a doctor as well as any unmet need for such discussions.

5.2 Ethical considerations

Study I: As this study examined no additional or new developments in the treatment of patients with hip fractures, written informed consent from the patients or relatives was unnecessary. The study was approved by the local ethics committees of the Lahti City Hospital and the Päijät-Häme Central Hospital.

Studies II and III: After receiving a complete description of the study, each patient provided his/her written informed consent. In cases of poor judgement capacity or moderate cognitive impairment (Mini Mental State Examination [MMSE] (Folstein et al. 1975) score < 20 points), informed consent was obtained from the patient's closest proxy. The study was approved by the local ethics committee of the Helsinki University Hospital.

Studies IV and V: The cover letter of the questionnaire described the aims of the study to the caregivers, who were invited to contact one (MR) of the researchers if they had any questions or concerns about the study. The study design and questionnaire were approved by the local ethics committee of the Helsinki University Hospital.

5.3 Statistical methods

Study I: The Chi-Square test was used to compare proportions and their differences between groups, and the T-test, when comparing means and their differences at baseline**.** The one-sided Mann-Whitney U-test was used to compare median rehabilitation times and their differences.

Study II: Patients with or without dementia were categorized as having PIDs or not. To test for differences in the proportions, we used the Chi-Square test and Fisher's exact test. The Mann-Whitney U-test served for non-normally distributed continuous variables. Among users and nonusers of PIDs, the prognosis was considered as one and two-year mortality. We used the Chi- Square test to compare the proportions of those among PID users who died during the two-year follow-up period to those of non-users. Differences between the groups (days spent in acute hospitals and number of hospital admissions) were analyzed with the Mann-Whitney U-test. To determine the independent prognostic significance of inappropriate drug use on mortality, we used the Cox proportional hazard model. We then constructed unadjusted Kaplan-Meyer curves to illustrate the cumulative rate of mortality between the groups during the two-year follow-up period, and calculated the log-rank test. To determine the effect of PIDs on hospital admissions (patients admitted/not admitted to hospital), we used logistic regression analysis with the following covariates: age > 85 years, sex, education < 7 years, comorbidity (Charlson Comorbidity Index > 2), dementia, placement in a nursing home versus a hospital, number of medications without PIDs, and functional impairment (CDR "personal care" ≥ 1).

Study III: We compared the characteristics of the patients, both with and without dementia, with the Chi-Square test. Patients with dementia were categorized into three groups: those using atypical antipsychotics or conventional antipsychotics or both or neither. We used the Chi-Square test to test for differences in proportions, and the Kruskal-Wallis test for testing the non-normally distributed continuous variables. To study the prognosis of demented patients using atypical or conventional antipsychotics or both and of those using neither, we created two endpoints: 1) two-year mortality and 2) hospital admission or death (a combined endpoint). We compared the proportions of these groups with the Chi-Square test, and used the Cox proportional hazard model to determine the independent prognostic significance of the use of atypical or conventional antipsychotics on mortality in comparison to that of non-users. As covariates, we used age over 85, gender, delirium, dementia, comorbidity (Charlson index > 2) (Charlson et al. 1987), functional impairment (CDR class in personal care > 1) (Hughes et al. 1982), the number of medications, and the use of restraints. We constructed unadjusted Kaplan-Meyer curves to illustrate the cumulative rate of mortality between the groups during the two-year follow-up period, and calculated the log-rank test.

Study IV-V: The characteristics of the spouses with AD and their caregivers were cross-tabulated according to the caregiver's gender. To test differences between the categorical variables, we used the Chi-Square test. The Mann-Whitney U-test and the Kruskall-Wallis test served for non-normally distributed variables.

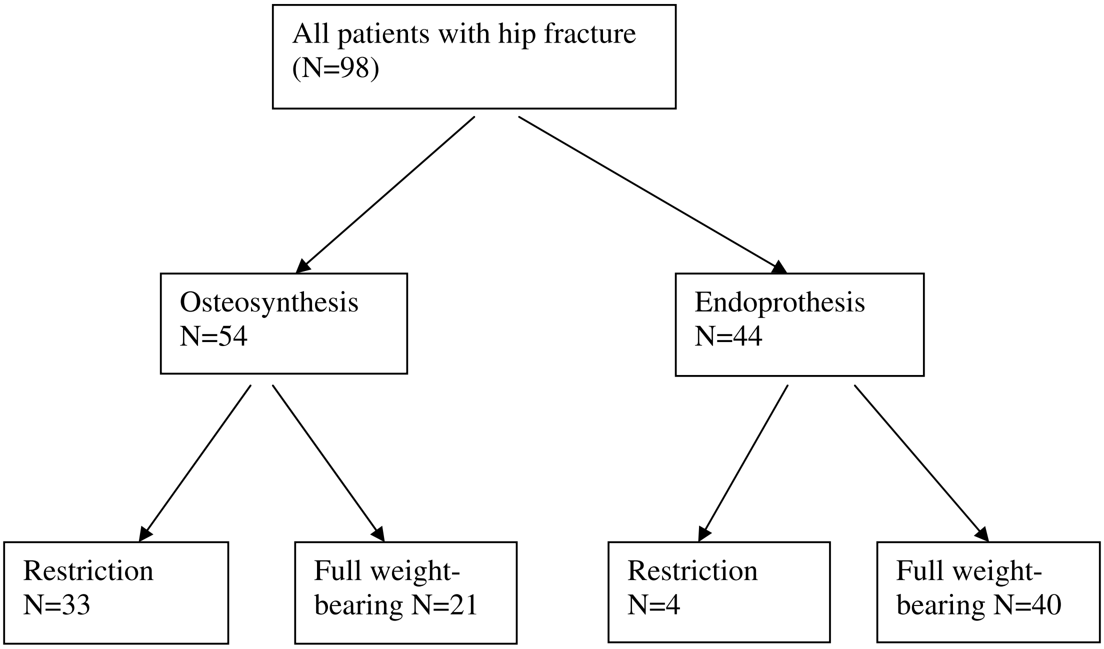
Data in all studies were analysed with the NCSS for Windows statistical program (www.ncss.com) and P values < 0.05 were considered significant.

6 RESULTS

6.1 Clinical pitfalls in the postoperative rehabilitation of hip fractures in persons with AD (I)

The study sample comprised 98 patients with hip fractures who underwent surgery at the Päijät-Häme Central Hospital. Postoperative rehabilitation took place at the Lahti City Hospital. Doctors recommended postoperative weight-bearing restrictions for 37 patients, mostly after osteosynthesis (33 patients, 89%), while only 4 patients (11 %) had endoprothesis (Figure 4). The ean age of the patients was 80.2 years, and most of them (72.4 %) were female.

Figure 4. All hip fracture patients according to operation type and restriction orders



The active rehabilitation time was significantly longer among patients with weight-bearing restriction than among those allowed to walk normally immediately after surgery. While 84% of patients in the non-restriction group learned to walk independently in six weeks, less than half of those (41%) in the restricted group were able to do so ($p < 0.001$) (Table 3).

Table 3. Outcome data by weight-bearing restriction for all hip fracture patients who underwent surgery

Variable	Restriction N = 37	No restriction N = 61	p
Mean number of rehabilitation days (range)	53.1 (5 to 142)	38.4 (9 to 102)	0.03 [1)]
Learned to walk in six weeks (%(N))	41(15)	84 (51)	< 0.001 [2)]
Discharged (%(N))			
Home	81 (30)	80 (49)	
Institution	19 (7)	20 (12)	0.93 [2)]
Deceased within one year (%(N))	16 (6)	23 (14)	0.42 [2)]

[1)] Differences between medians by one-sided Mann-Whitney U-test

[2)] Differences between proportions by X^2 test

Of the 98 patients, 36 met the specified criteria for dementia (MMSE points ≤ 24/30). Their mean age was 83.5, most were female (N = 30, mean age 83.3), and only 6 were male (mean age 84.6). Most of the patients with dementia (81%) were living at home prior to the fracture. After the hip fracture, surgery, and rehabilitation, only half of them (56%) could return to live in their own home again, while 44% required permanent institutional care.

Of those with dementia, the mean rehabilitation period in the weight-bearing restriction group was significantly longer than that of the non-restricted group. Of the 24 in the non-restricted group, 20 learned to walk in six weeks, but only 1 of the 12 in the weight-restricted group learned to walk again ($p < 0.001$) (Table 4). The patients' capacity to walk again had a significant effect on institutionalization and one-year mortality in the whole group (Table 5).

Table 4. Outcome data on patients with dementia according to weight-bearing restrictions after hip fracture surgery

Variable	Weight-bearing restriction (N = 12)	No restriction (N = 24)	p
Mean rehabilitation time (days (range))	73.5 (27-142)	45.1 (9-58)	0.03 [1)]
Learned to walk in six weeks (%(N))	8.0 (1)	83.8 (20)	< 0.001 [2)]
Discharged (%(N))			
Home	50.0 (6)	58.3 (14)	
Institution	50.0 (6)	41.7 (10)	0.64 [2)]
Deceased within one year (%(N))	25.0 (3)	20.8 (5)	0.78 [2)]

[1)] Differences between medians by one-sided Mann-Whitney U-test

[2)] Differences between proportions by X^2 test

Table 5. Outcome data on all hip fracture patients by their capacity to learn to walk within six weeks after hip fracture surgery (N = 98)

Variable	Learned to walk N = 66	Did not learn to walk N = 32	p [1)]
Discharged (%(N))			
Home	81.8 (54)	40.6 (13)	
Institution	18.2 (12)	59.4 (19)	< 0.001
Deceased within one year (%(N))	6.1 (4)	34.4 (11)	< 0.001

[1)] Differences between proportions by X^2 test

6.2 Possible pitfalls in the use of medication in patients with AD

6.2.1 Use and prognostic significance of inappropriate medication among hospital and nursing home patients (II)

According to the geriatricians, 60% (255) of the 425 patients in this sample were demented. The patients with dementia were mainly female (85.5% vs 75.9%, $p = 0.012$), had more comorbidities (Charlson comorbidity index > 2, 42.4% vs 30.6%, $p = 0.014$), and were more dependent on their ADL (CDR "personal care" ≥1, 76.9% vs 21.2%, $p < 0.001$) than were those without dementia. No differences in mean age were observed between patients with and without dementia. Most dementia patients suffered from severe dementia (mean MMSE 9.9) and 76.9% had a CDR of 2 or 3. Polypharmacy was common, since the mean number of medications in the whole population (9.0) was higher among patients without dementia than among those with dementia ($p = 0.02$). Only two patients in the entire population took no regular medication.

One third (36.2%) of all patients took at least one PID (according to the Beers criteria, 1997) daily. Most (28.7%) took only one, 5.9% two, and 0.9 % three. A total of 36.9% of those with dementia, and 35.3% of those without dementia, were on at least one PID. Among those with dementia, no significant differences appeared between those with or without PIDs in gender, age, marital status, educational level, Charlson comorbidity index, or dependence on ADL. Among the patients without dementia, only the mean number of medications was higher among patients on PIDs than among those without. Baseline characteristics of patients with dementia appear in Table 6.

Table 6. Baseline characteristics of patients with dementia and the use of potentially inappropriate drugs (PID)

	Patients with dementia (N = 255)		
%	On inappropriate medication (N = 94)	No inappropriate medication (N = 161)	P-value[1]
Females	83.0	87.0	0.38
Age > 85	57.0	61.9	0.44
Education < 7 years	55.3	61.5	0.33
Mean number of medications (SD)	8.6 (3.0)	7.7 (3.1)	0.04
Charlson comorbidity index > 2[2]	46.8	39.8	0.27
Dependence on ADL (CDR "personal care" ≥ 1)[3]	76.6	77.0	0.94

[1] Differences between users and nonusers of PIDs among patients with dementia tested with the X^2 test for categorical variables and the Mann-Whitney test for continuous variables

[2] Charlson et al. 1987

[3] Hughes et al. 1982

SD = Standard deviation

By far the most common inappropriate medication among all patients was temazepam, which, at a dose of 20 mg daily, was in wide use as a hypnotic among institutionalized patients. Among patients with dementia, the most common PIDs were high-dose temazepam (13.3%), oxybutynin (5.5%), dipyridamol (4.3%), and hydroxyzine (3.5%), while among those without dementia, the most common PID was high-dose temaxepam (14.7%), amitriptyline (4.7%), dipyridamol (4.1%), and oxybutynine (2.9%). No differences in the proportions of PIDs were observed among these groups, except for amitriptyline, which was significantly more commonly used among patients without dementia (p = 0.011) (Table 7).

The use of PIDs showed no impact on two-year mortality, acute hospital days, or the number of hospital admissions among patients with or without dementia. This result showed no change even when we performed another analysis with high-severity PIDs (Beers et al. 1997). The results for patients with dementia appear in Table 8. Mortality curves were similar across time among PID users and non-users (Figure 6).

We also performed additional analyses to determine whether mortality would differ between PID users (N = 175) and non-users (N = 250), according to the latest Beers 2003 criteria (Fick et al. 2003). No significant differences were observed between the users (1-year mortality 25.1%, 2-year mortality 48.6%) and the non-users (1-year mortality 24.8%, 2-year mortality 45.2%) in our sample. According to the Beers criteria (2003), 41.2% of Finnish nursing home and hospital patients received PIDs.

Figure 6. Survival of users (N = 154) and non-users (N = 271) of PIDs in the whole population during two-year follow-up, P = 0.856

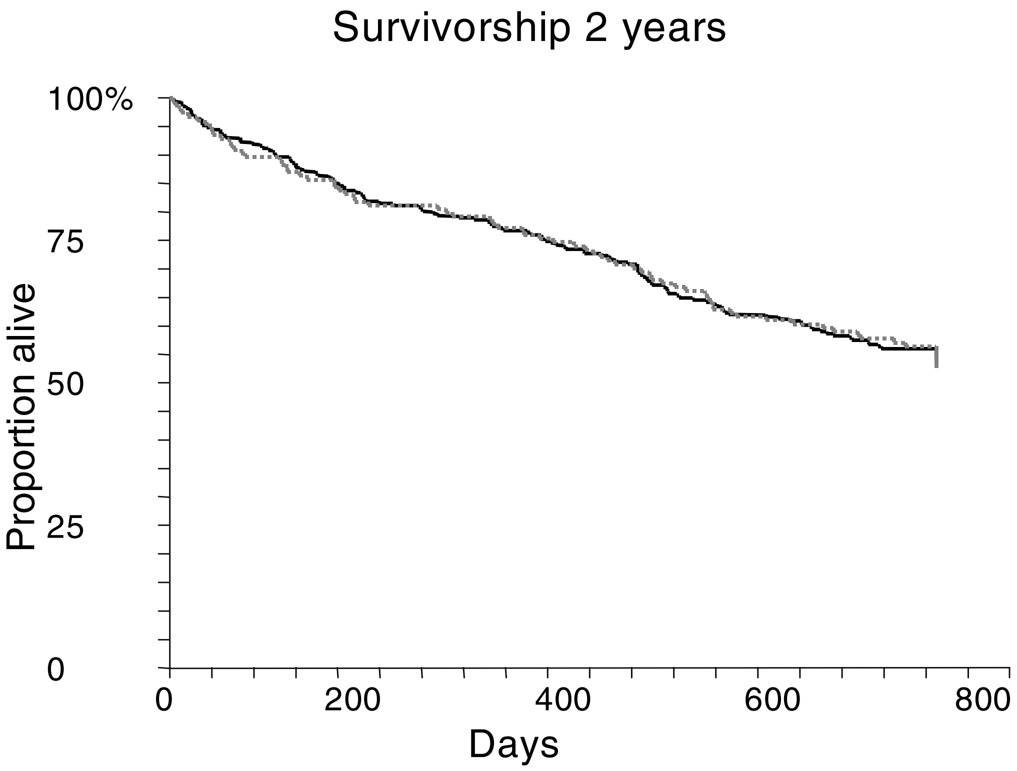


Table 7. Use of inappropriate drugs (according to the Beers criteria fully applied)[1] (Beers et al. 1997) among those with and without dementia

Medication % (n)	Summary of prescription concerns (according to Beers)	Patients without dementia (N = 170)	Patients with dementia (N = 255)	P-value[1,2]
Propoxyphene and combination products	Little analgesic advantage over acetaminophen, yet has the side-effects of other narcotic drugs	0.6 (1)	0.8 (2)	1.00
Indomethacin	Central nervous system side-effects	None	None	
Methocarbamol, carisoprodol, oxybutynin, chlorzoxazone, metaxalone, cyclobenzaprine	Anticholinergic side-effects, sedation, and weakness. Effectiveness at doses tolerated by the elderly is questionable	2.9 (5)	5.5 (14)	0.24
Amitriptyline	Strong anticholinergic and sedating properties	4.7 (8)	0.8 (2)	0.011
Doxepin	Strong anticholinergic and sedating properties	2.4 (4)	1.2 (3)	0.44
Meprobamate	Highly addictive and sedating anxiolytic	0.59 (1)	0.39 (1)	1.00
Loratzepam > 3 mg, oxazepam > 60 mg, alprazolam > 2 mg, temazepam > 15 mg, zolpidem > 5 mg, triazolam > 0.25 mg	Due to increased sensitivity to benzodiazepines among the elderly, smaller doses may be both effective and safer	14.7 (25)	13.3 (34)	0.87
Chlordiazepoxide, diazepam	Long half-life in the elderly, thus producing prolonged sedation and increasing risk for falls and fractures	1.8 (3)	2.0 (5)	1.00
Disopyramide	Potent negative inotrope may induce heart failure in the elderly	None	0.39 (1)	1.00
Digoxin over 0,125 mg	Decreased renal clearance	0.59 (1)	1.2 (3)	0.65
Dipyridamole	Orthostatic hypotension. Beneficial only in patients with artificial heart valves	4.1 (7)	4.3 (11)	0.86

