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Supporting community care of demented patients

Doctoral Dissertation

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ABSTRACT

Demented patients are placed in long-term institutional care at a higher rate than non-demented elderly people. In Finland, 40 to 50% of all demented patients are in long-term institutional care. This lays a heavy economic burden on the social and health care system. Managing community care of demented patients relies largely on family members, especially on spouses who are often committed to continue in caregiving even at more advanced stages of dementia. Institutional respite care may provide relief to a caregiver but often deteriorates a patient's functional capacity and may increase the risk for institutionalization.

The aims of the present study were to study (1) the effects of a nurse case manager (NCM) intervention on community care of elderly people with cognitive impairment, (2) the effects of institutional respite care on demented patients' functional capacity, and (3) the influence of dementia on marriage.

The Kuopio Dementia Study and the Kuopio Delirium Study were used to study the effects of NCM intervention. The main population of the Kuopio Dementia Study comprised 100 patients living in the community and receiving primary support from an informal caregiver in eastern Finland. Patients were recruited from the register of the Social Insurance Institution and randomly allocated to either the intervention (n=53) or control group (n=47). Intervention patients with their caregivers were provided with a 2-year intervention by a NCM. The intervention patients (n=51) participating in the Kuopio Delirium Study were provided with similar intervention by a NCM. In the Kuopio Dementia Study, the intervention by a NCM deferred placement in long-term institutional care. Results also suggest that the intervention used in the study may be especially beneficial to patients with severe dementia and those with problems threatening the continuity of community care. In the Kuopio Delirium Study, 67% of the intervention patients were diagnosed as having dementia in the three-year follow-up. The survival in community care was significantly longer in the intervention than in the control patients. In both studies, the need for intervention by NCMs increased remarkably when a problematic situation arose. After diagnosing the cause of the problem, the NCMs implemented measures that often requiring consultation with the study physician.

To evaluate the long-term effect of the intervention by NCM, semi-structured telephone interviews were used to collect further data on all those caregivers (n=64) in the Kuopio Dementia Study who had experienced cessation of caregiving. Community care support had protected the caregivers from loneliness, depressive feelings and sorrow. An increased amount of leisure activities was associated with the intervention group. Cessation of caregiving caused more negative emotional reactions and provided less relief to the spouse than to non-spouse caregivers.

To investigate influence of dementia on marriage, further data were collected by telephone interviews with the spouse caregivers in the Kuopio Dementia Study. Spouse caregivers (n=42) felt that dementia had had a major negative impact on many dimensions of their marital relationship. However, the results also indicate that some positive aspects were preserved in the marriage after the onset of dementia. In one-third of the patients, expressions of tenderness towards the caregiver had increased. Dementia did not significantly affect the general atmosphere of the marriage. Dementia seemed to have surprisingly little impact on whether the couple continued to have sexual intercourse as compared with the general aging population.

To evaluate whether institutional respite care of demented patients is possible without deterioration of cognitive and functional capacity, the data of patients in respite care in two special care units (SCU), one in Helsinki and one in Vaasa were collected. The patients' MMSE scores improved significantly in both SCUs. The caregivers reported improvement in the functional capacity of 40% of the patients in SCU 1 and 26% in SCU 2. The positive changes in the patients' mood were common (in 76% and 68% of the patients in SCU 1 and SCU 2, respectively).

In conclusion, NCM intervention proved to be effective in prolonging the community care of elderly people with cognitive impairment. The intervention also had long-term effects on the caregivers of demented patients and helped them to return to a normal life with an increased amount of leisure activities. The cessation of caregiving provided less relief to spouse caregivers, and even tended to give rise to negative life changes. Dementia had a major negative impact on many dimensions of marriage. However, there were also some positive changes and aspects of marriage preserved that may explain why especially spouse caregivers are often committed to continue in caregiving even at more advanced stages of dementia.

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*To Raimo and to my children
Amia, Miikus, Henri, Konsta, Joel and Maria*

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Helsinki May 1st, 2002

Ulla Eloniemi-Sulkava

ABBREVIATIONS

ADL	Activities of daily living
BPSD	Behavioral and psychological symptoms of dementia
CERAD	Consortium to Establish a Registry for Alzheimer's Disease
CGIC	Clinical General Impression of Change
CI	Confidence interval
CM	Case manager
DSM-III-R	The third edition of the Diagnostic and Statistical Manual of Mental Disorders, revised
DSM-IV	The fourth edition of the Diagnostic and Statistical Manual of Mental Disorders
MMSE	Mini-Mental State Examination
n	Number
NCM	Nurse case manager
OR	Odds ratio
SCU	Special care unit
SD	Standard deviation

LIST OF ORIGINAL PUBLICATIONS

- I** Eloniemi-Sulkava U, Notkola I-L, Hentinen M, Kivelä S-L, 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.
- II** Rahkonen T, Eloniemi-Sulkava U, Paanila S, Halonen P, Sivenius J, Sulkava R. Systematic intervention for supporting community care of elderly people after a delirium episode. *Int Psychogeriatr* 2001; 13: 37-49.
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- IV** Eloniemi U, Tervala J, Sulkava R. Special Care Units (SCUs) are efficient in respite care of demented patients. *Res Pract Alzheimer Dis* 1998; 1: 223-232.
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1. INTRODUCTION

There are approximately 80 000 patients with moderate and severe dementia in Finland (Viramo and Sulkava 2001). The number of patients is expected to increase to 128 000 by the year 2030. The cost of demented patients imposes a heavy economic burden on the social and health care system (Livingston et al. 1997, Gutterman et al. 1999). Studies show that demented patients tend to be placed in long-term institutional care at a higher rate than non-demented elderly people (Severson et al. 1994, Smith et al. 2000). In Finland, 40 to 50% of all demented patients are in long-term institutional care (Viramo and Sulkava 2001). Another important group of the elderly at great risk of becoming institutionalized is comprised of those patients suffering a delirium episode (Francis et al. 1990, Levkoff et al. 1992). This group also has been shown to have an increased risk for dementia (Rockwood et al. 1999, Rahkonen et al. 2000).

Patients and their caregivers often prefer community care (Yamamoto et al. 1997). Especially spouse caregivers are often committed to continue caregiving even at more advanced stages of dementia (Pruchno and Potashnik 1989).

There are both patient and caregiver variables which have been found to be predictors of institutionalization in community-living demented patients. Behavioral and psychological symptoms (BPSD), functional disabilities and severity of dementia are often reported as patient variables (Gold et al. 1995, Hope et al. 1998, Juva et al. 1997). Such caregiver variables as caregiver distress, female sex and being a non-spouse caregiver are important predictors of institutionalization (Brodaty et al. 1993, Vernooij-Dassen et al. 1997, Hope et al. 1998). The above-mentioned patient variables usually lead to caregiver distress. Furthermore, one risk factor for institutionalization may be an unsatisfied marital relationship experienced by spouse caregivers (Wright 1994).

Intervention studies supporting community care have been primarily focused on the caregiver variables that pose a threat to the continuity of community care. Promising results have been obtained from those studies in which several types of interventions with the caregiver and family training have been tested in order to decrease caregiver burden, as well as to provide

education and support the management of BPSD (Mohide et al. 1990, Mittelman et al. 1996, Brodaty et al. 1997, Marriott et al. 2000, Hepburn et al. 2001).

The cessation of caregiving may not necessarily have only positive effects on caregivers, even when the caregivers might have experienced burdens during the care. Especially spouse caregivers are known to have difficulties in coping with the situation and may themselves experience increased health problems (Kiecolt-Glaser et al. 1991, Kaplan and Boss 1999, Rudd et al. 1999).

The present study was undertaken to determine whether the community care of demented patients can be prolonged through two-year support program that primarily focused on those patient variables predicting institutionalization. The support program was based on case management. Since delirious elderly patients have an increased risk for dementia (Rockwood et al. 1999, Rahkonen et al. 2000), we tested the similar support program by a nurse case manager (NCM) for the elderly discharged from hospital after a delirium episode.

In a further study, it was investigated whether the intervention had any long-term effects on caregivers of demented patients after the cessation of caregiving. Since spouse caregivers play a very important role in the community care of demented patients, the influence of dementia on marriage was also studied. It was wanted to investigate this rarely studied subject and to find possible new aspects to support spouse caregivers.

Respite care services are provided to offer a temporary break to caregivers of demented patients from caregiving. Institutional respite care may decrease caregiver distress but may also cause deterioration in the demented patient's functional capacity (Larkin and Hopcroft 1993). Therefore, a study was undertaken to evaluate whether it would possible to provide institutional respite care without any further deterioration of demented patients' cognitive and functional capacity.

2. REVIEW OF LITERATURE

2.1. Dementia

2.1.1. Criteria for dementia

Dementia is a syndrome of cognitive impairment produced by organic brain dysfunction. The diagnosis of dementia can be made on a clinical basis according to DSM-IV criteria (American Psychiatric Association 1995) (Table 1). In Finland the three most common causes of dementia are Alzheimer's disease (65%), vascular dementia (15%) and dementia with Lewy bodies (15%) (Viramo and Sulkava 2001). Detection of dementia is important for proper treatment and care of patients, such as when supporting independent functioning and community care.

Table 1. Diagnostic criteria for dementia according to DSM-IV (American Psychiatric Association 1995).

A.	The development of multiple cognitive deficits manifested by both
(1)	memory impairment (impaired ability to learn new information or to recall previously learned information)
(2)	one (or more) of the following cognitive disturbances:
(a)	aphasia (language disturbance)
(b)	apraxia (impaired ability to carry out motor activities despite intact motor function)
(c)	agnosia (failure to recognize or identify objects despite intact sensory function)
(d)	disturbance in executive functioning (i.e., planning, organizing, sequencing, abstracting)
B.	The cognitive deficits in Criteria A1 and A2 each cause significant impairment in social and occupational functioning and represent a significant decline from a previous level of functioning.