Methyldopa	Bradycardia and exacerbation of depression	None	None	
Reserpine, reserpine-hydrochlorothiazide	Depression, impotence, sedation, and orthostatic hypotension	None	None	
Dicyclomine, hyocyamine, propantheline, belladonna alkaloids, clinidium-chlordiazepoxide	Highly anticholinergic and generally produce substantial toxic effects	1.7 (3)	None	0.063
Chlorpheniramine, diphenhydramine, hydroxyzine, cyproheptadine, promethazine, tripelennamine, dexchlorpheniramine	Potent anticholinergic properties	1.8 (3)	3.5 (9)	0.42
Diphenhydramine	Potently anticholinergic	None	None	
Hydergine, cyclospasmol	Not shown to be effective	0.59 (1)	0.39 (1)	1.00
Iron supplements over 325 mg	At higher doses, total absorption not substantially increased, but constipation often occurs	None	None	
All barbiturates except phenobarbital	Barbiturates cause more side-effects in the elderly than do most other sedative or hypnotic drugs and are highly addictive	None	None	
Ticlopidine	Not shown to be better than aspirin in preventing clotting, but is more toxic	None	None	

[1] PIDs unavailable in Finland for safety reasons from 1999 to 2000 (according to the Beers criteria 1997): phenylbutazone, pentazocine, trimethobenzamide, methocarbamol, carisoprodol, chlorzoxazone, metaxalone, cyclobenzaprine, flurazepam, chlorpropamide, dicyclomine, hyoscyamine, propantheline, belladonna alkaloids, chlorpheniramine, difenhydramine, cyproheptadine, promethazine, tripelennamine, dexchlorpheniramine, meperidine, and ticlopidine

[2] Differencies between the proportions of PID users among patients with and without dementia tested with the X^2 test or the Fisher exact test

Table 8. Two-year mortality, days in institutions, and the use of potentially inappropriate drugs (PIDs) among patients with dementia

Patients with dementia (N = 255)			
	On inappropriate medication N = 94	No inappropriate medication N = 161	P-value[1]
Number of days in acute hospitals/first year Mean (SD)	22.2 (32.7)	24.9 (38.6)	0.978
Total number of hospital admissions/first year	57	82	
Mean (SD)	0.51 (0.79)	0.61 (0.87)	0.340
Two-year mortality (%)	43.6	47.8	0.515

[1] P values are for differences between users and non-users of PIDs among patients with dementia tested with the X^2 test for categorical variables and the Mann-Whitney test for continuous variables

In the Cox proportional hazard model, using age > 85 y, gender, education < 7 years, comorbidity (Charlson index > 2), dementia, placement in a nursing home vs. hospital, number of medications without PIDs, and functional impairment (CDR "personal care" 1 or more) as covariates, the use of inappropriate drugs had no prognostic significance for mortality (HR 1.02, 95% CI 0.76-1.37, p = 0.89). Age > 85 (HR 1.73, 95% CI 1.27-2.36, p < 0.001) increased two-year mortality while patients residing in nursing homes had a lower mortality than did hospital patients (HR 0.49, 95% CI 0.35-0.69, p < 0.001). We repeated the analysis with the same covariates, but used the number of PIDs as one covariate instead of the use of any PID. This also showed no effect on mortality (HR 1.06, 95% CI 0.84-1.34). We performed a logistic regression analysis on hospital admission with the same covariates, and the use of PIDs had no impact on hospital admission (OR 1.40, 95% CI 0.93-2.11, p = 0.11).

6.2.2 Prevalence and prognostic significance of the use of antipsychotics among hospital and nursing home patients (III)

The mean age of the sample (described previously) was 86 years. One patient was excluded from the sample due to his/her use of both conventional and atypical antipsychotic drugs. Thus the sample comprised 424 patients, of which 254 suffered from dementia. Both atypical and conventional antipsychotics were administered to patients with dementia significantly more often than to those without. A larger proportion of the patients with dementia had been physically restrained during the previous two weeks (12.2%) than of those without dementia (4.7%) (Table 9).

Table 9. Use of antipsychotic medication and restraints according to dementia

%	Patients without dementia (N = 170)	Patients with dementia (N = 254)	P-value [1]
Users of atypical antipsychotics	4.1	11.0	0.011
Users of conventional antipsychotics	17.1	37.4	< 0.001
Physically restrained during previous two weeks	4.7	12.2	0.009

[1] Differences between proportions were tested with the Chi Square test, degrees of freedom 1

About half of the patients with dementia received antipsychotics: 37.4% received conventional, 11% atypical antipsychotics, and 51.6% were non-users. The most commonly used conventional neuroleptics were melperone (40 users) and haloperidol (30 users); the latter was also the most common antipsychotic used “as needed”. Polypharmacy and delirium were significantly more common among patients with dementia receiving antipsychotic medication than among non-users (Table 10). The use of acetylcholinesterase inhibitors (donepezil, rivastigmine, galantamine) in this severely demented sample (mean MMSE 9.9) was rare in 1999-2000: only 3.1% received these drugs. The use of antipsychotic medication had no impact on mortality or on hospital admission or on the combined endpoint of these two (Table 10).

Table 10. Baseline characteristics of the patients with dementia according to their use or non-use of antipsychotic medication

Variable	Users of conventional antipsychotics (N = 95)	Users of atypical antipsychotics (N = 28)	No antipsychotic medication (N = 131)	P-value
Females (%)	82.1	100.0	84.7	0.058 [1]
Age > 85 (%)	57.4	46.4	64.6	0.17 [1]
Education < 7 years (%)	52.0	54.5	49.1	0.86 [1]
Widowed (%)	47.2	54.2	60.3	0.16 [1]
Charlson > 2[3] (%)	45.3	32.1	42.7	0.47 [1]
Dependent in ADL-functioning[4] (%)	82.1	78.6	72.5	0.24 [1]
Delirium[5] (%)	36.8	25.0	18.3	0.007 [1]
Physically restrained during previous two weeks (%)	12.6	17.9	10.7	0.57 [1]
Mean number of medications (SD)	9.5 (3.2)	9.5 (2.6)	7.4 (3.3)	< 0.001 [2]
Deceased within 1 year (%)	17.9	14.3	26.7	0.17 [1]
Deceased within 2 years (%)	45.3	32.1	49.6	0.24 [1]
Mean number of hospital admissions (SD)	0.38 (0.70)	0.54 (0.88)	0.67 (0.87)	0.029 [2]
Hospitalized or deceased within 2 years (%)	58.9	53.6	71.8	0.056 [1]

Differences between proportions were tested with the 1)Chi Square test, degrees of freedom 2; and between means and their differences with the 2)Kruskall-Wallis test, degrees of freedom 2

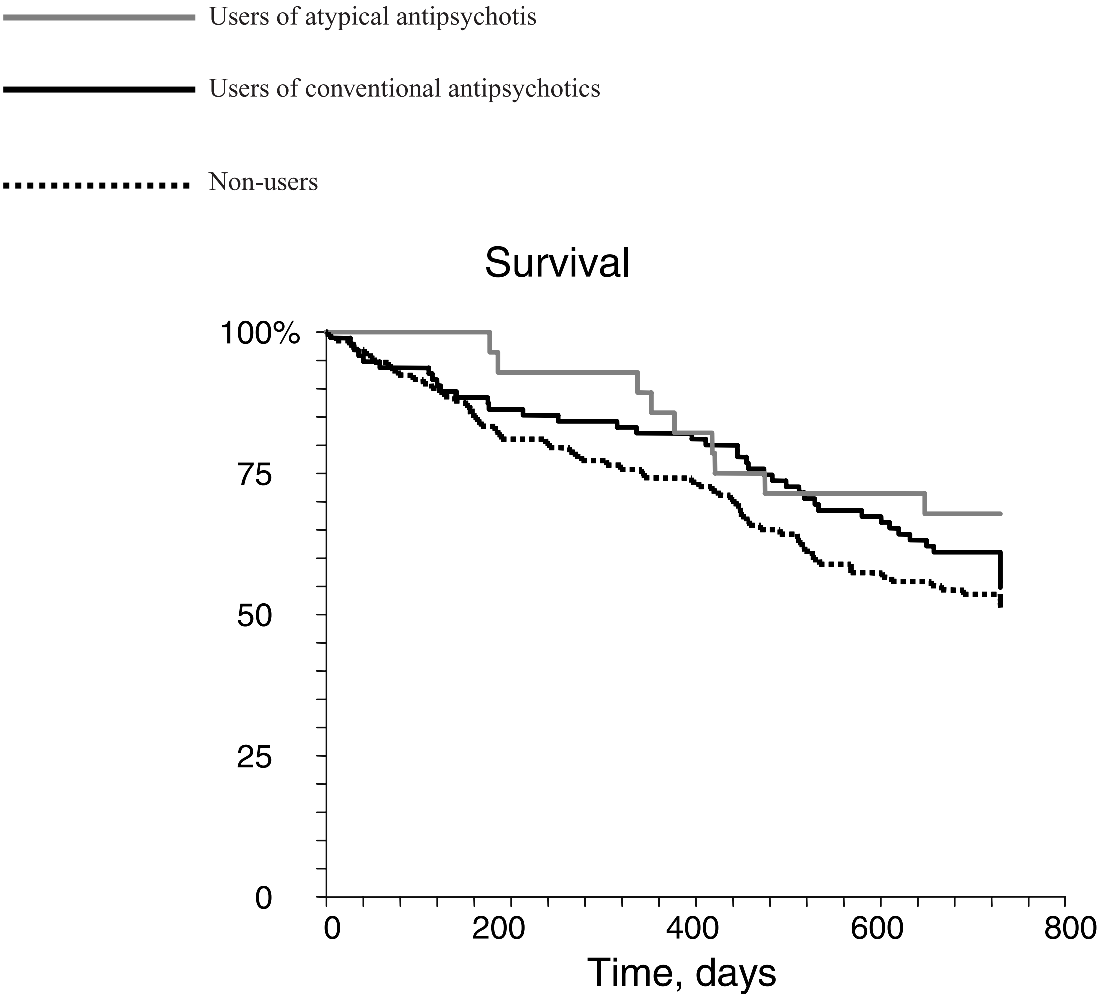
3) Charlson comorbidity index (Charlson et al. 1987)

4) Those classified in CDR “personal care” > 1 (Hughes et al. 1982)

5) Delirium according to the DSM-IV criteria (American Psychiatric Association 1994)

Survival of the users of atypical antipsychotics, of the users of conventional antipsychotics, and of the non-users during the two follow-up years appears in the unadjusted Kaplan-Meyer analysis (Figure 7). The cumulative mortality of all users of antipsychotics compared to that of non-users appears in the Kaplan-Meyer curves (Figure 8). The use of antipsychotic medication had no impact on mortality in our sample.

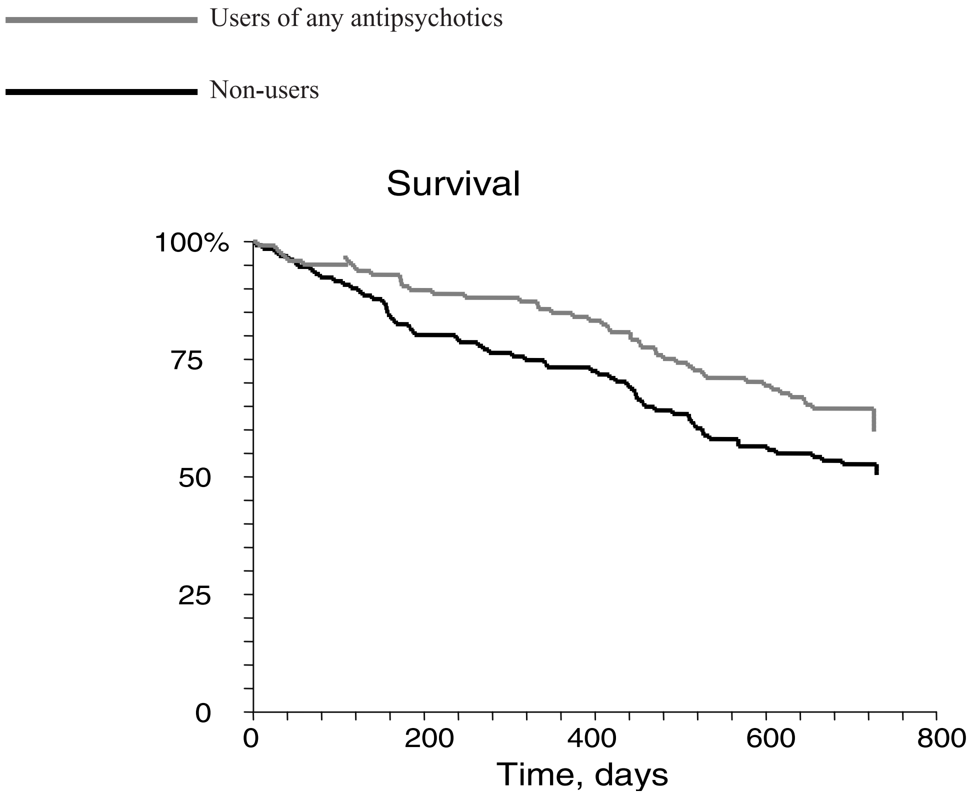
Figure 7. Two-year survival of patients with dementia according to their use of atypical, conventional antipsychotics, and non-use.



Log rank test p = 0.195

(Chi Square = 3.27, df 2)

Figure 8. Two- year survival of patients with dementia according to their use of antipsychotics and non-use.



Log-rank test p = 0.148
(Chi Square = 2.09, df 1)

To clarify which factors had independent prognostic value in mortality at two years, we performed a Cox proportional hazard model. By entering age, gender, delirium, high comorbidity (Charlson index > 2), functional impairment (CDR class in "personal care" > 1), the use of physical restraints, number of medications, and the use of conventional or atypical antipsychotics in the model, and age over 85 years, the high number of medications and the use of physical restraints predicted higher mortality at two years among these patients with dementia. Surprisingly, the use of atypical antipsychotic agents seemed to decrease the mortality risk (HR 0.49 (0.24-0.99), p = 0.047). The effect of conventional antipsychotics was non-significant (Table 11).

Table 11. Selected risk indicators (hazard ratios) for two-year mortality among institutionalized dementia patients

HR (CI)	Patients with dementia (N = 254)	
	Mortality risk at 2 years	P value
Age > 85	1.65 (1.10-2.48)	0.014 [1]
Females	1.21 (0.71-2.05)	0.48
Delirium	1.26 (0.84-1.89)	0.27
Charlson > 2	1.09 (0.75-1.60)	0.65
CDR > 1	0.99 (0.64-1.53)	0.95
Use of restraints	1.72 (1.04-2.83)	0.034 [3]
Number of medications	1.12 (1.05-1.20)	< 0.001 [2]
Use of conventional antipsychotics	0.68 (0.46-1.03)	0.069
Use of atypical antipsychotics	0.49 (0.24-0.99)	0.047

Wald z-tests from a Cox regression:

[1] 3.35

[2] 4.24

[3] 2.18

6.3 Pitfalls in services for persons with AD

6.3.1 Officially organized services and their unmet needs (IV)

The caregivers of spouses with AD were old and often sick themselves (mean age 78.2 years), and one third (35.1%) had poor subjective health. Male caregivers were older than females (80.2 years vs. 76.7 years, $p < 0.001$). As in prior international studies, most of the caregivers were females, but the proportion of male caregivers in Finland was also quite high (37%), especially considering the old age of the respondents. Marriages were very long among female and male caregivers: 52 and 54 years, respectively. Over half of the caregivers and spouses with dementia had received less than seven years of education and most families regarded their income as moderate.

Of the spouses with AD, 40% required continuous support from their caregiver (Table 12). Half of them suffered symptoms of depression, more than two thirds exhibited symptoms of agitation, and almost half (44%) experienced hallucinations. Urinary or bowel incontinence was surprisingly common (46%)

among these home-dwelling spouses with AD. One in three was unable to move indoors without aid. Male spouses with AD experienced significantly more agitation and urinary or bowel incontinence thank did females (Table 12).

Table 12 .Prevalence of symptoms and care needs of Finnish home-dwellers with Alzheimer's disease (AD) according to their spousal caregiver (n = 1 214)

%	Female spouses with AD (N = 452)	Male spouses with AD (N = 762)	All (N = 1 214)	p[1]
Requires aid when walking indoors	33.3	36.2	35.1	0.31
Urinary or bowel incontinence	40.0	48.9	45.6	0.002
Requires the continuous presence of the caregiver	39.3	40.1	39.8	0.77
Symptoms of hallucinations	42.3	44.6	43.8	0.44
Symptoms of depression	51.5	53.7	52.9	0.48
Symptoms of agitation	68.3	73.5	71.6	0.06

[1] Differences in proportions between genders were tested with the Chi Square test, df 1

The services these couples most often received included community financial support for the caregiver (35.9%), various technical devices (33.4%), physiotherapy for the Alzheimer's patient (32.4%), and respite care in a local nursing home for the care recipient (31.1%) (Table 13). Because half of those with AD in our sample were war veterans, 71% of the physiotherapy received was constituted the yearly rehabilitation entitlement for World War II veterans, which is set by Finnish law. Only 14% of those with AD who were not war veterans had received physiotherapy organized by the community. Skilled home nursing and domestic help was rarer than expected: it was offered to only 26% and 15% of the families, respectively. Male caregivers were offered more skilled home nursing, domestic help, house cleaning and meals-on-wheels, whereas female caregivers were more often offered financial support, physiotherapy, transport services, and respite care in a nursing home for the spouse with AD.