Dementia is commonly divided into mild, moderate and severe stages (American Psychiatric Association 1995). The need for help from others and for services from the social and health care system increases with the severity of dementia.

Besides cognitive symptoms (Table 1), demented patients often have BPSD manifestations (Haupt et al. 2000, Ballard et al. 2001, Brodaty et al. 2001). Such symptoms are not only distressing for patients and caregivers, but may constitute a risk factor for long-term institutionalization (Knopman et al. 1988, Reichman and Negron 2001). Because the treatment and care of BPSD is often complicated, and inappropriate strategies may affect the functional capacity of patients (McShane et al. 1997), management of BPSD should be a major focus in the care of community-living demented patients (O'Donnell et al. 1992).

2.1.2. Epidemiology of dementia

Understanding the epidemiology of dementia is important in order to plan social and health care strategies and services. In a collaborative study of population-based cohorts in Europe, the prevalence of dementia in persons 65 years and older was 6.4% (Lobo et al. 2000). The prevalence increased continuously with age and was 0.8% in the age group of 60 to 64 years and 28.5% in the group of 90 years and older. In the population-based Vantaa 85+ Study, the prevalence of neuropathologically defined Alzheimer's disease was 33% (Polvikoski et al. 2001). Dementia is also known to increase the risk of death (Aguero-Torres et al. 1999) and has been suggested as a risk factor for functional dependence in the elderly (Aguero-Torres et al. 1998).

The incidence of dementia increases with age (Fragtigloni et al. 2000). It has been estimated that in Finland 11 000 people will develop a dementing disease each year (Viramo and Sulkava 2001).

2.2. Poor prognosis after a delirium episode

Delirium, or acute confusional state, represents a common problem for hospitalized elderly (Levkoff et al. 1992). It is characterized by disturbances in attention and awareness of the environment, perception, intellectual function and emotions (American Psychiatric Association 1995). Aggressive treatment and proper support of elderly people are needed after a delirium episode, since delirium is a predictor of poor prognosis. Delirium identifies the elderly as being at risk for death (Rockwood et al. 1999), functional decline (Murray et al.

1993), longer hospitalization (Francis et al. 1990, Levkoff et al. 1992), and institutionalization (Francis et al. 1990, Levkoff et al. 1992). Furthermore, the risk of dementia is increased after a delirium episode (Rockwood et al. 1999, Rahkonen et al. 2000). Rahkonen (2001) has reported in her study that 67% of the elderly who had suffered a delirium episode were diagnosed as having dementia in the three-year follow-up.

2.3. Community care of demented patients

Demented patients are more likely than non-demented patients to enter institutional care according to a collaborative study of 11 population-based cohorts in Europe (Jagger et al. 2000). The cumulative incidence of placement in nursing homes over seven years of surveillance has been reported to vary from 75 % to 84% (Berg et al. 1988, Welch et al. 1992). Smith et al. (2000) reported that only 10% of demented patients died without requiring nursing home placement. Heyman et al. (1987) found that the median survival time to nursing home or death in Alzheimer patients was 3.1 years. The result was based on the multicenter Consortium to Establish a Registry for Alzheimer's Disease (CERAD) experience. In the study of Hope et al (1998), 100 demented patients living in the community with a caregiver were followed up until the beginning of long-term institutional care at four-monthly intervals. The mean time of community care was 7.6 years.

Patients' behavioral symptoms (Hope et al. 1998), co-morbidity (Ouslander et al. 1990), functional disabilities (Severson et al. 1994, Osterweil et al. 1995, Juva et al. 1992) and severity of dementia (Brodaty et al. 1993, Gold et al. 1995, Knopman et al. 1999) are important predictors of long term institutionalization. Certain caregiver variables may also predict institutionalization, such as female gender (Colerick and George 1986, Vernooij-Dassen et al. 1997, Hope et al. 1998), caregiver psychological morbidity (Colerick and George 1986, Brodaty et al. 1993), and being a non-spouse caregiver (Colerick and George 1986).

2.3.1. Informal caregiving

Managing community care of demented patients relies largely on the ability of family members to provide caregiving (Perenboom et al. 1996). However, this care often leads to distress in informal caregivers (Lieberman and Kramer 1991, Coen et al. 1997, Teri 1997). The total frequency of problems in demented patients is associated with caregiver distress (Ouslander et al. 1990). The most common problems include behavioral symptoms and functional disabilities suffered by patients, and the lack of support and knowledge needed by caregivers in caring for demented patients (Graham et al. 1997, Juva et al. 1997, Scott et al. 1997, Vernooij-Dassen et al. 1997, Clyburn et al. 2000).