Table 13. Proportions among female and male caregivers of spouses with Alzheimer's disease receiving official services and having unmet needs, but not receiving the service in question

Social services	Female caregivers (N = 762)	Male caregivers (N = 452)	All (N = 1 214)	p
Skilled home nursing	20.8	35.7	26.3	< 0.001
- unmet needs	9.7	15.9	11.7	0.008
Domestic help	12.6	18.1	14.6	0.01
- unmet needs	13.3	19.2	15.4	0.013
House cleaning	26.2	33.1	28.7	0.01
- unmet needs	39.0	44.3	39.9	0.14
Meals on wheels	16.6	25.1	19.8	< 0.001
- unmet needs	6.5	15.7	9.6	< 0.001
Physiotherapy for care recipient	37.4	23.9	32.4	< 0.001
- unmet needs	58.1	54.0	56.4	0.25
Technical devices	33.8	32.9	33.4	0.75
- unmet needs	11.3	12.2	11.6	0.73
Transport service	34.0	15.1	27.1	< 0.001
- unmet needs	44.3	32.1	39.1	< 0.001
Day care	19.3	18.4	19.0	0.72
- unmet needs	30.0	29.3	29.8	0.81
Respite care in a nursing home	33.2	27.6	31.1	0.045
- unmet needs	22.6	26.1	24.0	0.26
Home respite	8.3	11.2	9.4	0.10
- unmet needs	39.2	41.2	39.9	0.53
Financial support	38.3	31.8	35.9	0.024
- unmet needs	50.9	48.7	50.0	0.55

Difference in the proportions between genders were tested with the Chi Square test, df 1

The services most desired by those couples who received none of the services in question included physiotherapy for the person with AD (56.4%), community's financial support for the caregiver (50.0%), house cleaning (39.9%), and home respite to provide the caregiver with a few hours of free time (39.9%). Of those already receiving such services, 16.1% to 30.8% needed more of the same service (Table 13).

Only half (53.5%) of the caregivers felt that the official services had responded to their needs in a timely manner. Only 39.3% of the spousal caregivers were satisfied with the services received. Less than a third (29%) of them found it easy to obtain information about available services. The majority of the caregivers (69.4%) felt unable to influence the services they received.

6.3.2 Use of guardianship and financial powers of attorney (V)

The sample was the same as that used in the study of officially organized services. In Finland, the use of guardians was rare: only 4.3 % of the entire sample had made such an arrangement. No gender differences were found between female and male patients (5.1 vs. 3.8, p = 0.30). Patient- related factors associated with the arrangement of guardianship include poor functioning, depression in the patient with AD, symptoms of dementia for more than three years, and cooperation difficulties (Table 13). The couple's level of education or income showed no association with the use of guardianship. The need for continuous care-giving, symptoms of agitation, and urinary or bowel incontinence did not associate with the use of guardians. In contrast to the use of financial powers of attorney, the physical more than the mental strain of care-giving was associated with the arrangement of guardianship (Table 14).

Discussing these arrangements with the doctor was quite rare: only 9.9 % of the couples had done so. However, the need for such discussion with a doctor was common (47.9%). In most of the cases in which guardianship had been arranged, discussion with a doctor had taken place (57.1% vs. 7.6%, p < 0.001) and financial powers of attorney had been organized (83.0% vs.35.7%, p < 0.001). More guardianship arrangements had been carried out among those who had also arranged financial powers of attorney (8.8% vs.1.3%, p < 0.001, Chi Square test, df1).

Table 14. Factors related to the use of guardianship among home-dwellers with Alzheimer's disease (AD) with a spouse caregiver (N = 1 170)

%	Guardianship is arranged (N = 50)	Guardianship not arranged (N = 1 120)	p[1]
Poor functioning	77.5	55.8	0.003
Requires continuous care-giving	46.0	39.5	0.36
Depression	67.3	52.3	0.04
Hallucinations	57.1	43.8	0.07
Agitation	75.0	71.9	0.64
Urinary or bowel incontinence	53.1	45.7	0.31
Cooperation difficulties	61.4	45.4	0.04
Heavy mental strain of care-giving	66.0	61.6	0.53
Heavy physical strain of care-giving	44.7	23.2	< 0.001
Symptoms of dementia > 3 years	88.4	76.7	0.012

1) Differences between proportions were tested with Chi Square test, df 1

Financial powers of attorney were quite common (37.8%); there were no gender differences between female and male patients with AD (35.6% vs. 39.1%, p = 0.23, Chi Square test, df 1). Patient-related factors associated with the arrangement of financial powers of attorney include poor functioning, hallucinations, and urinary or bowel incontinence. Neither the education of the spouse with AD nor of the caregiver or the income of the couple was associated with the use of financial powers of attorney. Exhibiting symptoms of dementia for more than three years was associated with the arrangement of financial powers of attorney, but the need of continuous care-giving, symptoms of depression in the patient with AD, and agitation showed no significance (Table 15).

Table 15. Factors related to the use of financial powers of attorney among home-dwellers with Alzheimer's disease with a spouse caregiver (N = 1 159)

%	Financial powers of attorney arranged (N = 438)	Financial powers of attorney not arranged (N = 721)	p [1)]
Poor functioning	65.9	51.1	< 0.001
Requires continuous care-giving	41.3	39.2	0.47
Depression	55.7	51.6	0.19
Hallucinations	48.6	41.2	0.02
Agitation	75.0	70.2	0.08
Urinary or bowel incontinence	52.8	42.0	< 0.001
Cooperation difficulties	54.0	41.7	< 0.001
Heavy mental strain of care-giving	69.4	57.3	< 0.001
Heavy physical strain of care-giving	32.4	19.0	< 0.001
Symptoms of dementia > 3 years	82.7	74.1	< 0.001

[1)] Differences between proportions were tested with the Chi Square test, df 1

7 DISCUSSION

AD is a long-lasting disease which changes the lives not only of the persons developing the disease, but of those closest to him/her. AD is one of the most common diseases among the oldest of the elderly, and affects about a third of those over 85. As the population ages, the number of persons with dementia has been estimated to increase by about 60% until the year 2030 (Viramo and Frey 2006).

From the point of society, AD may also be the most expensive of diseases, with permanent institutional care, which almost every person with AD requires sooner or later, comprising the bulk of the treatment costs (Viramo and Frey, 2006). Before choosing institutional care, these persons attempt to cope with this disease with the help of their caregivers and by using needed services. This thesis identifies certain pitfalls in our health care and social service system that may affect such persons during the course of their disease (Figure 9).

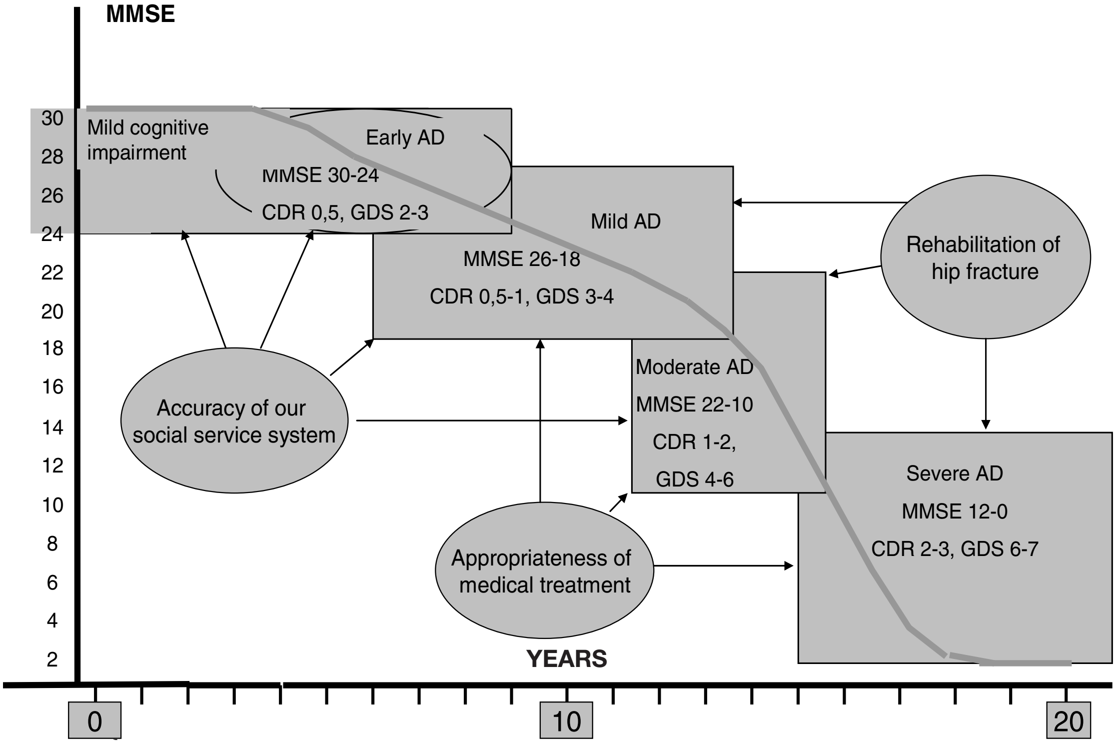
7.1 Rehabilitation of elderly hip fracture patients

Certain clinical pitfalls can be recognized in the rehabilitation of hip fracture patients with dementia. According to our data, the postoperative rehabilitation period is clearly longer among hip fracture patients with weight-bearing restrictions than among those who had no such restrictions. Furthermore, difficulties in learning to walk were very common among all elderly patients with such restrictions regardless of dementia: just under half (41%) learned to walk within six weeks. In addition, weight-bearing restrictions seemed especially harmful among patients with dementia: only 1 of the 12 patients could walk after six weeks.

The most significant factors predicting mortality and long-term disability among patients with hip fracture include age, functional impairment, and comorbidity, and especially dementia (Kennie et al. 1988; Cameron et al. 1993; Huusko et al. 2000; Jette et al. 1987; Gilchrist et al. 1988; Galvard and Samuelsson 1995; Kuokkanen and Korkala 1992; Luethje et al. 1995). Our data are very much in line with these results, as almost half (44%) of our patients with dementia and hip fracture required permanent hospitalization after rehabilitation even though most of them (81%) were home-dwellers before.

Our sample of patients with hip fracture was retrospective, which means that the patients may not have been medically the same at the starting point, which is one limitation of this study. However, our sample could be considered a “real-life” geriatric sample. Organizing large-scale randomized clinical trials on the effect of weight-bearing restrictions would be impossible for ethical reasons. Secondly, our subgroup

Figure 9. Certain clinical pitfalls according to stage of Alzheimer's disease (AD).



Adapted from Reisberg et al Alzh Dis Assoc Disord, 1994, 8

MMSE = Mini Mental State Examination
CDR = Clinical Dementia Rating Scale
GDS = Global Deteriorating Scale/Functional Assessment Staging

of patients with dementia was quite small, and we may have been unable to include all demented patients into that analysis, because the definition of dementia was based only on the MMSE scores available in the medical records. Those with no tests performed or the frailest ones with delirium or other serious illnesses were excluded. However, even in the small group of patients with dementia and with low statistical power, we were able to show significant differences in outcomes between those who did and did not have weight-bearing restrictions. Thirdly, the definition of dementia as having an MMSE score < 24 points may also include delirious patients. With such an orthopedic sample of elderly patients, however, systematically gathering information for definite dementia diagnosis was impossible, so the information available had to suffice. In addition, studies have shown that a great proportion of those developing delirium suffer from poor cognitive reserves and develop dementia in a few years (Rahkonen et al. 2001;Lundström et al. 2003).

Surgeons do recognize patients with severe dementia, but still find it challenging to recognize their mildly or moderately demented patients (Raivio et al. 2001). However, this is the group which benefits most from rehabilitation (Huusko et al. 2000). Since dementia caries a strong risk factor for hip fractures, the number of these patients is evidently growing (Huusko et al. 2000; Buckner and Larson 1987). Therefore, in order to select the most suitable surgical method and to minimize the risk for poor rehabilitation outcome and prolonged institutional care, cognitive status should be evaluated preoperatively.

Dementia is the obvious reason for difficulties in understanding and learning about weight-bearing restrictions. What happens to those who cannot learn to walk in six weeks? According to our study, weight-bearing restrictions often mean confining such patients to a chair for six weeks or longer. This practice undermines the objectives of rehabilitation. Our study shows that after six weeks many patients with dementia never walk again and most of them require permanent institutional care.

Perhaps the stability of the fracture is more important than previously appreciated because weight-bearing restrictions seldom succeed in enabling patients to walk independently. Endoprothetic devices fixed with acrylic cement may be a surgical method for elderly people if stable osteosynthesis is impossible. Although the subgroups of weight-bearing without restrictions and with restrictions also reflect subgroups of fractures (i.e., stable osteosynthesis or endoprothesis versus unstable fracture fixation), the difference in outcome is clear. Regardless of possible dementia, most elderly patients would benefit from surgical management of hip fractures requiring no weight-bearing restrictions.

7.2 Use of medication among elderly patients with dementia

7.2.1 Potentially inappropriate medication

In Finland, over a third of elderly patients in nursing homes and acute hospitals use potentially inappropriate medications. High-dose temazepam explains the majority of this problem. No differences were found in the proportions or use of various classes of PIDs among patients with and without dementia. The use of PIDs had no impact on mortality or on days spent in acute hospitals.

The proportion of nursing home and hospital patients using PIDs is much higher (36.2%) than that of community-dwelling elderly Finnish people (12.5%) (Pitkälä et al. 2001). The same trend appears in other studies: The more frail and dependent the population, the larger the proportion on PIDs. PID use among nursing home patients according to the Beers criteria has been studied only in the USA and Canada (Beers et al. 1992; Williams et al. 1995; Spore et al. 1997; Dhalla et al. 2002; Lau et al. 2004; Perri et al. 2005) and most other studies have used less inclusive criteria, making prevalence figures across studies incomparable (Table 16).Only two studies have fully applied the Beers 1997 list of inappropriate medications, and they showed even higher use of PIDs among USA nursing home residents: 50.3% (Lau et al. 2004) and 46.5% (Perri et al. 2005). Dhalla et al. (2002) omitted all dose-dependent PIDs from their list, including short-acting benzodiazepines at high doses, which contributed most to the usage of our patients.

Table 16. Potentially inappropriate medications among permanently institutionalized patients

Study	**Country**	**Use on PIDs ,%**	**Criteria used**
Beers et al. 1992	USA	40.3	Beers 1991
Williams et al. 1995	USA	12	10 drugs were based on Beers 1991 (20 drugs were excluded)
Spore et al. 1997	USA	18 on Stuck criteria 25 on Beers Criteria	Stuck 1994 and Beers 1991 criteria
Dhalla et al. 2002	Canada	20.8	Beers 1997, not drug-disease conditions, clonazepam added
Gray et al. 2003	USA	22	Beers 1997, clonazepam added
Lau et al. 2004	USA	50.3	Beers 1997
Perri III et al. 2005	USA	46.5	Beers 1997
Raivio et al. 2005	Finland	36.2	Beers 1997, not drug-disease conditions

Notes:

Beers 1991:
- 19 medications and 11 doses, frequencies or durations
- including dose-dependent antipsychotic medications
- temazepam excluded

The Stuck 1994 criteria are less inclusive than those of Beers 1991

Hydroxyzine, amitriptyline, and expecially oxybutynin, with their anticholinergic side-effects, may be potentially harmful for patients with dementia. Amitriptylin was rarely used among those with dementia in Finland. From 1999 to 2000, the only available medication for incontinence in Finland was oxybutynin, which may explain its high usage. Nowadays, alternatives also exist. Other PIDs (according to the Beers criteria) were fairly rare in the Finnish population. In the USA, the most common PIDs for nursing home and hospital patients have been propoxyphene, promethazine, diphenhydramine, hydroxyzine, oxybutynin, amitriptyline, cyproheptadine, high-dose iron supplements, digoxin in high doses, and ranitidine (Perri et al. 2005; Lau et al. 2005).

The high use of temazepam, which in Finland is used almost solely for insomnia, may be explained by the low hospital-staffing rate in Finland both in hospitals and in nursing homes, especially in dementia care (Noro et al. 2005). If only one nurse is working during the night and is responsibe for 20 to 40 mostly demented patients, the most convenient way to manage is to administer enough hypnotic medication to patients who are “too lively” for such circumstances. The association of hypnotic use with falls remains uncertain, however, although one study from Michigan (Avidan et al. 2005) suggests that insomnia itself, rather than hypnotic use, is associated with risk for falls.

The use of PIDs among elderly persons in geriatric and internal medicine wards have been studied in Italy (Onder et al. 2003) and in emergency department wards in the USA (Chin et al. 1999, Caterino et al. 2004) with less inclusive criteria than those based on Beers 1997. In a recent Italian study, PID use among in-hospital geriatric patients had no effect on in-hospital mortality or length of hospital stay (Onder et al. 2005). This study used the Beers criteria 2003 (not fully applied).