The majority of the caregivers of demented patients are spouses (Hope et al. 1998). Spouses are more committed to caring than other caregivers (Hope et al. 1998, Pot et al. 2001). They maintain the role of caregiver longer and tolerate greater levels of disability than other caregivers (Pruchno and Potashnik 1989). However, negative effects of caregiving on the physical and mental health of spouse caregivers have also been reported (Pruchno and Potashnik 1989, Kiecolt-Glaser et al. 1991, Baumgarten et al. 1992).

The effects of dementia on companionship and the total quality of the marital relationship may be one of the most difficult aspects of dementia (Motenko 1989, Wright 1991, Knop et al. 1998, Murray et al. 1999). Negative changes in marital closeness are associated with reduced gratification from caregiving (Morris et al. 1988, Motenko 1989). An unsatisfactory marital relationship experienced by the caregiver of a demented patient may predict the patient having to be placed in a nursing home (Wright 1994).

Dementia also affects the patient's sexual activity (Wright 1991, Devanand et al. 1992, Ballard et al. 1997). Davies (1992) indicated that sexual needs do not disappear in demented patients. In the study of Ballard et al. (1997), 22.5% of the 40 married patients with mild to moderate dementia continued to "have a sexual relationship" (mean age 77.8 years). In the study of Wright (1991), 27% of 30 married Alzheimer patients with moderate to severe dementia were still "sexually active" (mean age 69.5 years). It is not known if the concepts used in these two studies only refer to intercourse.

Appearance of sexual behavioral symptoms can be most distressing to spouse caregivers (Quayhagen and Quayhagen 1988, Wright 1994). Furthermore, negative changes in sexual behavior have been found in 63-76% of Alzheimer patients (Derouesne et al. 1996), while

increased sexual activity has been reported in 2-13% of demented patients (Wright 1991, Derouesne et al. 1996, Tsai et al. 1999).

2.3.2. Support interventions of community care of demented patients and their caregivers

Mittelman et al. (1996) reported that the family intervention significantly delayed nursing home placement of patients with Alzheimer's disease. The intervention had the greatest effect on the risk of placement for patients with mild and moderate dementia. The intervention consisted of two individual and four family counseling sessions, followed by weekly group sessions for spouse caregivers (n=103), and continuous availability of counselors to caregivers and families. The sessions provided education, techniques for problem solving, management of behavioral symptoms, and emotional support. The caregivers in the control group (n=103) were offered the services normally provided to families by formal service systems. The follow-up time lasted up to eight years. The spouse caregivers were recruited from the health and social system, the local Alzheimer's Association, and through media announcements and referrals from different professionals.

In the eight-year follow-up study by Brodaty et al. (1997), the results showed that those patients whose caregivers received training stayed in community care significantly longer and tended to live longer. The control group was comprised of patients who had been provided the ten days' respite period together with a memory retraining program. The study patients (n=96) were mildly or moderately demented. The 10-day residential, intensive training program aimed to reduce caregiver distress and social isolation, as well as to support normal life activities, and new ways of thinking and coping with behavioral problems. Moreover, a variety of topics in the care of demented patients was provided, including medical aspects of dementia, using community services, and knowledge of fitness. Meanwhile, the patients had their own 10-day program consisting of different ward activities and specific programs. The coordinator in the study provided all caregivers with follow-up support by telephone conferences for over 12 months.

In the recent studies of Marriott et al. (2000) and Hepburn et al. (2001), the intervention consisted of group sessions for caregivers. The primary caregivers were recruited through the community health and social service. In both studies, the group sessions included components

of caregiver education, stress management, and coping skills. The study of Hepburn et al. (2001) employed a wait-list control group (n=34). The training program of seven weekly two-hour sessions for five to six months had a positive impact on the caregivers in the intervention group (n=60). The caregivers showed a significant decrease in depression and feelings of burden, and their beliefs about caregiving work and reactions to the patients' problem behaviors also significantly improved. In the study of Marriott et al. (2000), the intervention consisted of 14 sessions in two-weeks interval. Two control groups received the assessment interviews, with one receiving audiotaped interviews (n=14) and the other none (n=14). The intervention was found to significantly reduce distress and depression in the caregivers of the intervention group (n=14) compared with the controls. Furthermore, the behavioral symptoms of the patients had significantly decreased. Neither study tested the effect of the intervention on the time spent in community care.

2.3.3. Institutional respite care of demented patients

Respite care is provided to give the primary caregiver a temporary break from caregiving. It covers the following services: in-home respite care, adult day care and institutional respite care for a constant or a fixed period of time (Jones and Peters 1992, Larkin and Hopcroft 1993, Feinberg and Kelly 1995). In Finland, institutional respite care is widely used, though little studied.