Only a few studies have examined the impact of PID use on mortality or on the use of health services (Hanlon et al. 2002; Fillenbaum et al. 2004; Perri et al. 2005; Klarin et al. 2005; Lau et al. 2005). Our study showed no effect on two-year risk of death or on the use of health services, although our population showed exceptionally high use of PIDs. Many competing causes of death in this vulnerable population may explain the high total mortality (46.6%) in the two-year follow-up period. Our results are well in line with the findings of previous studies investigating the impact of PIDs on mortality among elderly people with shorter follow-up periods (Onder et al. 2005; Hanlon et al. 2002; Klarin et al. 2005; Lau et al. 2005). Few studies show that the increased risk for hospital admission (Perri et al. 2005; Klarin et al. 2005; Lau et al. 2005) and for use of outpatient services (Fillenbaum et al. 2004) is associated with PID use, but none to date has reported the actual total use of hospital days.

The accuracy and significance of the Beers list of PIDs may be questioned if PID use cannot be verified to affect hard outcomes. However, mortality or hospital days may not be the only relevant end-points in situations where the remaining lifespan is so short. Acute side-effects and the quality of life, instead of mortality, may be more important end-points in frail elderly samples.

The Beers list could benefit from being updated based on recent findings from prognostic studies. Some drugs may be less harmful than previously thought, although frail elderly patients evidently use a lot of potentially inappropriate medications and are exposed to different side-effects, which could impair the quality of their life.

7.2.2 Use of antipsychotic medication

In our sample of patients with dementia, nearly half received antipsychotics. Neither the use of conventional or atypical antipsychotics nor non-use showed any effect on mortality or on hospital admissions. On the contrary, the number of hospital admissions was lower among users of conventional or atypical antipsychotics than among non-users. In the Cox proportional hazard model, taking into account the old age, delirium and frailty of the sample, the effect of atypical antipsychotic use (risperidone, olanzapine) in two-year mortality showed lower risk than did non-use. The use of restraints in nursing homes and geriatric wards was still in practise in Finland at the time of this study: about 12% of these frail, mostly female, patients with dementia had experienced physical confinement to a bed or wheelchair, the practice of which almost doubled the mortality risk in our sample. Most (45.2%) of them received no antipsychotic medication, 38.7% received conventional, and 16.1% atypical antipsychotics ($p = 0.57$, Chi Square, df 2). However, the statistical power limits the conclusions that can be drawn.

Only one previous study has compared the mortality risk of patients with dementia using any antipsychotic medication to that of non-users (Suh and Shah 2005). The results of our two-year follow-up period are in line with this previous study with a one-year follow-up period, thus showing lower mortality among patients using any antipsychotic medication than among non-users. Another study, with no control group of non-users, showed that users of atypical antipsychotics experienced lower mortality than did users of conventional antipsychotics (Wang et al. 2005). Our study, with the longest follow-up period to date, showed decreasing trends in both the mean number of admissions to hospitals and in the mortality rate. Thus, the use of antipsychotics in this particular patient sample may, if at all, be somewhat protective. However, since only multivariate analyses showed these results, this should be interpreted cautiously.

A recent meta-analysis of Schneider et al. (2005) concluded that the use of atypical antipsychotics may slightly increase the risk of death, although no such studies of conventional antipsychotics were available at that time. Later, a Canadian study suggested that conventional antipsychotics are at least as likely as atypical drugs to increase mortality (Wang et al. 2005). Our study enables the comparison of mortality risk between these two antipsychotic medication groups and non-users.

Why do the results of randomized controlled trials differ from those of long-term follow-up studies? Firstly, previous randomized studies have typically spanned only a few months. With a longer follow-up period of up to two years, the benefits of the antipsychotics may compensate for the risks of their side-effects. Secondly, many of the randomized controlled trials under strict investigation criteria may have to exclude high-risk patients, thus leading to weaker representativeness of the sample. Our patients represent the frailest and oldest of dementia patients at high risk for neuropsychiatric symptoms and their complications. The antipsychotics may provide even more benefit than harm in this more "real-life" sample.

What could be the explanation of a trend that mortality was even higher among patients not receiving antipsychotics? In Finland, the vast majority (90%) of nursing home and long-term hospital patients suffer from cognitive deficits (Noro et al. 2005). Behavioral disorders are the leading cause of admission to nursing homes (Phillips et al. 2003; Laurila et al. 2004a; DeVugt et al. 2005). In addition, over one third of these patients in acute geriatric wards suffered from delirium (Laurila et al. 2004b). The behavioral symptoms of dementia (Schneiderman 2005) and delirious episodes (Pitkälä et al. 2004) comprise a complication hazard that could potentially lead to falls and fractures, to cardiovascular complications, and possibly to the use of restraints as well. Thus, such patients with dementia are particularly vulnerable to complications. Our previous study found that the vast majority (87.5%) of these dementia patients suffered from behavioral symptoms (Pitkälä et al. 2004). Of these patients, 47.8% exhibited psychotic symptoms, 20.8%, aggression, and 25.5%, agitation. These symptoms may be considered target symptoms for antipsychotic use and may themselves comprise such a hazard for death (Craig et al. 2005; Wilson et al. 2005) as well as explain the benefit of the long-term use of antipsychotic medications, which may compensate for any harm.

Several studies have shown that antipsychotic use was much higher in Finland than in other countries (Avorn et al. 1995; Gurwitz et al. 2000; Llorente et al. 1998; Lasser et al. 1998; Liperoti et al. 2003; McGrath et al. 1996; Oborne et al. 2002; Ford et al. 2002; van Dijk et al. 2000; Ruths et al. 2001; Sorensen et al. 2001; Holmquist et al. 2003; Hosia-Randell et al. 2005; Snowdon 1999; Draper et al. 2001). The high prevalence of delirium in hospital settings as well as dementia with frequent behavioural symptoms could partly explain this high use (Pitkälä et al. 2004; De Vugt et al. 2005). In 1999 and 2000, when the data were collected, atypical antipsychotics were quite new (only risperidine and olanzapine were available at that time) and the use of them was rare. Handling very common behavioral disorders in dementia care with non-medical means was very limited, especially given the limited availability of nursing staff for dementia care in Finland (Noro et al. 2005). Acetylcholinesterase inhibitors (AChEI) are recommended nowadays as a first medical choice to handle behavioral disorders in patients with dementia (Sink et al. 2005). Use of this medical treatment for dementia in our population was quite rare in 1999 and 2000; only 3.1% received it. However, this information related to the benefits of AChEIs was unavailable in 1999. In conclusion, antipsychotic medication was the primary treatment for such behavioral symptoms in patients with dementia in wards lacking sufficient nursing staff. However, even when a specific treatment for dementia is ongoing, we sometimes need additional alternatives to treat serious psychotic disorders in such patients. The use of antipsychotic medication may be justifiable in some situations, and may be a more effective/safer treatment strategy than the use of physical restraints.

The extensive and careful assessment of all patients at baseline is one of the strengths of our sample in these two medication-related studies, which benefited from a long and thorough follow-up period of two years. Both dementia and delirium were defined critically. Our relatively small number of patients, raising the question of the representativeness of our sample, can be considered a limitation of the studies. However, our results are in line with the very large, recently published RAI database (n = 7032) of the characteristics of nursing home and hospital populations in Finland (Noro et al. 2005). Another limitation of our sample, which was not randomized, is that we had examined the medications only at baseline. Nevertheless, when antipsychotics are introduced, they are usually continued for long periods of time. With regard to the randomization issue, our study can support and complement the results of pure randomized studies on selected populations by offering results from a “real-life” situation.

7.3 Pitfalls in the services received and the unmet needs of caregivers of persons with AD

7.3.1 Use and unmet needs for official services

Our large-scale sample of the spousal caregivers of persons with AD pointed out that the caregivers were themselves very old (mean age 78 years), and many of them were in poor health. Marriages among these couples frequently exceeded 50 years, and almost half of those with AD were war veterans. The various common behavioral symptoms of the spouses with AD demanded the continuous care and support of the caregivers. In addition, physical impairments and incontinence among these home-dwellers with AD were surprisingly frequent. Support services in Finland tend to meet the needs of such families rather poorly; in addition to financial support, services offerer them include more technical aid and short-term respite care in institutions, when what these families actually seek is more services in the home, such as physiotherapy, home respite, and house cleaning. Only half announced that they had been offered official services when they needed them, and only a third was satisfied. In conclusion, the autonomy aspect of these families tended to be poorly realized in our official service system, since only two in three of the caregivers felt they had any influence on the services they were offered.

Behavioral symptoms in our sample were surprisingly common, even higher than in some previoud population-based studies (Lyketsos et al. 2002). The questions concerning these symptoms were based on the well-validated Neuropsychiatric Inventory Scale (Cummings et al. 1994), so our results can be considered reliable. However, the questions were asked without their usual time frame of four weeks. Therefore, the prevalence of symptoms may reflect their existence over a longer period of time. Two studies of home-dwelling AD patients support our results on the high prevalence of behavioral symptoms (Engelborghs et al. 2005; Fuh et al. 2005), which constitute the main cause for the breaking point of home care and increase the risk for permanent institutional care (Gilley et al. 2004; De Vugt et al. 2005).

The elderly care-giving families of AD patients in our study seemed quite inconspicuous to the official Finnish service system. Dissatisfaction with services among caregivers has been reported to be common in studies in other countries as well. In one Italian study, Dello Buono reported that only 40% of caregivers (N = 120) were satisfied with services (Dello Buono et al. 1999). A US study published 15 years ago showed that care-giving families (N = 46) seek opportunities to influence the services they receive (MaloneBeach et al. 1992). Those families experienced difficulties in finding appropriate and good-quality services and had no opportunity to actively participate in the planning of those services, while official workers regretted the families' lack of interest in using the services offered (DelloBuono 1999; Zarit and Leitsch 2001). An Australian study (N = 134) showed that unmet needs among care-giving families were quite common: 20% had unmet needs for skilled nursing, 33% for domestic help, 24% for home respite, 25% for meals-on–wheels, and 28% for respite care in a rest home (Philp et al. 1995). Our results are in line with those of this smaller study. The difference in the unmet needs of female and male caregivers may/likely reflects traditional gender roles.

The service most often desired by these families was physiotherapy for the spouse with dementia, which is seldom offered by the communal service system. As half of the persons with AD in our sample were war veterans, the physiotherapy offered to them was mainly (90%) the annual war veteran rehabilitation set by Finnish law. The inequality that currently exists between the war veterans and the females or younger males with AD in opportunities to receive community-offered physiotherapy is obvious. If this situation in Finnish society continues, almost all the physiotherapy offered to persons with AD will vanish when Finland's war veterans pass away.

Well-organized, tailored services may postpone institutionalization among those at greates risk for it: persons with dementia (Mittelman et al. 1996; Eloniemi-Sulkava et al. 2001). The greater the caregiver distress, the greater the families' need for social services or nursing home placement of the person with dementia (Ganzer et al. 1994). The stage of dementia as well as physical impairments and behavioral symptoms related to dementia affect the needs of the care-giving family (Gordon et al. 1997; Prescop et al. 1999), while the physical and mental strain on the caregiver (Hope et al. 1998; Eloniemi-Sulkava et al. 2001; Pot et al. 2001; Toseland et al. 2002; Thomas et al. 2006) significantly affects his/her need for, use of, and satisfaction with such services (Dello Buono et al. 1999).

The persons with AD in our sample, who have been approved by the Social Insurance Institution of Finland for reimbursement of AD medication and who have a spousal caregiver at home, may/likely represent the most fortunate of dementia patients. They belong to that minority (25%) of all those with dementia in Finland who have thoroughly undergone diagnostic procedures by a neurologist, geriatrician, or psychogeriatrician, and who have received medication for AD. We can also assume that they have received more information about available services than have other patients with dementia. At the end of 2005, 25 000 such patients existed in Finland. About 65 000 home-dwellers with dementia remain in a worse situation with no specific diagnosis or information about services (Viramo and Sulkava 2006). Taking this into consideration, our results provide a rather rosy picture of the services and health situation of these families, while "real-life"situations may be even worse.

7.3.2 Use and needs for discussion of medico-legal services

Only 4.3% of Finnish persons with AD in our sample used a court-appointed guardian, possibly because they all had a spouse taking care of them. Symptoms of dementia over three years, poor functioning, depressive symptoms, cooperation difficulties of the person with AD, and caregivers' heavy physical strain were associated with the use of a guardian. Discussions with the doctor about these medico-legal issues were quire rare: only 9.9% of these couples had had the opportunity, although almost half sought it. These families obviously have an unmet need for information, support, and counselling in ways to cope with the weakening ability of the person with AD to handle financial or other affairs.

It can be assumed that most of the financial powers of attorney were made in bank offices, since they were used in 37.8% of these care-giving families. The severity of dementia, such as symptoms of dementia over three years, poor functioning, hallucinations, urinary or bowel incontinence, cooperation difficulties of the person with AD, and caregivers' heavy mental or physical strain were associated with the use of financial powers of attorney. Arranging a financial power of attorney requires presentation of the person's own will and signature. The factors associated with both guardianship and financial powers of attorney reflect the severity of dementia.

Only one Italian study with a smaller sample (N = 100) has examined the prevalence of guardianship among home-dwelling dementia patients. Our results are quite well in line with those of this Italian study, in which 10.4% to 11.5% of persons with AD in a moderate or severe stage, and 7% of the entire sample, used a guardians (Ruggieri et al. 2003). In the UK, the prevalence of guardianship among more severe AD patients in nursing homes was 23.6% (Janowsky et al, 1993). We did found no previous studies of the use of financial powers of attorney or of families' needs for discussion of these medico-legal issues with a doctor. Studies about the needs of care-giving families as a whole have concluded that such families have many unmet needs, including the need for discussions and support (Mittelman et al. 1996; Dello Buono et al. 1999; Eloniemi-Sulkava et al. 2001).

The society bears the responsibility to protect an incompetent person with deteriorating cognition from acting against his/her own best interest. This most likely occurs in moderate stages of dementia (Mäki-Petäjä-Leinonen 2003). Appointing a legal guardian is one option for legal protection, but Finnish legislation aims to restrict/limit as little as possible one's legal right to make decisions (English website of Finnish Ministry of Justice:
www.om.fi/Etusivu/Julkaisut/Esitteet/Holhoustoimipalvelut/Mitenedunvalvojanvoisaada?lang=en).

Based on the duration of symptoms for more than three years, neuropsychiatric symptoms, poor functioning, and the urinary or bowel incontinence of AD patients in our sample, we can assume that most of our patients were in a moderate stage of dementia. As they were all living with their spouses, other means by the family or society may have been enough to protect them, so guardianship was rarely necessary. In conclusion, most cases require no guardian and the most sophisticated way to handle such situations is with the trustworthy help of those closest to the patient and/or with financial powers of attorney. The most challenging situations occur with AD patients who live alone, a group which will likely grow in the future as the population ages and long-term marriages become rarer. In such complicated situations, a guardian is often needed despite their more rigid nature. Discussion between the doctors and lawyers could be beneficial in creating a modern service system for such families in Finnish society. We agree with previous researchers on the need for regularly renewed national guidelines, which do not yet exist in Finland. Care-giving families would benefit from discussions with a doctor and/or with a lawyer about these issues as soon as possible after diagnosis. This could help persons with AD in their individual planning of the future.

The strength these national data on available services was a cross-sectional large-scale sample of home-dwellers with properly diagnosed and medically treated AD living with their spousal caregivers. The response rate was very high, taking into account the caregivers' old age. Because our study was a cross-sectional survey, we are unable to investigate the time span of the needs and symptoms in these families, which is a limitation of this study. Nor do we know the exact severity of the care recipients' AD, but based on the duration of the symptoms and the behavioral and physical disorders, we can assume that most of them were in a moderate stage of dementia. This home-dwelling sample represents the most fortunate group of AD sufferers in Finland; in "real life", many persons with AD remain undiagnosed or may live alone. Consequently, we have no data on those who may face the most challenging problems, which is a limitation of our study. However, our results suggest that our official service system should also respond to the medico-legal information needs of these patients and their families.

8 CONCLUSIONS

I. A hip fracture is one of the most dangerous fractures for the elderly, with high mortality and function decline. All patients, especially those with dementia, stand to benefit from the possibility to walk normally with no weight-bearing restrictions after surgery, fracture type and chosen surgical method permitting, of course. The dementia status of the patient should be evaluated preoperatively, which remains a challenge for surgeons. The group that stands to benefit most from rehabilitation is that with mild or moderate dementia. Elderly hip fracture patients with dementia may benefit from surgery with endoprothetic devices fixed with acrylic cement, if stable osteosynthesis is impossible.

II. Over one third of Finnish nursing home and geriatric hospital patients use medications identified as PIDs according to the Beers list 1997 and 2003. The most commonly used PID was temazepam, in doses exceeding 15 mg, to treat insomnia. However, PIDs showed no impact on two-year mortality or hospital admissions. Some medications on the Beers list may be less harmful than previously thought. We recommend updating the Beers list based on the findings of prognostic studies.

III. Nearly half of the patients with dementia in Finnish nursing homes and geriatric hospitals received antipsychotics. We primarily used conventional antipsychotics, which are cheaper than atypical ones. The high drug use had no impact on two-year mortality or hospital admissions in the frail and elderly population studied. Whenever a drug treatment for psychotic disorders is needed, atypical antipsychotics, with fewer side effects, proved as safe as conventional ones and a better alternative than the use of restraints.