In the study of Burdz et al. (1988), a total of 55 caregivers of elderly people were interviewed using a pretest-posttest design. The subjects consisted of 35 intervention patients admitted to a nursing home for respite care, and 20 wait-list controls. The intervention group comprised 15 patients diagnosed with dementia, and the control group of 12 patients. Regardless of the patients' diagnosis, the caregivers reported positive effects on the behavior of the patients. Almost half of the caregivers (48%) reported that the patient's condition had worsened during institutional respite care. Institutional respite, however, did not have a significant effect on caregivers' burden.

Adler et al. (1993) and Larkin and Hopcroft (1993) reported a reduction in caregivers' distress. However, in both studies the levels of distress returned to baseline following the patients' return to the home. In the study of Larkin and Hopcroft (1993), the functional capacity of patients deteriorated during institutional respite care, whereas in the study of

Adler et al. (1993) a two-week in-hospital stay had no effect on Alzheimer patients' BPSD manifestations or performance in activities of daily living.

Larkin and Hopcroft (1993) investigated the impact of respite care in a Dementia Study Unit on 21 Alzheimer patients and their 22 primary caregivers. The aim of the unit was to meet the health care needs of Alzheimer patients and to provide supportive services to the families. Data concerning caregiver stress and patient functional capacity were collected from caregivers three days before admission, three days before discharge and 14 days after discharge. Within two weeks of their respite stay, 29% of the patients, and within 30 days 38% of the patients, had been admitted to long-term institutional care. The authors concluded that institutional respite care might increase the likelihood of nursing home placement, a finding similar to that of Cohen and Pushkar (1999).

In previous studies, the influence of the environment and therapeutic methods used in institutional respite care have not undergone examination.

2.4. Case manager in supporting community care of the elderly

A case manager (CM) is defined as a professional whose central function is the coordination and arrangement of social and health care services (Eggert et al. 1991). The core tasks of CMs commonly include (1) case finding, (2) care plan development, (3) coordination of services, (4) care monitoring, (5) advocacy of patients, and (6) reassessment involving possible revision of the care plan (Arnsberger 1997). Often, a CM is both a member as well as the operational arm of a multidisciplinary team.

The use of CMs has been rather extensively studied. There is some evidence that CMs' performance and training could have an impact on the outcome of patients (Applebaum and Wilson 1988, Landi et al. 1996, Arnsberger 1997, Baxter 1997, Naylor et al. 1999, Stuck et al. 2000, Diwan and Phillips 2001). However, no curriculum has yet been defined for CM posts. CMs come from many different educational backgrounds, ranging from doctors and nurses to social workers and paid helpers. Furthermore, the procedures used in the interventions have varied, thus complicating comparisons between studies. Only a few studies have provided

detailed descriptions of the procedures used by the case manager (Gagnon et al. 1999, Naylor et al. 1999).

A published meta-analysis of 28 controlled trials suggests that programs with geriatric evaluation, control over recommendations, and strong long-term management have positive effects on survival in community care and on the functional capacity of the elderly (Stuck et al. 1993). Several studies have suggested that the case management concept would be useful in supporting community-living frail elderly people at great risk of institutionalization (Hendriksen et al. 1984, Townsend et al. 1988, Stuck et al. 1995, Landi et al. 1999).

Table 2 presents a summary of the studies examining CM intervention among community-living elderly people. In a randomized controlled study with a six-month follow-up time among depressed elderly, CM intervention was reported to have a significant effect on recovery from depression (Banarjee et al. 1996). The CM was a physician working as one member of a community psychogeriatric team. In the randomized trial of Bernabei et al. (1998), an intervention consisting of integrated care and case management was used in the elderly (n=100) living in the community. The follow-up time was one year. Two CMs were constantly available to deal with problems, monitor the provision of services and to guarantee extra help when needed. Admissions to nursing homes and hospitals were less common and significantly deferred. The intervention also resulted in cost reductions. These findings are similar to those of Naylor et al. (1999). In their study, the intervention patients (n=177) received a comprehensive discharge plan and home follow-up lasting for up to 24 weeks and implemented by advanced practice nurses after hospital discharge. In a stratified randomized trial by Stuck et al (2000), the intervention consisted of annual multidimensional assessments and quarterly follow-up in-home visits lasting up to three years. Three public health nurses in collaboration with geriatricians evaluated problems, gave recommendations and provided health education. The intervention was effective in low-risk, but not in high-risk elderly. The researchers suggested that the positive effects observed are most likely related to the nurses' performance.

It has been suggested that the CM would be useful in supporting community-living demented patients (Mohide et al. 1990, Mittelman et al. 1996). In the study of Fox et al. (2000), reductions in caregivers' burden and depression were achieved through CM intervention

(Table 2). However, a significant increase in service use was also reported. The follow-up time was three years and the CMs were from different professional backgrounds.