IV. Home-dwellers with AD in Finland are surprisingly disabled yet they are still cared for by those closest to them. Caregivers do amazingly heavy work, although they themselves are old and sick. Finland's official service system meets the needs of these care-giving families rather poorly. Most of the services caregivers seek, such as home respite, home cleaning, or physiotherapy for the person with AD, are either insufficient or do not exist. In addition, our service system is fragmented and complex, making it difficult for the families to understand. More services tailored to these families are needed.

V. One unmet need of these families was counselling in medico-legal affairs, such as guardianship. Receiving adequate information about options for handling such issues as soon as possible after the diagnosis of dementia would be in the best interest of the family. We recommend more cooperation with the lawyers and doctors who handle such affairs as well as creating national guidelines.

9 FUTURE DIRECTIONS AND CLINICAL IMPLICATIONS

Persons with dementia are the most challenging group to care for and to live with. Unless caregivers take total, 24/7 responsibility of them, the aid provided by our social and health care system is sorely needed. Financial community support and organized information should be available to all caregivers regardless of age, activity, education level or living conditions.

Our study showed that one of the most desired/sought-after services was physiotherapy for the AD sufferer. At present, insufficient data are available on the impact of physiotherapy in such situations, but some recent studies have shown promising results (Teri et al. 2004, Rolland et al. 2007). More studies are needed to investigate the long-term effect of physiotherapy on AD sufferers. Finland has been active in creating special fitness centers for the elderly, which now exist in most cities. Nevertheless, we have a solid basis to begin wide-scale organized physical rehabilitation of such elderly patients, particularly if future studies reveal positive results among persons with AD.

A rehabilitative attitude is not limited to physical aspects, but includes social, medical and emotional care. In Finland, persons with dementia may suffer from underdiagnosis and inappropriate medication, especially the high and long-term use of antipsychotics (Löppönen 2006). Education is available to doctors, and the use of antipsychotics seems to be connected to the low staffing rate in Finnish nursing homes, which is currently only half of recommended rates (Noro et al. 2005). We also suffer from a lack of sufficiently trained staff. This is an ethical and political problem that cannot be remedied by health care workers alone. More discussions and cooperation is needed between the Ministry of Social and Health Care, ethics committees, and social and health care workers.

One recent Finnish study revealed very positive results citing cost savings of up to EUR 8 000 annually per family by offering multidimensional services organized by a coordinator to care-giving families of dementia patients. This intervention consisted also emotional support for caregivers. In this study, most savings came from a decrease in the use of institutional care (Eloniemi-Sulkava et al. 2006). In Finland, where 50% to 60% of 85 000 patients with moderate or severe dementia dwell in communities, 15 000 of whom are cared for by their spouses, this model promises savings of EUR 75 million annually.

Elderly people, especially those with dementia, benefit from appropriate medical and surgical care, which allows them to remain mobile as long as possible. Caregivers themselves regarded their work most as emotionally stressful, while our society tends to offer them mostly physical devices or solutions. Emotional support and information about available services need new strategies. Such families require more cooperation and education with the lawyers and doctors who handle medico-legal issues. Preparing national guidelines for assessing cognitive and mental capacity could be valuable. In addition, creating new vacancies for dementia coordinators in the Finnish health and social care system could provide more tailored services for such care-giving families and thus postpone permanent institutional care.

10 ACKNOWLEDGEMENTS

This thesis was carried out from 1999 to 2007 at the Department of Geriatrics, University of Helsinki with the collaboration of the Department of Public Health, the University of Helsinki, the Lahti City Hospital, the Päijät-Häme Central Hospital, the Central Union of Welfare for the Aged, and the Social Insurance Institution of Finland.

First, I offer deep thanks to Professor Kaisu Pitkälä. Her wisdom has provided the basis for the success of this work. I appreciate her wealth of not only scientific, but also human skills. Her accuracy and trustworthiness are appreciated worldwide among geriatricians, and I have had the great honour to work beside her with my thesis. We have had many discussions over the years ranging from science to the arts, and from children to the elderly. I eagerly await future collaboration with her.

Professor Reijo Tilvis was my supervisor from the very beginning. He is exemplary among geriatricians in Finland, and has contribution considerably to trimming this work and providing more perspectives on the analyses. He encouraged me to participate in the Nordic Geriatric Research School, which represents a significant landmark in my scientific work. I am grateful for all his support and for the discussions we have had on the ways of science and life.

Many thanks also go to professor Timo Strandberg for his many new perspectives and, especially toward the end of my work, his remarkable engagement and rapid responses to commentaries. Your humor and creativity are admirable. And special thanks for those last bits of advice scribbled on a piece of paper with your wife Riitta Ahonen in Sibelius Hall after a concert of the King's Singers!

When I first began to plan for this scientific work while working at the Lahti City Hospital, docent Olli Korkala was a mentor to me. In the beginning, there were years in which I would have no clarity without his support and belief in my study plans. I will not forget our discussions in his office – filled with the flavorful smoke from his pipe – in the orthopedics department, his handwritten corrections to my drafts, and the cards with his drawings beside them. Orthopedics was as unfamiliar to me as geriatrics were to orthopedists, but together we made it possible. Thank you, Olli.

I also wish to thank orthopedist Raimo Niskanen, who helped me with my first data collections and analyses and took the time to discuss and encourage me during those years working at the Lahti City Hospital. Docent Juha-Pekka Kaukonen and Professor Risto Mokka also engaged in remarkable

collaboration with many links to the Department of Orthopedics at the Päijät-Häme Central Hospital. I also thank Terttu Mokka, head of the Geriatric Clinic at the Lahti City Hospital at the time my study began, for being my guide and teacher of geriatrics.

I am grateful to my reviewers, Professor Timo Erkinjuntti and Docent Miia Kivipelto, both respected worldwide as fine researchers, for the many discussions, comments, and memorable moments during this work. It has been an honour to me to collaborate with you. Your innovative ideas and systematic working is highly esteemed.

The Social Insurance Institution and its staff have been of remarkable help to me during this work. Special thanks go to Professor Timo Klaukka, Marjatta Sjödin, Irma Heldan, Leena Peltonen, and Heikki Helasti. Kristiina Tyrkkö provided me with her professional assistance with many issues regarding data management and information retrieval. I am thankful to English editors Carol Norris, Julie Uusinarkaus, and Stephen Stalter of the University of Helsinki for their valued collaboration in this work.

My scientific colleagues and friends gave me strength and belief when I needed it. I extend my special thanks to Marja-Liisa Laakkonen, Anna Mäki-Petäjä-Leinonen, Jouko Laurila, Ulla Eloniemi-Sulkava, Merja Suominen, Taina Lupsakko, Niina Savikko, Helka Hosia-Randell, Tiina Huusko, Harriet Finne-Soveri, Terhi Rahkonen, Lauri Soinne, Merja Hallikainen, Tuula Pirttilä, Risto Vataja, Kari Alhainen, Matti Jokelainen, Veijo Pulliainen, and Suvi Ilmonen.

My deep thanks to artist Nanna Susi, who provided her painting as a cover of this book. I also thank for dancer Tiina Lindfors for the possibility to use her poem in the beginning of this work. Art and science go together and they may have common tasks!

Many friends have encouraged me and given me perspective on everyday life as well as psychological support during these years. I am grateful to Leena Saloheimo, Susanne and Kari Valkama, Pirjo Ahtiluoto, Kaija-Liisa and Jari Honkanen, Sirkku Suontausta-Kyläinpää and Heikki Kyläinpää, Martti and Kirsi Pesonen, Kari and Eija Leinonen, Tuula and Erkki Pesonen, Ulla Parviainen, Sirkku Lavonius, Inkeri Jaakkola, Marja Aho, Liisa Kauppila, Eija Silvennoinen, Eija Korhonen and Jyrki Loima.

Deep thanks to my parents, Paavo and Anita Nykänen, for their loving and support. You have encouraged me and even pushed me to go on in situations where I might have given up. Mother – thank you for the sense of art, which you have bequeathed to me. Father – thank you for the words you spoke to me when I was a child: “Minna, you can be whatever you want.” And special thanks for your practical support to my family during these years.

This work is dedicated to my beloved three daughters: Ronja, Tuuli, and Heini, and to my son, Ilpo. You have wonderfully given to me study suggestions even, and have critically discussed many issues, and even mentored me in your personal lovely ways according to your ages. Through your lives I have seen the depth of the sea and the height of the sky. Through your eyes I can see the light, and I know that life will carry us and go on. I am grateful to God that I have been given the possibility to walk beside you.

This study benefited from the financial support of the Social Insurance Institution of Finland, the Päivikki and Sakari Sohlberg Foundation, the Uulo Arhio Foundation, the Medical Society of Kyminlaakso, the Duodecim, the Societas Gerontologica Fennica, and the Association of Finnish Geriatrists, and was partly realized with the cooperation of the Central Union of the Welfare for the Aged, Finland.

Lahti, October 2007

Minna Raivio

11 REFERENCES

Alzheimer A. Neuere Arbeiten über die dementia senilis und die auf atheromatöser Gefässerkrankung basierendenn Gehirnkrankheiten.Monatsschrift für Psychiatrie und Neurologie 1898; 3:101-115.

Alzheimer A. Über eine eigenartige Erkrankung der Hirnrinde. (A characteristic disease of the cerebral cortex.) Allgemeine Zeitschrift für Psychiatrie und Psychisch-Gerichtliche Medizin 1907; 64:146-148.

American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 4th ed. DSM-IV. Washington, D.C: American Psychiatric Association, 1994.

American Psychiatric Association and Finnish Psychiatric Association, 1997.

Ancelin ML, Artero S, Portet F, Dupuy AM, Touchon J, Ritchie K. Non-degenerative mild cognitive impairment in elderly people and use of anticholinergic drugs: longitudinal cohort study. BMJ 2006; 332(7539): 455-459.

Anttila T, Helkala EL, Viitanen M, Kareholt I, Fratiglioni L, Winblad B, Soininen H, Tuomilehto J, Nissinen A, Kivipelto M. Alcohol drinking in middle age and subsequent risk of mild cognitive impairment and dementia in old age: a prospective population based study. BMJ 2004;329 (7465):539.

Aparasu RA, Mort JR. Inappropriate prescribing for the elderly: Beers criteria-based review. Ann Pharmacother 2000; 34(3): 338-346.

Avidan AY, Fries BE, James ML, Szafara KL, Wright GT, Chervin RD. Insomnia and hypnotic use, recorded in the minimum data set, as predictors of falls and hip fractures in Michigan nursing homes. J Am Geriatr Soc June 2005; 53(6): 955-962.

Avorn J, Gurwitz JH. Drug use in the nursing home. Ann Intern Med 1995; 123(3):195-204.

Bassett SS. Attention: neuropsychological predictor of competency in AD. J Geriatr Psychiatry Neurol 1999; 12(4): 200-205.

Beers MH, Ouslander JG., Rollinger I, Reuben DB, Brooks J, Beck JC. Explicit Criteria for Determining Inappropriate Medication Use in Nursing Home Residents. Arch Intern Med 1991 Sept; 151: 1825-1832.

Beers MH, Ouslander JG, Fingold SF et al. Inappropriate medication prescribing in skilled-nursing facilities. Ann Intern Med 1992 Oct 15; 117(8): 684-689.

Beers MH. Explicit Criteria for Determining Potentially Inappropriate Medication Use by the Elderly. An update. Arch Intern Med 1997; 157: 1531-1536.

Bhandari M, Devereaux PJ, Swiontkowski MF et al. Internal fixation compared with arthroplasty for displaced fractures of the femoral neck. A meta-analysis. J Bone Joint Surg Am 2003; 85-A(9): 1673-1681.

Bick KL and Amaducci L. Alois Alzheimer and Gaetano Perusini: Alzheimer's First Case Rediscovered. Liviana Press, Padova, 1987.

Bick KL, Amaducci L, Pepeu G.(eds) for the Italian Study Group on Brain Ageing and the World Federation of Neurology Research Group on the Dementias. The Early History of Alzheimer's Disease, Translation of the Historical papers by Alois Alzheimer, Oskar Fischer, Francesco Bonfiglio, Emil Kraepelin, Gaetano Perusini. Liviana Press, Padova, 1987.

Blessed G, Tomlinson BE, Roth M. The association between quantitative measures of dementia and of senile change in the cerebral gray matter of elderly subjects. Br J Psychiatry 1968:114; 797-811.

British Medical Association and The Law Society. Assessment of mental capacity: guidance for doctors and lawyers 2nd ed. London: BMJ Books, 2004.

Brodaty H, Thomson C, Thompson C, Fone M. Why caregivers of people with dementia and memory loss don't use services. Int J Ger Psych 2005; 20:537-546.

Buckner DM, Larson EB. Falls and fractures in patients with Alzheimer-type dementia. JAMA 1987; 257: 1492-1495.

Cameron ID, Lyle DM, Quine S. Accelerated rehabilitation after proximal femoral fracture; randomised controlled trial. Disabil Rehabil 1993; 15; 29-35.

Caralis Pv. Ethical and legal issues in the care of Alzheimer's patients. Med Clin North Am. 1994; 78(4): 877-93. Review.

Caterino JM, Emond JA, Camargo CA Jr. Inappropriate medication administration to the acutely ill elderly: a nationwide emergency department study, 1992-2000. J Am Geriatr Soc 2004;52(11):1847-1855.

Charlson ME, Pompei P, Ales KL, MacKenzie CR. A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. J Chronic Dis. 1987; 40(5): 373- 383.

Chin MH, Wang LC, Jin L et al. Appropriateness of medication selection for older persons in an urban academic emergency department. Acad Emerg Med 1999; 6(12): 1189-1193.

Couris CM, Duclos A, Rabilloud M, Couray-Targe S, Ecochard R, Delmas PD, Schott AM. A seventy percent overestimation of the burden of hip fractures in women aged 85 and over. Bone. 2007 Jul 10; [Epub ahead of print]

Craig D, Mirakhur A, Hart DJ, McIlroy SP, Passmore AP.A cross-sectional study of neuropsychiatric symptoms in 435 patients with AD. Am J Ger Psych 2005 ;13(6): 460-468.

Cronin-Stubbs D, Beckett LA, Scherr PA et al. Weight loss in people with AD: a prospective population based analysis. BMJ 1997; 314(7075):178-179.

Cummings JL, Mega M, Gray K, Rosenberg-Thompson S, Carusi DA, Gornbein J. The Neuropsychiatric Inventory: comprehensive assessment of psychopathology in dementia. Neurology 1994; 44(12): 2308-2314.

Curtis LH, Ostbye T, Sendersky V et al. Inappropriate prescribing for elderly Americans in a large outpatient population. Arch Intern Med 2004;164(15): 1621-1625.

De Vugt ME, Stevens F, Aalten P, Lousberg R, Jaspers N, Verhey FR. A prospective study of the effects of behavioral symptoms on the institutionalization of patients with dementia. Int Psychogeriatr 2005; 17: 577-589.

Dello Buono M, Busato R, Mazzetto M et al. Community care for patients with AD and non-demented elderly people: use and satisfaction with services and unmet needs in family caregivers. Int J Ger Psych 1999; 14(11):915-924.

Dhalla IA, Anderson GM, Mamdani MM, Bronskill SE, Sykora K, Rochon PA. Inappropriate prescribing before and after nursing home admission. J Am Geriatr Soc 2002; 50(6): 995-1000.

Draper B, Brodaty H, Low LF et al: Use of psychotropics in Sydney nursing homes: associations with depression, psychosis, and behavioral disturbances. Int Psychogeriatr 2001; 13(1): 107-120.

Eloniemi-Sulkava U, Notkola IL, Hentinen M, Kivela SL, Sivenius J, Sulkava R. Effects of supporting community-living demented patients and their caregivers: a randomized trial. J Am Geriatr Soc 2001; 49: 1282-1287.

Eloniemi-Sulkava U, Rahkonen T, Suihkonen M, Halonen P, Hentinen M, Sulkava R. Emotional reactions and life changes of caregivers of demented patients when home caregiving ends. Aging Ment Health 2002; 6(4): 343-349.

Eloniemi-Sulkava U, Saarenheimo M, Laakkonen M-L, Pietilä M, Savikko N, Pitkälä K. Omaishoito yhteistyönä. Iäkkäiden dementiaperheiden tukimallin vaikuttavuus. Tutkimusraportti. (Caregiving as co-operation. The effectiveness of a support model to elderly caregiving families of persons with dementia). In Finnish. Vanhustyön Keskusliitto, 2006.

Engelborghs S, Maertens K, Nagels G et al. Neuropsychiatric symptoms of dementia: cross-sectional analysis from a prospective, longitudinal Belgian study. Int J Geriatr Psychiatry 2005; 20(11): 1028-1037.

Fialova D, Topinkova E, Gambassi G et al. Potentially inappropriate medication use among elderly home care patients in Europe. JAMA 2005; 293(11): 1348-1358.

Fick DM, Cooper JW, Wade WE, Waller JL, Maclean JR, Beers MH. Updating the Beers Criteria for Potentially Inappropriate Medication Use in Older Adults. Arch Intern Med 2004; 163: 2716-2724.

Fillenbaum GG, Hanlon JT, Landerman LR et al. Impact of inappropriate drug use on health services utilization among representative older community-dwelling residents. Am J Geriatr Pharmacother 2004; 2(2): 92-101.

Finkel S, Kozma C, Long S et al. Risperidone treatment in elderly patients with dementia: relative risk of cerebrovascular events versus other antipsychotics. Int Psychogeriatr 2005; 17(4): 617-629.

Finnish Ministry of Justice, available in English at:
www.om.fi/Etusivu/Julkaisut/Esitteet/Holhoustoimipalvelut/Mitenedunvalvojanvoisaada?lang=en).

Folstein, MF, Folstein SE, McHugh PR.”Mini-mental state”. A practical method for grading the cognitive state of patients for the clinician. J Psychiatr Res 1975; 12:189-198.

Ford GA, Ballard C, Thomas SH: Anti-psychotic drug use in older people. Age & Ageing 2002; 31(4): 225-226.

Fu AZ, Liu GG, Christensen DB. Inappropriate medication use and health outcomes in the elderly. J Am Geriatr Soc 2004; 52(11):1934-1939.

Fuh JL, Wang SJ, Cummings JL. Neuropsychiatric profiles in patients with AD and vascular dementia. J Neurol Neurosurg Psychiatr 2005; 76(10): 1337-1341.

Galvard H, Samuelsson SM. Orthopedic or geriatric rehabilitation of hip fracture patients: a prospective, randomized, clinically controlled study in Malmö, Sweden. Aging 1995; 7(1): 11-16.

Ganzer C, England SE. Alzheimer’s care and service utilization: generating practice concepts from empirical findings and narratives.Health Soc Work 1994; 19(3): 174-181.

Gaugler JE, Kane RL, Kane RA, Clay T, Newcomer R. Caregiving and institutionalization of cognitively impaired older people: utilizing dynamic predictors of change. Gerontologist 2003; 43(2): 219-229.

Gaugler JE, Kane RL, Kane RA, Newcomer R. Early community-based service utilization and its effects on institutionalization in dementia caregiving. Gerontologist 2005a; 45(2):177-185.

Gaugler JE, Kane RL, Kane RA, Newcomer R. Unmet care needs and key outcomes in dementia. J Am Geriatr Soc 2005b; 53(12): 2098-2105.

Gilchrist WJ, Newman RJ, Hamblen DL, Williams BO. Prospective randomized study of an orthopedic geriatric inpatient service. Br Med J 1988; 297: 1116-1118.

Gill SS, Rochon PA, Herrmann N et al. Atypical antipsychotic drugs and the risk of ischaemic stroke: population based retrospective cohort study. Br Med J 2005; 330(7489): 445.

Gillespie WJ. Extracts from"Clinical Evidence". Hip fracture. Br Med J 2001; 322: 968-975.

Gilley DW, Bienias JL, Wilson RS, Bennett DA, Beck TL, Evans DA. Influence of behavioral symptoms on rates of institutionalization for persons with AD Psychol Med 2004; 34: 1129-1135.

Golden AG, Preston RA, Barnett SD, Llorente M, Hamdan K, Silverman MA. Inappropriate Medication Prescribing in Homebound Older Adults. J Am Geriatric Soc 1999; 47: 948- 953.

Gove D,Georges J. Perspectives on legislation relating to the rights and protection of people with dementia in Europe. Aging & Mental Health 2001; 5(4): 316-321.

Graeber MB, Kösel D, Grasbon-Frodl E, Möller HJ, Mehraein P. Histopathology and APOE genotype of the first Alzheimer disease patient, Auguste D. Neurogenetics 1998; 1:223-228.

Gray SL, Hedrick SC, Rhinard EE et al. Potentially inappropriate medication use in community residential carefacilities. Ann Pharmacother 2003; 37(7-8): 988-993.

Gurwitz JH, Field TS, Avorn J et al. Incidence and preventability of adverse drug events in nursing homes. Am J Med 2000; 109(2):87-94.

Hanlon JT, Fillenbaum GG, Schmader KE, Kuchibhatla M, Horner RD. Inappropriate drug use among community- dwelling elderly. Pharmacother 2000; 20(5): 575- 582.

Hanlon J, Fillenbaum G, Kuchibhatia M et al. Impact of inappropriate drug use on mortality and functional status in representative community dwelling elders. Med Care 2002; 40(2): 166- 176.

Hartikainen S, Rahkonen T, Kautiainen H, Sulkava R. Use of psychotropics among home-dwelling nondemented and demented elderly. Int J Geriatr Psychiatry 2003; 18(12): 1135-1141.

Herrmann N, Mamdani M, Lanctot KL. Atypical antipsychotics and risk of cerebrovascular accidents. Am J Psych 2004;161(6):1113-1115.

Holmquist IB, Svensson B, Hoglund P. Psychotropic drugs in nursing- and old-age homes: relationships between needs of care and mental health status. Eur J Clin Pharmacol 2003; 59(8-9): 669-676.

Hosia-Randell H, Pitkälä K. The use of psychotropic drugs among elderly nursing home residents with and without dementia in Helsinki, Finland. Drugs Aging 2005; 22(9):793-800.

Hughes CP, Berg L, Danziger WL, Coben LA, Martin RL. A new clinical scale for the staging of dementia. Br J Psychiatry 1982; 140: 566- 572.

Huusko TM, Karppi P, Avikainen V, Kautiainen H, Sulkava R. Randomised, clinically controlled trial of intensive geriatric rehabilitation in patients with hip fracture: subgroup analysis of patients with dementia. Br Med J 2000; 7269:1107-1111.

Huusko T, Arnala I, Hirvensalo E et al. Lonkkamurtuman Käypä hoito- suositus. (Treatment of patients with hip fracture – Finnish guidelines) In Finnish. Duodecim 2006; 122(3): 358-379.

Janowsky JS, McCarthy RJ, Folstein ME. The Hopkins Competency Assessment Test: A brief method for evaluating patients' capacity to give informed consent. Hosp Comm Psychiatry 1992; 43:132-136.

Janowsky JS, Rovner BW. Prevalence of advance directives and guardianship in nursing home patients. J Geriatr Psychiatry Neurol 1993; 6(4): 214-216.

Jette A, Harris BA, Cleary PD, Campion EW. Functional recovery after hip fracture. Arch Phys Med Rehabil 1987; 68: 735-740.

Jette AM, Tennstedt S, Crawford S. How does formal and informal community care affect nursing home use? J Gerontol B Psychol Sci Soc Sci 1995; 50(1): S4-S12.

Kane Mn. Legal guardianship and other alternatives in the care of elders with AD. Am J Alzheimers Dis Other Demen. 2001; 16(2): 89-96.

Kannus P, Niemi S, Parkkari J, Palvanen M, Vuori I, Jarvinen M. Nationwide decline in incidence of hip fracture. J Bone Miner Res 2006; 21(12):1836-1838.

Karlawish JH, Casarett DJ, James BD, Xie SX, Kim SY. The ability of persons with Alzheimer disease (AD) to make a decision about taking an AD treatment. Neurology 2005; 64(9):1514-1519.

Kaye Jeffrey. Care Givers in the Therapeutics of Dementia. In: Evidence-based dementia practise. Oxford, Blackwell Science Ltd, 2002, p.368.

Kennie DC, Reid J, Richardson IR, Kiamari AA, Kelt C. Effectiveness of geriatric rehabilitative care after fractures of the proximal femur in elderly women : a randomised clinical trial. Br Med J 1988; 297:1083-1086.

Kim SY, Karlawish JH, Caine ED. Current state of research on decision-making competence of cognitively impaired elderly persons.Am J Geriatr Psychiatry. 2002; 10(2):151-165. Review.

Kivipelto M, Ngandu T, Fratiglioni L, Viitanen M, Kareholt I, Winblad B, Helkala EL, Tuomilehto J, Soininen H, Nissinen A. Obesity and vascular risk factors at midlife and the risk of dementia and Alzheimer disease.Arch Neurol. 2005;62(10):1556-1560.

Kivipelto M, Solomon A. Cholesterol as a risk factor for Alzheimer's disease - epidemiological evidence. Acta Neurol Scand Suppl. 2006 a;185:50-7. Review.

Kivipelto M, Ngandu T, Laatikainen T, Winblad B, Soininen H, Tuomilehto J. Risk score for the prediction of dementia risk in 20 years among middle aged people: a longitudinal, population-based study. Lancet Neurol 2006 b; 5(9): 735-741.

Klarin I. Wimo A. Fastbom J. The association of inappropriate drug use with hospitalisation and mortality: a population-based study of the very old. Drugs Aging 2005; 22(1): 69-82.

Knopman D. AD. Clinical Picture. In: Evidence-based dementia practise. Oxford, Blackwell Science Ltd, 2002, p. 234-237.

Koponen H, Saarela T. Treatment of behavioral disorders. In: Memory Disorders and Dementia ed. Erkinjuntti T, Alhainen K, Rinne J, Soininen H. In Finnish. Duodecim 2006, pp. 501-514.

Kuokkanen HOM, Korkala OL. Factors affecting survival of patients with hip fractures. Acta Ortoped Belg 1992; 58: 425- 428.

Kuokkanen H, Räty S, Korkala O, Niskanen R, Syrjänen K. Osteosynthesis and allogenic bone grafting in complex osteoporotic fractures. Orthopedics 2001; 24:249-256.

Laitinen MH, Ngandu T, Rovio S, Helkala EL, Uusitalo U, Viitanen M, Nissinen A, Tuomilehto J, Soininen H, Kivipelto M. Fat intake at midlife and risk of dementia and Alzheimer's disease: a population-based study.Dement Geriatr Cogn Disord. 2006;22(1):99-107.

Lane J, Bronskill SE, Sykora K et al. Potentially Inappropriate Prescribing in Ontario Community-Dwelling Older Adults and Nursing Home Residents. J Am Geriatr Soc 2004; 52(6): 861-866.

Lasser RA, Sunderland T. Newer psychotropic medication use in nursing home residents. J Am Geriatr Soc1998; 46(2): 202-207.

Lau DT, Kasper JD, Potter DE, Lyles A. Potentially inappropriate medication prescriptions among elderly nursing home residents: their scope and associated resident and facility characteristics.
Health Serv Res 2004; 39(5): 1257-1276.

Lau DT, Kasper JD, Potter DE, Lyles A, Bennett RG. Hospitalization and death associated with potentially inappropriate medication prescriptions among elderly nursing home residents. Arch Intern Med. 2005; 165(1): 68-74.

Laurila JV, Pitkälä KH, Strandberg TE, Tilvis RS. The impact of different diagnostic criteria on prevalence rates for delirium. Dement Geriatr Cogn Disord 2003; 16: 156-162.

Laurila JV, Pitkala KH, Strandberg TE, Tilvis RS. Detection and documentation of dementia and delirium in acute geriatric wards. Gen Hosp Psychiatry. 2004a; 26(1): 31-35.

Laurila JV, Pitkala KH, Strandberg TE, Tilvis RS. Impact of different diagnostic criteria on prognosis of delirium: a prospective study. Dement Geriatr Cogn Disord 2004b; 18(3-4): 240-244.

Liperoti R, Mor V, Lapane KL, Pedone C, Gambassi G, Bernabei R. The use of atypical antipsychotics in nursing homes. J Clin Psych 2003; 64(9): 1106-1112.

Llorente MD, Olsen EJ, Leyva O, Silverman MA, Lewis JE, Rivero J. Use of antipsychotic drugs in nursing homes: current compliance with OBRA regulations. J Am Geriatr Soc 1998; 46(2): 198-201.

Lord Chancellor's Department: Making Decisions - helping people who have difficulty deciding for themselves. A guide for healthcare professionals, 2003.

Luethje P, Kataja M, Nurmi I, Santavirta S, Avikainen V. Four- year survival after hip fractures – an analysis in two Finnish health care regions. Ann Chirurg Gynaecol 1995; 84: 395-401.

Lundstrom M, Edlund A, Bucht G, Karlsson S, Gustafson Y. Dementia after delirium in patients with femoral neck fractures.J Am Geriatr Soc. 2003; 51(7): 1002-1006.

Lyketsos CG, Lopez O, Jones B, Fitzpatrick AL, Breitner J, DeKosky S. Prevalence of neuropsychiatric symptoms in dementia and mild cognitive impairment: results from the cardiovascular health study. JAMA 2002; 288: 1475-1483.

Löppönen M. Elderly Patients with Dementia in Primary Health care. A study of Diagnostic Work-Up, Co-Morbidity and Medication Use. Academic dissertation. Annales Universitas Turkuensis, 2006.

MaloneBeach EE, Zarit SH, Spore DL. Caregivers' perceptions of case management and community-based services: barriers to service use. J Appl Gerontol 1992; 11(2): 146-159.

Markson L, Clark J, Glantz L, Lamberton V, Kern D, Stollerman G. The doctor's role in discussing advance preferences for end-of-life care: perceptions of physicians practicing in the VA. J Am Geriatr Soc 1997 ;45(4): 399-406.

Maurer K, Volk S, Gerbaldo H. Auguste D and AD. Lancet 1997; 349: 1546-1549.

McGrath AM, Jackson GA. Survey of neuroleptic prescribing in residents of nursing homes in Glasgow. Br Med J 1996; 312(7031): 611-612.

McKhann G, Drachman D, Folstein M, Katzman R, Price D, Stadlan EM. Clinical diagnosis of Alzheimer's disease: report of the NINCDS-ADRDA Work Group under the auspices of Department of Health and Human Services Task Force on Alzheimer's Disease. Neurology. 1984; 34(7):939-44.

Medicines and Healthcare products Regulatory Agency. Summary of clinical trial data on cerebrovascular adverse events (CVAEs) in randomised clinical trials of risperidone conducted in patients with dementia: March 9, 2004. Available at: http://medicines.mhra.gov.uk. Accessibility verified September 6, 2005.

Mittelman MS, Ferris SH, Shulman E, Steinberg G, Levin B. A family intervention to delay nursing home placement of patients with Alzheimer disease. A randomized controlled trial. JAMA 1996; 276(21): 1725-1731.

Mäki-Petäjä-Leinonen A. Dementoituvan henkilön oikeudellinen asema. (Legal status of a person with dementia). Academic dissertation (English summary). Suomalainen lakimiesyhdistys 2003, A-sarja n:o 241.

Nankervis J, Schofield H, Herrman H, Bloch S. Home-based assessment for family carers: a preventative strategy to identify and meet service needs. Int J Geriatr Psychiatry 1997; 12(2):193-201.

Nasrallah HA, White T, Nasrallah AT. Lower mortality in geriatric patients receiving risperidone and olanzapine versus haloperidol: preliminary analysis of retrospective data. Am J Geriatr Psychiatry 2004; 12(4): 437-439.

NCSS (Number Cruncher Statistical System) program (www.ncss.com).

Ngandu T, Helkala EL, Soininen H, Winblad B, Tuomilehto J, Nissinen A, Kivipelto M. Alcohol drinking and cognitive functions: findings from the Cardiovascular Risk Factors Aging and Dementia (CAIDE) Study.Dement Geriatr Cogn Disord. 2007;23(3):140-149.

Noro A, Finne-Soveri H, Björkgren M, Vähäkangas P, eds. Ikääntyneiden laitoshoidon laatu ja tuottavuus – RAI- järjestelmä vertailukehittämisessä. (Quality and productivity in institutional care for elderly residents - benchmarking with the RAI). In Finnish. National Research and Development Centre for Welfare and Health (STAKES), Helsinki, 2005.

Oborne CA, Hooper R, Li KC, Swift CG, Jackson SH. An indicator of appropriate neuroleptic prescribing in nursing homes. Age Ageing 2002; 31(6): 435-439.

Oleske DM, Wilson RS, Bernard BA, Evans DA, Terman EW. Epidemiology of injury in people with AD. J Am Geriatr Soc. 1995; 43: 741-746.

Onder G, Landi F, Cesari M et al. Inappropriate medication use among hospitalized older adults in Italy: results from the Italian group of pharmacoepidemiology in the elderly. Eur J Clin Pharmacol 2003; 59(2):157-162.

Onder G, Landi F, Liperoti R, Fialova D, Gambassi G, Bernabei R. Impact of inappropriste drug use among hospitalized older adults. Eur J Clin Pharmacol 2005; 61(5-6):453-459.

Overman W Jr, Stoudemire A. Guidelines for legal and financial counseling of AD patients and their families. Am J Psychiatry 1988; 145(12): 1495-500. Review.

Parker MJ, Blundell C. Choice of implant for internal fixation of femoral neck fractures. Meta-analysis of 25 randomised trials including 4,925 patients. Acta Orthop Scand. 1998; 69(2): 138-143.

Perri M 3rd, Menon AM, Deshpande AD et al. Adverse outcomes associated with inappropriate drug use in nursing homes. Ann Pharmacother2005; 39(3): 405-411.

Phillips VL, Diwan S. The Incremental Effect of Dementia- Related Problem Behaviors on the Time to Nursing Home Placement in Poor, Frail, Demented Older People. J Am Ger Soc 2003; 51: 188-193.

Philp I, McKee KJ, Meldrum P et al. Community care for demented and non-demented elderly people: a comparison study of financial burden, service use, and unmet needs in family supporters. BMJ 1995; 310(6993): 1503-1506.

Piecoro LT, Browning SR, Prince TS, Ranz TT, Scutchfield FD. A database analysis of potentially inappropriate drug use in an elderly Medicaid population. Pharmacother 2000; 20(2): 221- 228.