Some researchers have been less convinced of the benefits of the CM approach as shown in Table 2. Some improvement, though non-significant, in social activities was reported in community-living stroke patients who were supported by nurse care managers (NCM) (Forster and Young 1996). The intervention of a stroke family worker with a social worker background was found to have negative effects on the patients' disabilities, though it increased the satisfaction of patients and their caregivers with respect to the care received (Dennis et al. 1997). In the study of Gagnon et al. (1999), NCMs coordinated and provided health care services with daily 12-hour availability to elderly people discharged from an emergency department. As a result, the study reported significantly increased use of emergency health services.

Table 2. Summary of studies of case manager intervention among community-living elderly people

Reference location	Subjects	Case manager intervention	Design and outcomes	Educational background and training of case manager	Results by intervention
Banarjee et al. 1996 UK	Depressed elderly ≥ 65 yrs enrolled in community-based long-term care (n=33,36*).	Individual of physical, psychological and social interventions formulated by a community psychiatric team and implemented by a keyworker.	Randomized controlled trial, 6-month follow-up. Recovery from depression.	Physician	Significant effect on recovery from depression.
Forster and Young 1996 UK	Community-dwelling patients with new stroke ≥ 60 yrs, in the designated urban area (n=120, 120*).	Provision of information, advice and support, counseling and enabling model, addressing psychosocial factors.	Randomized trial, 12-month follow-up of functional ability, social activity, perceived health status, stress among caregivers.	Five nurses, experienced in assessing disability in elderly people and in problem solving approaches using community based services. A two-day training before the trial.	A small but non-significant improvement in social activities only for the mildly disabled patients.
Dennis et al. 1997 UK	Patients (mean age 67.1 yrs, 68.4 yrs*) after an acute stroke discharged home from hospital (n=210, 207*).	Stroke family care worker: target at patients and their caregivers, identifying and fulfilling unmet needs using available resources, counseling.	Randomized controlled trial, 6-month follow-up. Physical, social, and psychological status of stroke patients and their caregivers.	Social worker with considerable experience in working with voluntary agencies for disabled people.	Patients and their caregivers were more satisfied with certain aspects of post-hospital care (non-significant). Patients tended to be more helpless, less well adjusted socially, and possibly more depressed.

* The first number refers to subjects in the intervention group, the second to subjects in the control group.

Table 2. Cont.

Reference location	Subjects	Case manager intervention	Design and outcomes	Educational background and training of case manager	Results by intervention
Barnabei et al. 1998 Italy	People ≥ 65 yrs enrolled in community-based long-term care (n= 100, 100*).	Multidisciplinary team including case manager and general practitioner, initial assessments by case manager, team meetings if problems, case manager represented the operational arm of team.	Randomized controlled trial, 1-year follow-up. Admission to institution, use and costs of health services, variations in functional status.	Not known. Initially, intensive training for case manager skills and geriatric assessment technology.	Hospital and nursing home admissions deferred (significant) and less common, less frequent home visits of general practitioners (significant), improved physical function, reduced decline in cognitive status, reduced costs.
Gagnon et al. 1999 Canada	Frail elderly ≥ 70 yrs, discharged home from emergency department (n= 212, 215*).	Care plan, coordination and provision of health care services, 12-hour availability 7 days a week, medical consultation from an appointed geriatrician.	Randomized controlled trial, 10-month follow-up. Quality of life, satisfaction with care, functional status, admission to hospital, length of hospital stay.	Four nurses with minimum of 2 years of geriatric nursing experience. Initial training of 24 hours, continuous support of a clinical supervisor.	Significantly increased use of emergency health services.
Naylor et al. 1999 USA	People ≥ 65 yrs at risk for re-admissions admitted to hospital (n=186, 177*).	Comprehensive discharge planning and follow-up, target efforts at unresolved health problems, focus on medical follow-up, diet, activity, emotional status of patients and caregivers. Telephone availability 7 days a week, collaboration with a physician.	Randomized controlled trial, 24-week follow-up. Re-admissions, time to first readmission, acute care visits, costs, functional status, depression, patient satisfaction.	Five part-time, master's prepared, gerontological advanced practice nurses with a mean of 6.5 post-degree geriatric nursing experience.	Significantly reduced readmissions, fewer hospital days per patient and decreased costs.

* The first number refers to subjects in the intervention group, the second to subjects in the control group.

Table 2. Cont.

Reference location	Subjects	Case manager intervention	Design and outcomes	Educational background and training of case manager	Results by intervention
Fox et al. 2000 USA	Community-living patients with dementia (mean age 78.9 yrs) from the Medicare program, (n=4151, 3944*).	Provision of community-based formal services for caregivers, psychological support and education of caregivers.	Randomized controlled trial, 3-year follow-up. Caregiver burden and depression, use of services, costs, institutionalization rates.	Different professional backgrounds, e.g. nurses, social workers, gerontology professionals.	Reductions in burden and depression of caregivers, significant increase in use of formal home care and day care services, no effect on nursing home entry rates.
Stuck et al. 2000 Switzerland	Community-living people >75 yrs at low and high risk for nursing home admission recruited from health insurance list (low risk n=148, 296*; high risk n=116, 231*).	Annual multidimensional assessments and quarterly follow-up in-home visits, evaluating problems, giving recommendations, health education, collaboration with geriatricians.	Randomized trial, 3-year follow-up. Need for assistance in basic and instrumental activities of daily living, number of institutionalization health care costs.	Three public health nurses, additional training in physical assessment, gerontology and in conducting preventive home visits before and during the project.	Significantly reduced disabilities among the low risk elderly and increased nursing home admissions among the high risk elderly, positive effects likely related to nurses' performance, resulting net cost savings.