Pitkala KH, Valvanne J, Kulp S, Strandberg TE, Tilvis RS. Secular trends in self-reported functioning, need for assistance and attitudes towards life: 10-year differences of three older cohorts. J Am Geriatr Soc 2001; 49(5): 596-600.

Pitkälä KH, Strandberg TE, Tilvis RS. Inappropriate Drug Prescribing in Home- Dwelling, Elderly Patients. A population- based survey. Arch Intern Med 2002; 162: 1707-1712.

Pitkala KH, Laakkonen ML, Strandberg TE, Tilvis RS. Positive life orientation as a predictor of 10-year outcome in an aged population. J Clin Epidemiol 2004; 57(4): 409-414.

Pitkälä KH, Laurila JV, Strandberg TE, Tilvis RS. Behavioural symptoms and the administration of psychotropic drugs to aged patients with dementia in nursing homes and in acute geriatric wards. Int Psychogeriat 2004; 16(1): 61- 74.

Pot AM, Deeg DJ, Knipscheer CP. Institutionalization of demented elderly: the role of caregiver characteristics. Int J Geriatr Psychiatry 2001; 16: 273-280.

Qizilbash N, Arrieta JL. Feeding Problems ans Weight Loss. In: Evidence-based dementia practise. Oxford, Blackwell Science Ltd, 2002, pp.733-734.

Rahkonen T, Luukkainen-Markkula R, Paanila S, Sivenius J, Sulkava R. Delirium episode as a sign of undetected dementia among community dwelling elderly subjects: a 2 year follow up study. J Neurol Neurosurg Psychiatry 2000; 69(4): 519-521.

Rolland Y, Pillard F, Klapouszczak A, Reynish E, Thomas D, Andrieu S, Riviere D, Vellas B. Exercise program for nursing home residents with Alzheimer's disease: a 1-year randomized, controlled trial. J Am Geriatr Soc. 2007;55(2):158-165.

Roman GC. Historical evolution of the concept of dementia: a systematic review from 2000 BC to AD 2000. In: Evidence-based dementia practise. Oxford, Blackwell Science Ltd, 2002, pp. 199-227.

Racoosin JA. Evaluating a safety signal in the postmarking period: cerebrovascular adverse events associated with risperidone and olanzapine. Paper presented at: 17th Annual Meeting of the American Association for Geriatric Psychiatry; February 21-24, 2004; Baltimore, Md.

Raivio M, Niskanen R, Korkala O, Kaukonen J, Tilvis R. Lonkkamurtumapotilas oppii harvoin varausrajoituksen (Hip fracture patient seldom learns weight-bearing restriction). In Finnish. Suom Lääkärilehti 2001; 15-16: 1731-1743.

Routasalo PE, Savikko N, Tilvis S, Strandberg TE, Pitkälä KH. Social contacts and their relationship to loneliness among aged people – a population-based study. Gerontology 2006; 52(3): 181-187.

Rovio S, Kareholt I, Helkala EL, Viitanen M, Winblad B, Tuomilehto J, Soininen H, Nissinen A, Kivipelto M. Leisure-time physical activity at midlife and the risk of dementia and Alzheimer’s disease. Lancet Neurol. 2005;4(11):705-711.

Rovio S, Kareholt I, Viitanen M, Winblad B, Tuomilehto J, Soininen H, Nissinen A, Kivipelto M. Related Articles, Work-related physical activity and the risk of dementia and Alzheimer’s disease. Int J Geriatr Psychiatry. 2007;22(9):874-882.

Ruggieri RM, Piccoli F. Legal and assistance aspects of AD: analysis of 100 cases. Neurol Sci. 2003; 24(3):125-129.

Ruths S, Straand J, Nygaard HA. Psychotropic drug use in nursing homes--diagnostic indications and variations between institutions. Eur J ClinPharmacol 2001; 57(6-7): 523-528.

Saarela M, Valvanne J. Geriatrisen kuntoutuksen vaikuttavuus (Effectiveness of geriatric rehabilitation). In Finnish. Duodecim 1999; 115: 1611-1618.

Saarenheimo M. Exploring the borderlines of family caregiving in Finland. In: Family Caregiving for Older Disabled People: Relational and Institutional Issues, Paoletti (eds). Nova Science Publishers, 2007.

Savikko N, Routasalo P, Tilvis RS, Strandberg TE, Pitkala KH. Predictors and subjective causes of loneliness in an aged population. Arch Gerontol Geriatr 2005; 41: 223-233.

Schneider J, Murray J, Banerjee S, Mann A. EUROCARE: a cross-national study of co-resident spouse carers for people with AD: Factors associated with carer burden. Int J Geriatr Psychiatry 1999; 14(8): 651-661.

Schneider Lon S, Dagerman Karen S, Insel Philip: Risk of death with atypical antipsychotic drug treatment for dementia: meta-analysis of randomized placebo-controlled trials. JAMA 2005; 294(15): 1934-1943.

Schneiderman H: Did the neuroleptics or the agitation increase the death rate? eLetter for Singh and Wooltorton. CMAJ 2005; 173(3): 252.

Simon SR, Chan A, Soumerai SB et al. Potentially Inappropriate Medication Use by Elderly Persons in U.S Health Maintenance Organizations, 2000- 2001. J Am Geriatr Soc 2005; 53(2): 227- 232.

Singh S, Wooltorton E: Increased mortality among elderly patients with dementia using atypical antipsychotics. CMAJ 2005; 173(3): 252.

Sink KM, Holden KF, Yaffe K: Pharmacological treatment of neuropsychiatric symptoms of dementia: a review of the evidence. JAMA 2005; 293(5): 596-608.

Snowden M, Roy-Byrne P. Mental illness and nursing home reform: OBRA-87 ten years later. Omnibus Budget Reconciliation Act. Psychiatric Services 1998; 49(2): 229-233.

Snowdon J. A follow-up survey of psychotropic drug use in Sydney nursing homes. Med J Australia 1999; 170(7):299-301.

Socialstyrelsen. Indikatorer for utvärdering av kvaliteten i äldres läkemedelsterapi. 2003.

Social Welfare Office, available at: http://www.kela.fi/in/internet/suomi.nsf/NET/131201115055HR?openDocument

Soininen H, Hänninen T. The diagnostics of memory disorders. In: Memory Disorders and Dementia. Duodecim, 2006.

Sorensen L, Foldspang A, Gulmann NC, Munk-Jorgensen P. Determinants for the use of psychotropics among nursing home residents. Int J Geriatr Psych 2001; 16(2): 147-154.

Spore DL, Mor V, Larrat P, Hawes C, Hiris J. Inappropriate Drug Presriptions for Elderly Residents of Board and Care Facilities. Am J Public Health 1997; 87: 404- 409.

Stuart B, Kamal-Bahl S, Briesacher B et al. Trends in the prescription of inappropriate drugs for the elderly between 1995 and 1999.Am J Geriatr Pharmacother 2003; 1(2): 61-74.

Stuck AE, Beers MH, Steiner A, Aronow HU, Rubenstein LZ, Beck JC. Inappropriate medication use in community- residing older persons. Arch Intern Med 1994; 154: 2195- 2200.

Suh GH, Shah A. Effect of antipsychotics on mortality in elderly patients with dementia: a 1-year prospective study in a nursing home. Int Psychogeriatr 2005; 17(3): 429-441.

Suominen M, Laine T, Routasalo P, Pitkala KH, Rasanen L. Nutrient content of served food, nutrient intake and nutritional status of residents with dementia in a finnish nursing home. J Nutr Health Aging. 2004;8(4):234-238.

Teri L, Gibbons LE, McCurry SM, Logsdon RG, Buchner DM, Barlow WE, Kukull WA, LaCroix AZ, McCormick W, Larson EB. Exercise plus behavioral management in patients with Alzheimer disease: a randomized controlled trial.JAMA 2003; 290(15):2015-2022.

Thomas P, Lalloue F, Preux PM et al. Dementia patients caregivers quality of life: the PIXEL study. Int J Geriatr Psychiatry 2006; 21: 50-56.

Tombaug TN, McIntyre NJ. Mini Mental State Examination: A comprehensive review. J Am Geriatr Soc 1992; 40: 922-935.

Toseland RW, McCallion P, Gerber T, Banks S. Predictors of health and human services use by persons with dementia and their family caregivers. Soc Sci Med 2002; 55(7): 1255-1266.

Wade DT, de Jong BA. Recent advances in rehabilitation. Br Med J 2000; 320: 1385-1388.

Wadley VG, Harrell LE, Marson DC. Self- and informant report of financial abilities in patients with AD: reliable and valid? J Am Geriatr Soc. 2003; 51(11): 1621-1626.

Vajanto I, Kuokkanen H, Niskanen R, Haapala J, Korkala O. Complications after treatment of proximal femoral fractures. Ann Chirurg Gynaecol 1998; 87: 49-52.

Waldorff FB, Rishoj S, Waldemar G. Identification and diagnostic evaluation of possible dementia in general practise. A prospective sudy. Scandinavian Journal of Primary Health Care 2005; 23(4):221-226.

van Dijk KN, de Vries CS, van den Berg PB, Brouwers JR, de Jong-van den Berg LT. Drug utilisation in Dutch nursing homes. Eur J Clin Pharmacol 2000; 55(10): 765-771.

Wang PS, Schneeweiss S, Avorn J et al. Risk of Death in Elderly Users of Conventional vs. Atypical Antipsychotic Medications. N Engl J Med 2005; 535(22): 2335-2341.

Wattis JP, Grant W, Traynor J, Harris S. Use of guardianship under the 1983 Mental Health Act. Med Sci Law 1990; 30(4): 313-316.

Wechsler D. The Measurement and Appraisal of Adult Intelligence. Williams&Wilkins 1958, Baltimore, MD.

Williams B, Betley C. Inappropriate use of nonpsychotropic medications in nursing home. J Am Geriatric Soc 1995; 43(5): 513-519.

Willcox SM, Himmelstein DU, Woolhandler S. Inappropriate drug prescibing for the community-dwelling elderly. JAMA 1994; 272: 292- 296.

Wilson RS, Krueger KR, Kamenetsky JM et al. Hallucinations and mortality in Alzheimer disease. Am J Geriatr Psychiatry 2005; 13(11): 984-990.

Viramo P, Frey H. The health and economical meaning of dementia. In: Memory Disorders and Dementia ed. Erkinjuntti T, Alhainen K, Rinne J, Soininen H. In Finnish. Duodecim 2006, pp. 40-52.

Viramo P, Sulkava R. Epidemiology of the memory disorders and dementia. In: Memory Disorders and Dementia ed. Erkinjuntti T, Alhainen K, Rinne J, Soininen H. In Finnish. Duodecim 2006, pp. 23-39.

Wolf-Klein BP, Silverstone FA. Weight loss in AD: an international review of the literature. Int Psychogeriatr. 1994; 6: 135-142.

Woods B, Pratt R. Awareness in dementia: ethical and legal issues in relation to people with dementia. Aging Ment Health. 2005; 9(5): 423-429. Review.

Wooltorton E. Olanzapine increased (Zyprexa) increased incidence of cerebrovascular events in dementia trials. CMAJ 2004; 170(9): 1395.

Wooltorton E. Risperidone (Risperdal) increased rate of cerebrovascular events in dementia trials. CMAJ 2002; 167(11): 1269-1270.

Young J. Rehabilitation and older people. Br Med J 1996; 313: 677-681.

Zarit SH, Gaugler JE, Jarrott SE. Useful services for families: research findings and directions. Int J Geriatr Psychiatry 1999; 14(3):165-77; discussion 178-181.

Zarit SH, Leitsch SA.Developing and evaluating community based intervention programs for Alzheimer's patients and their caregivers. Aging Ment Health 2001; 5 Suppl 1: S84-S98.

Zhan C, Sangl J, Bierman A et al. Potentially Inapproproate Medication Use in the Community- Dwelling Elderly. Findings From the 1996 Medical Expenditure Panel Survey. JAMA 2001; 286(22): 2823-2829.

12 APPENDICES

VANHUSTYÖN KESKUSLIITON KIRJEKYSELY

15.9.2005 Helsinki

Hyvä vastaanottaja!

Teemme tutkimusta omaishoitajien saamista palveluista ja tuesta sekä niiden tarpeesta. Kelan rekisteritiedon mukaan puolisonne sairastaa dementoivaa sairautta ja sen vuoksi olette mahdollisesti saanut tai ollut tekemisissä joidenkin tukipalveluiden kanssa. Toivoisimme Teidän vastaavan oheiseen kyselyyn joka tapauksessa, vaikka ette mitään palvelua olisi saanutkaan. Tarkoituksenamme on kartoittaa palveluiden alueellista jakaantumista Suomessa. Haluamme selvittää omaisten kokemuksia dementiaa sairastavan hoidosta sekä tutkia, miten erilaiset dementiaan liitetyt oireet ja omaishoitajan terveys ovat yhteydessä palveluiden ja tuen saatiin.

Tutkimuksen perusteella voidaan palveluita kehittää paremmin vastaamaan omaishoitoperheiden tarpeita.

Tutkimukseen osallistuminen on vapaaehtoista. Kerättävät tiedot ovat luottamuksellisia, ja ne julkaistaan niin, että yksittäistä vastaajaa ei pystytä niistä tunnistamaan. Tutkimuksen kaikissa vaiheissa tullaan noudattamaan henkilötietolain ja potilastietosuojalain säännöksiä. Tutkimukseen osallistuminen ei vaikuta muuhun mahdolliseen hoitoonne ja saamiinne palveluihin.

Vastatkaa kysymyksiin ja palauttakaa lomake 21.11.2005 mennessä oheisessa palautuskuoressa.

Tarvittaessa lisätietoja tutkimuksesta antaa geriatrian erikoislääkäri
Minna Raivio p. 040- 415 3122.

Ystävällisin terveisin

Reijo Tilvis
Geriatrian professori
HYKS Helsingin
Yliopistollinen
Keskussairaala

Kaisu Pitkälä
LKT Geriatrian erikoislääkäri
Tutkimusjohtaja
Vanhustyön keskusliitto

VASTAAMISEN OHJEITA

Tämä on kysely dementiaa sairastavan puolisolle. Pyydämme Teitä lukemaan koko kysymyksen ennen vastaamista. Rengastakaa mielestänne lähinnä oikea vaihtoehto ja vain yksi vaihtoehto, jos kysymyksessä ei ole toisin mainittu. Tarvittaessa täyttäkää kysytty tieto sitä varten varattuun tilaan.

ESIMERKKI:

Mikä on siviilisäätynne?

1. **naimisissa_tai avoliitossa, _____________ vuotta**
2. **naimaton**
3. **asumuserossa tai eronnut**
4. **leski** (olen ollut leskenä ____vuotta)

Jos olette naimisissa puolisonne kanssa, rengastakaa kohta 1 ja kirjoittakaa tyhjään tilaan avioliittovuosien määrä.

Yrittäkää vastata kaikkiin kysymyksiin.

Pyytäkää tarvittaessa apua lähiomaiseltanne tai läheiseltänne.

Vastauksenne ovat ehdottoman luottamuksellisia.

Täytetyn lomakkeen voitte laittaa oheisessa jo valmiiksi maksetussa palautuskirjekuoressa postilaatikkoon.

Osoitelähde: Kansaneläkelaitos Alzheimer lääkettä saavien rekisteri

ALUKSI KYSYMME TAUSTATIETOJANNE

1. Mikä on Teidän siviilisäätynne?

1. naimisissa tai avoliitto _____ vuotta
2. naimaton
3. asumuserossa tai eronnut
4. leski (olen ollut leskenä _____ vuotta)

2. Mikä on sukupuolenne?

1. nainen
2. mies

3.a. Ikänne ________

3.b. Puolisonne ikä ________

4.a. Koulutuksenne?

1. kansakoulu tai vähemmän
2. ammattikoulu
3. keskikoulu
4. lukio
5. opistoasteen ammattikoulutus
6. korkeakoulu

4.b. Puolisonne koulutus

1. kansakoulu tai vähemmän
2. ammattikoulu
3. keskikoulu
4. lukio
5. opistoasteen ammattikoulutus
6. korkeakoulu

5. Asutteko puolisonne kanssa

1 Kyllä 2 Ei

6. Missä asutte?

1. kotona
2. palvelutalossa
3. pysyvästi vanhainkodissa tai hoivakodissa
4. pysyvästi sairaalassa
5. muualla, missä ____

7. Hoidatteko kotona dementiaa sairastavaa puolisoanne?

1 Kyllä 2 Ei

8. Jos puolisonne ei asu kanssanne, missä hän asuu

1. Palvelutalossa
2. Pysyvästi vanhainkodissa tai hoivakodissa
3. Pysyvästi sairaalassa
4. Muualla, missä? ____

9. Miten tulette taloudellisesti toimeen?

1. hyvin
2. kohtuullisesti
3. huonosti

SEURAAVAKSI KYSYMME TEIDÄN JA PUOLISONNE NYKYISESTÄ TERVEYDENTILASTA JA TOIMINTAKYVYSTÄ

10. Millaisena pidätte <u>omaa</u> terveydentilaanne tällä hetkellä?

1. Pidän itseäni terveenä
2. Pidän itseäni melko terveenä
3. Pidän itseäni sairaana
4. Pidän itseäni hyvin sairaana

11.a. Onko <u>oma</u> toimintakykynne tai kuntonne yleisesti ottaen tällä hetkellä mielestänne

1. erittäin hyvä
2. hyvä
3. keskinkertainen
4. huono
5. erittäin huono

11.b. Onko puolisonne toimintakyky tai kunto yleisesti ottaen tällä hetkellä mielestänne

1. erittäin hyvä
2. hyvä
3. keskinkertainen
4. huono
5. erittäin huono

12 a. Onko oma yleiskuntonne sellainen että pystytte vaivatta liikkumaan sisällä?

1. Kyllä
2. ei, tarvitsen kepin tai rollaattorin
3. ei, tarvitsen toisen henkilön tukea
4. ei, en pysty kävelemään

12. b. Onko puolisonne yleiskunto sellainen että hän pystyy vaivatta liikkumaan sisällä?

1. Kyllä
2. ei, hän tarvitsee kepin tai rollaattorin
3. ei, hän tarvitsee toisen henkilön tukea
3. ei, hän ei pysty kävelemään

12. c. Onko puolisollanne seuraavia liikkumista haittaavia oireita?

1. Jäykkyyttä	a. kyllä	b. ei
2. Huimausta	a. kyllä	b. ei
3. Lihasheikkoutta	a. kyllä	b. ei
4. Kipuja	a. kyllä	b. ei

SEURAAVAKSI MUUTAMA KYSYMYS ELÄMÄNASENTEISTANNE

13. Oletteko tyytyväinen elämäänne? 1 kyllä 2 en

14. Tunnetteko itsenne tarpeelliseksi? 1 kyllä 2 en

15. Onko Teillä tulevaisuudensuunnitelmia? 1 kyllä 2 ei

16. Onko Teillä elämänhalua? 1 kyllä 2 ei

17. Oletteko masentunut?

1. harvoin tai ei koskaan
2. toisinaan
3. usein tai aina

18. Kärsittekö yksinäisyydestä?

1. harvoin tai ei koskaan
2. toisinaan
3. usein tai aina

SEURAAVAKSI KYSYMME TEILLE TÄRKEISTÄ IHMISISTÄ JA SEURAELÄMÄSTÄNNE

19. Millaisena koette nykyisen suhteen puolisoonne?

1. Erittäin tyydyttävänä
2. Tyydyttävänä
3. Keskinkertaisena
4. Epätyydyttävänä
5. Erittäin epätyydyttävänä

20. Onko Teillä lapsia (elossa olevia)? 1 Kyllä 2 Ei

21. Tapaatteko lapsianne niin usein kuin haluaisitte? 1 Kyllä 2 En

22. Onko Teillä ystäviä, joihin pidätte säännöllisesti yhteyttä?
1 Kyllä 2 Ei

23. Tapaatteko ystäviänne niin usein kuin haluaisitte? 1 Kyllä 2 En

24. Tuntuuko Teistä että läheisenne ymmärtävät elämäntilannettanne?

1. läheiseni ymmärtävät hyvin
2. läheiseni ymmärtävät kohtalaisesti
3. läheiseni eivät ymmärrä

SEURAAVAKSI KYSYMME PUOLISONNE DEMENTIAAN MAHDOLLISESTI LIITTYVISTÄ OIREISTA

25. Edellyttääkö puolisonne hoito jatkuvaa läsnäoloanne?
1 Kyllä 2 Ei, voin jättää häntä yksin vuorokauden aikana keskimäärin ______ tunniksi

26. Vaikuttaako puolisonne surulliselta tai masentuneelta?
1 Kyllä 2 Ei

27. Onko puolisonne ajoittain levoton, ahdistunut tai ärtyisä?
1 Kyllä 2 Ei

28. Onko tilanteita, jolloin puolisonne kieltäytyy yhteistyöstä tai ei ota vastaan apua?
1 Kyllä 2 Ei

29. Onko puolisollanne aistiharhoja, esimerkiksi näkö- tai kuuloharhoja? Vaikuttaako siltä, että hän näkee, kuulee tai kokee olemattomia asioita?

1 Kyllä 2 Ei

30. Onko puolisollanne virtsan tai ulosteen pidätysvaikeuksia?

1. Kyllä 2. Ei

SEURAAVAKSI KYSYMME NYKYISESTÄ ARKIELÄMÄSTÄNNE JA JAKSAMISESTANNE

31. Miten koette itse sopeutuneenne puolisonne sairauteen?

1. Hyvin
2. Kohtalaisesti
3. Huonosti

32. Koetteko puolisonne hoitamisen henkisesti rasittavana?

1 Kyllä 2 Ei

33. Estääkö puolisonne hoitaminen Teitä ottamasta osaa normaaliin kanssakäymiseen muiden ihmisten kanssa? (kuten vierailut ystävien luo, vapaa-ajan harrastukset)?

1. Kyllä 2. Ei

34. Onko puolisonne hoitaminen ruumiillisesti raskasta?

1. Kyllä 2. Ei

35. Häiritseekö puolisonne sairaus yöuntanne?

1. Kyllä 2. Ei

36. Oletteko joutunut muuttamaan uuteen asuntoon puolisonne sairauden aikana tai sen vuoksi?

1. Kyllä 2. Ei

SEURAAVAKSI KYSYMME PUOLISONNE DEMENTIAAN LIITTYVÄSTÄ TIEDONSAANNISTA

37. Milloin Teidän mielestänne puolisollanne alkoi esiintyä muistivaikeuksia tai muita dementiaoireita?

1. Alle vuosi sitten
2. 1-2 vuotta sitten
3. 3-4 vuotta sitten
4. 5 vuotta tai yli 5 vuotta sitten

38. Missä puolisonne dementiaa selvittävät tutkimukset tehtiin? (rengastakaa yksi tai useampia seuraavista)

1. terveysasemalla
2. sairaalan poliklinikalla
3. yksityislääkärin vastaanotolla
4. muualla, missä____

39. Kun puolisonne muistin heikentymisen vuoksi tehtyjen tutkimusten tulokset valmistuivat, olitteko vastaanotolla mukana kuulemassa tutkimustuloksia?

1. Kyllä 2. Ei

40. Kerrottiinko puolisollenne tai Teille suoraan, että kyse voi olla dementiasta?

1. Kyllä 2. Ei

41. Jos puolisollenne tai Teille kerrottiin dementiasta, puhuttiinko siinä yhteydessä dementian oireista ja kestosta?

1. Kyllä
2. Kyllä, muttei riittävästi
3. Ei lainkaan

42. Oletteko mielestänne saanut riittävästi tietoa puolisonne dementiasairaudesta ja sen oireista?

1. Kyllä 2. Ei

43. Mistä olette saanut tietoa? (rengastakaa yksi tai useampia seuraavista)

1. Lääkäriltä
2. Muilta terveydenhuollon tai sosiaalihuollon työntekijöiltä
3. Vapaaehtoisjärjestöiltä (esimerkiksi Alzheimer- tai dementiayhdistyksiltä)
4. Tiedotusvälineistä, kirjoista
5. Omaisilta, ystäviltä
6. Muualta, mistä? ____

44. Missä dementiasairauden jatkohoito tapahtui (rengastakaa yksi tai useampia seuraavista)

1. terveysasemalla
2. sairaalan poliklinikalla
3. yksityislääkärin vastaanotolla
4. muualla, missä ____
5. ei missään

45. Onko dementiasairauden jatkohoito järjestetty mielestänne hyvin?

1 Kyllä 2 Ei

46. Onko puolisonne tai oletteko Te itse kertonut puolison dementiasairaudesta läheisillenne, esim. lapsillenne?

1 Kyllä 2 Ei

47. Onko puolisonne tai oletteko Te itse kertonut puolison dementiasairaudesta ystävillenne?

1 Kyllä 2 Ei

48. Aiheuttiko tietoisuus sairaudesta ja sen kulusta masennusta puolisollenne?

1 Kyllä 2 Ei

49. Aiheuttiko tietoisuus sairaudesta ja sen kulusta masennusta Teille?

1 Kyllä 2 Ei

50. Onko mielestänne hyvä asia, että lääkäri kertoo potilaalle

a) suoraan dementiasairauden diagnoosin? 1 Kyllä 2 Ei
b) dementiaan liittyvistä oireista ja ongelmista 1 Kyllä 2 Ei

51. Onko mielestänne hyvä asia, että lääkäri kertoo omaiselle

a) suoraan dementiasairauden diagnoosin? 1 Kyllä 2 Ei

b) dementiaan liittyvistä oireista ja ongelmista ? 1 Kyllä 2 Ei

SEURAAVAKSI KYSYMME TEILTÄ, MITEN OLETTE VARAUTUNEET MAHDOLLISEEN TERVEYDENTILAN MUUTOKSEEN

52. Oletteko tehneet valtakirjan pankissa tai jonkin laajemman valtuutuksen puolisonne taloudellisten asioiden hoidon helpottamiseksi?

1 Kyllä 2 Ei

53. Oletteko hakeneet virallista edunvalvojaa puolisollenne taloudellisten tai muiden asioiden hoidon helpottamiseksi?

1 Kyllä 2 Ei

a) Oletteko keskustellut näistä asioista puolisoanne hoitavan lääkärin kanssa?

1 Kyllä 2 Ei

b) Haluaisitteko keskustella näistä asioista puolisoanne hoitavan lääkärin kanssa?

1 Kyllä 2 Ei

54. Oletteko keskustelleet puolisonne kanssa hänen hoitotoiveistaan mahdollisen vakavan sairauden varalle?

1 Kyllä 2 Ei

a) Onko puolisonne kirjannut paperille henkilökohtaisia hoitotoiveitaan (nk. hoitotestamentti) vakavan sairauden varalle? 1 Kyllä 2 Ei

b) Oletteko keskustellut näistä asioista puolisonne lääkärin kanssa?

1 Kyllä 2 Ei

c) Haluaisitteko keskustella näistä asioista puolisoanne hoitavan lääkärin kanssa?

1 Kyllä 2 Ei

ALLA ON LUETELTU JULKISIA PALVELUJA. RENGASTAKAA JOKAISEEN KOHTAAN, ONKO PERHEENNE SAANUT KYSEISTÄ PALVELUA JA OLISIKO PERHEELLÄNNE OLLUT TARVE SAADA TÄTÄ PALVELUA.

55. Kotiin tuodut sairaanhoidolliset palvelut puolisollenne
(esim. lääkkeiden jako, haavanhoito)

a Onko puolisonne saanut tätä palvelua? 1 Kyllä 2 Ei

b Jos puolisonne ei ole saanut, olisiko hänellä ollut tarvetta tähän palveluun?
1 Kyllä 2 Ei

56. Kotiin tuotu apu puolisonne henkilökohtaisissa toimissa (esim. peseytyminen tai muu päivittäisissä tarpeissa avustaminen)

a Onko puolisonne saanut tätä palvelua? 1 Kyllä 2 Ei

b Jos puolisonne ei ole saanut, olisiko hänellä ollut tarvetta tähän palveluun?
1 Kyllä 2 Ei

57. Siivouspalvelu

a Oletteko saanut tätä palvelua? 1 Kyllä 2 Ei

b Jos ette ole saanut, olisiko Teillä ollut tarvetta tähän palveluun?
1 Kyllä 2 Ei

58. Ateriapalvelu

a Oletteko saanut tätä palvelua? 1 Kyllä 2 Ei

b Jos ette ole saanut, olisiko Teillä ollut tarvetta tähän palveluun?
1 Kyllä 2 Ei

59. Fysioterapia (kuntoutus)

a Onko puolisonne saanut tätä palvelua? 1 Kyllä 2 Ei

b **Jos puolisonne ei ole saanut, olisiko hänellä ollut tarvetta tähän palveluun?**

1 Kyllä 2 Ei

60. Kunnan toimesta järjestetty apuväline (esim. WC-istuimen koroke, rollaattori)

a Onko puolisonne saanut tätä palvelua? 1 Kyllä 2 Ei

b Jos puolisonne ei ole saanut, olisiko hänellä ollut tarvetta tähän palveluun?

1 Kyllä 2 Ei

61. Kuljetustuki (yhteiskunnan kustantama taksikortti tai muu kuljetuspalvelu)

a Onko puolisonne saanut tätä palvelua? 1 Kyllä 2 Ei

b Jos puolisonne ei ole saanut, olisiko hänellä ollut tarvetta tähän palveluun?

1 Kyllä 2 Ei

62. Kunnan toimesta annetut vaipat

a Onko puolisonne saanut tätä palvelua? 1 Kyllä 2 Ei

b **Jos puolisonne ei ole saanut, olisiko hänellä ollut tarvetta tähän palveluun?**

1 Kyllä 2 Ei

63. Päivätoiminta

a Onko puolisonne saanut tätä palvelua? 1 Kyllä 2 Ei

b Jos puolisonne ei ole saanut, olisiko hänellä ollut tarvetta tähän palveluun?

1 Kyllä 2 Ei

64. Lyhytaikaishoitojakso (esim. ns. intervallijakso vanhainkodissa tai muussa hoitopaikassa)

a Onko puolisonne saanut tätä palvelua? 1 Kyllä 2 Ei

b Jos puolisonne ei ole saanut, olisiko hänellä ollut tarvetta tähän palveluun?

1 Kyllä 2 Ei

65. Kotiin tuleva sijaishoitaja joka mahdollistaa Teidän irrottautumisenne puolisonne hoidosta

a Oletteko saanut tätä palvelua? 1 Kyllä 2 Ei

b Jos ette ole saanut, olisiko Teillä ollut tarvetta tähän palveluun?

1 Kyllä 2 Ei

66. Kunnan Teille maksama rahallinen korvaus työstänne omaishoitajana

(omaishoidontuki)

a Oletteko saanut tätä tukea ? 1 Kyllä 2 Ei

b Jos ette ole saanut, olisiko Teillä ollut tarvetta tähän tukeen? 1 Kyllä 2 Ei

67. Teille kunnan antamat palvelusetelit, joilla olette voinut ostaa puolisonne hoitoon tarvittavia yksityisiä palveluja?

a Oletteko saanut tätä palvelua? 1 Kyllä 2 Ei

b Jos ette ole saanut, olisiko Teillä ollut tarvetta tähän palveluun? 1 Kyllä 2 Ei

68. Oletteko ollut tyytyväinen saamiinne tukipalveluihin?

a. erittäin tyytyväinen
b. melko tyytyväinen
c. en tyytyväinen enkä tyytymätön
d. melko tyytymätön
e. erittäin tyytymätön

LOPUKSI KYSYMME VIELÄ PERHEENNE SAAMASTA MUUSTA TUESTA.

70. Oletteko Te osallistunut omaishoitajien tukiryhmiin (esimerkiksi vertaistukitoimintaan)?

1 Kyllä 2 Ei

71. Jos ette ole osallistunut omaishoitajien tukiryhmiin, olisiko Teillä tarvetta tällaiseen ryhmätoimintaan?

1 Kyllä 2 Ei

72. Onko puolisonne sotaveteraani tai sotainvalidi?

1 Kyllä 2 Ei

73. Onko puolisonne saanut viimeisen vuoden aikana sotainvalidi- tai veteraanikuntoutusta?

1 Kyllä 2 Ei

74. Oletteko hankkinut perheellenne yksityisesti seuraavia palveluja (ympyröikää kaikki käyttämänne palvelut)

1 Kotiin tuodut sairaanhoidolliset palvelut puolisollenne
2 Kotiin tuotu apu puolisonne henkilökohtaisissa toimissa
3 Ateriapalvelu
4 Siivouspalvelu
5 Kotiin tuleva sijaishoitaja, joka mahdollistaa Teidän irrottautumisenne puolisonne hoidosta
6 Fysioterapia (kuntoutus)
7 Apuväline
8 Vaipat
9 Päivätoiminta
10 Lyhytaikaishoito (esim. ns intervallijakso vanhainkodissa tai muussa hoitopaikassa)

75. Onko teidän ollut helppo saada tietoa tarjolla olevista tukipalveluista dementiaperheille?

a. erittäin helppoa
b. melko helppoa
c. ei helppoa eikä vaikeaa
d. melko vaikeaa
e. erittäin vaikeaa

76. Saatteko mielestänne riittävästi käytännöllistä apua puolisonne hoitamiseen?

1. Lapsiltanne	a. Kyllä	b. En
2. Ystäviltänne	a. Kyllä	b. En
3. Muilta sukulaisilta tai tuttavilta	a. Kyllä	b. En
4. Oman kunnan palveluilta	a. Kyllä	b. En
5. Muualta, mistä_____________		

77. Saatteko mielestänne riittävästi henkistä tukea puolisonne hoitamiseen?

1. Lapsiltanne	a. Kyllä	b. En
2. Ystäviltänne	a. Kyllä	b. En
3. Muilta sukulaisilta tai tuttavilta	a. Kyllä	b. En
4. Oman kunnan palveluilta	a. Kyllä	b. En
5. Muualta, mistä ______________		

78. Onko teillä selkeä käsitys, keneen/ minne otatte yhteyttä, jos puolisonne sairaudessa tulee ongelmatilanteita?

1 Kyllä, keneen/ minne ____

2 Ei

79. Oletteko saanut julkisia palveluja puolisonne hoitoon silloin, kun olette niitä tarvinnut?

1 Kyllä 2 Ei

80. Oletteko mielestänne voinut vaikuttaa riittävästi siihen, mitä julkisia palveluita perheenne saa?

1 Kyllä 2 Ei

81. Millaisia ongelmia olette kohdannut palveluita tarvitessanne?

Sydämellinen kiitos vaivannäöstänne!