* The first number refers to subjects in the intervention group, the second to subjects in the control group.

Table 2. Cont.

Reference location	Subjects	Case manager intervention	Design and outcomes	Educational background and training of case manager	Results by intervention
Rahkonen 2001 Finland	People ≥ 65 yrs discharged from hospital after a delirium episode. By the three-year follow-up 67% of the intervention patients were diagnosed having dementia. (n=51, n=51*)	Follow-up contacts, care coordination based on individual care plans, problem solving in crises threatening continuity of community care, psychological support, annual rehabilitation courses, 24-hour telephone availability collaboration with a physician.	Controlled trial with age and gender-matched delirium patients from the same hospital treated in preceding four years, 2-year follow-up. Time in community care without institutionalization, death in community care.	One public health nurse, initial and continuous training in care of elderly people, and of cognitively impaired people.	Significantly longer survival in community care without institutionalization, decreased rate of long-term institutional care, positive effects likely related to nurse case manager's performance and problem solving approach.
The Kuopio Dementia Study Finland	Community-living demented patients ≥ 65 yrs having an informal caregiver, recruited from a national registry (n=53, 47*).	Follow-up contacts, care coordination based on individual care plans, problem solving in crises threatening continuity of community care, psychological support, annual rehabilitation courses, 24-hour telephone availability collaboration with a physician.	Randomized controlled trial, 2-year follow-up. Time in community care without institutionalization, death in community care.	One public health nurse, initial and continuous training in care of demented patients.	Deferred placement in long-term institutional care, rate of institutionalization significantly decreased during first months, especially beneficial for patients with severe dementia, positive effects likely related to nurse case manager's performance and problem solving approach.

* The first number refers to subjects in the intervention group, the second to subjects in the control group.

2.5. Effects of cessation of caregiving on caregivers

Many studies indicate that caregiving often causes burdens which decrease after the cessation of caregiving (Stephens et al. 1991, Zarit and Whitlatch 1992, Aneshensel et al. 1993, Gold et al. 1995, Grafström and Winblad 1995, Matsuda et al. 1997, Elmståhl et al. 1998). However, there are also contradictory findings suggesting that emotional strain may not actually be reduced (Grafström et al. 1992, Baumgarten et al. 1994, Almberg et al. 1997), but may instead be followed by guilt (Harper and Lund 1990, Mullan 1992, Zarit and Whitlatch 1992, Baumgarten et al. 1994). Some caregivers appear to have difficulties in adjusting to the new situation without caregiving (Zarit and Whitlatch 1992, Gold et al. 1995). Previous studies have reported cessation to have a negative impact, especially on spouse caregivers (Baumgarten et al. 1994, Kaplan and Boss 1999, Rudd et al. 1999), including deterioration in the health of spouse caregivers (Kiecolt-Glaser et al. 1991, Baumgarten et al. 1994).

2.6. The basis for the present study

Several intervention studies have been carried out in supporting the community care of demented patients. However, the primary focus has been on supporting caregivers, arranging training programs, and decreasing caregiver burden. No randomized controlled studies have as yet examined the support interventions directed primarily at demented patients and secondarily at their caregivers in an effort to prolong the period of community care.

Institutional respite care is often needed to provide a temporary break from caregiving. Some studies have reported that institutional respite care may decrease caregiver distress. However, the effects of institutional respite care on patients' functional capacity are rarely studied.

Dementia affects companionship and the quality of the marital relationship, as well as a patient's sexual activity. Negative changes in marital closeness are associated with reduced gratification from caregiving. The appearance of sexual behavioral symptoms can be most distressing to caregivers. An unsatisfactory marital relationship experienced by the caregiver of a demented patient may predict the patient having to be placed in a nursing home.

Many studies indicate that the caregiving of demented patients often causes burdens that decrease after the cessation of caregiving and are followed by positive life changes. However, there are also contradictory findings suggesting that this emotional strain may not actually vanish with the end of caregiving. Indeed, some caregivers appear to have difficulties in adjusting to the new situation without caregiving. Negative effects of cessation have been found especially for spouse caregivers.

3. AIMS OF THE STUDY

The general aim of this study was to investigate possible means of supporting the community care of demented patients.

The specific aims of this study were:

1. To assess whether community care of elderly people with cognitive impairment can be prolonged through systematic intervention based on nurse case management (I and II).
2. To describe in detail the measures used by the nurse case manager in supporting the community care of elderly people with cognitive impairment (III).
3. To assess whether institutional respite care of demented patients is possible without the deterioration of cognitive and functional capacity (IV).
4. To investigate the impact of dementia on the general atmosphere, happiness and relations in the marriage, as well as the sexual side of the marriage (V)
5. To investigate the effects of the cessation of caregiving on caregivers' experiences at the point of the cessation and on the caregivers' lives after the cessation (VI).

4. SUBJECTS AND METHODS

4.1. Subjects

The doctoral thesis consists of three different study populations: the community-living demented patients and their caregivers in the Kuopio Dementia Study (three substudies) (publications I, III, V, VI), the delirium patients in the Kuopio Delirium Study (publications II, III) and the respite care patients in two special care units (publication IV) (Table 3).

Table 4 shows the baseline demographic characteristics of the subjects included in the study.

Table 3. The configuration of the present study

Study (I-VI refers to original publications)	Study subjects	Data collection	Time
Kuopio Dementia study			
<u>Substudy I</u> Effects of support intervention on duration of community care (I) Nurse case manager for the cognitively impaired elderly (III)	Demented patients n=53 in intervention group, n=47 in control group	Two-year randomized controlled intervention study with yearly follow-up of demented patients	1996-1997
<u>Substudy II</u> Spouse caregivers' perceptions of the influence of dementia on marriage (V)	Caregivers n=42	Telephone interview with caregivers	1997
<u>Substudy III</u> Emotional reactions and life changes of caregivers when caregiving ends (VI)	Caregivers n=64	Telephone interview with caregivers	1999
Kuopio Delirium study			
Effects of support intervention on the duration of community care (II) Nurse case manager for the cognitively impaired elderly (III)	Delirium patients n=51 in intervention group, n=51 in matched controls	Three-year intervention study with yearly follow-up of delirium patients	1994-1997
Study of respite care			
Support interventions of demented patients in two special care units (IV)	Demented patients n=53 in special care unit 1, n=32 in special care unit 2	Follow-up of demented patients with pre-post test design, questionnaire for caregivers	Special care unit 1 in Helsinki: 1989-1991, special care unit 2 in Vaasa: 1995-1996

Table 4. Baseline demographic characteristics of study subjects at baseline in Publications I-II and IV-VI. In Publication III the study subjects consisted of the intervention patients of Publications I and II

	Publication I Demented patients		Publication II Delirium patients		Publication IV Demented patients in special care units (SCU)		Publication V Demented patients		Publication VI Caregivers of demented patients	
	Intervention group	Control group	Intervention group	Control group	SCU 1	SCU 2	Demented patients	Caregivers of demented patients		
Subjects, n	53	47	51	51	53	32	42	64		
Female, n (%)	26 (49)	27 (57)	46 (90)	46 (90)	28 (53)	22 (69)	13 (31)	47 (73)		
Mean age, years (range)	78 (65-97)	80 (67-91)	82 (71-93)	82 (72-93)	78 (54-91)	81 (67-92)	72 (59-85)	67 (39-92)		
Diagnosis										
Alzheimer's disease, n (%)	30 (57)	24 (51)			19 (36)	11 (34)	18 (43)			
Vascular dementia, n (%)	16 (30)	19 (40)			28 (53)	21 (66)	17 (40)			
Other, n (%)	7 (13)	4 (9)			6 (11)		7 (17)			
Stage of dementia according to MMSE										
Mild, n (%)	21 (40)	18 (38)			10 (19)	8 (26)				
Moderate, n (%)	13 (24)	18 (38)			22 (41)	12 (37)				
Severe, n (%)	19 (36)	11 (24)			21 (40)	12 (37)				
MMSE score, mean \pm SD	14.4 \pm 6.2	15.3 \pm 5.5			12.4 \pm 5.6	13.2 \pm 6.2				
Living alone, n (%)	6 (11)	3 (6)	42 (82)	35 (69)						

MMSE=Mini-Mental State Examination (Folstein et al. 1975); SD=standard derivation

4.1.1. The Kuopio Dementia Study

The main data for the Kuopio Dementia Study were collected in 1993-1996 during the intervention study (Substudy I) (Publication I, III). In 1997, further data regarding the influence of dementia on the marital relationship were collected through telephone interviews with the spouse caregivers of the study patients (Substudy II) (Publication V). In 1999, all the caregivers of the study patients who had experienced the cessation of caregiving were recruited into a further study (Substudy III), the aim of which was to study the effects of the cessation of community care on caregivers (Publication VI).

Patients were eligible for inclusion in the Kuopio Dementia Study if they were aged 65 years or over and were entitled to payments from the Social Insurance Institution for community care because of a dementing disease. The payment for community care is between € 50 and € 240 per month depending on the need for care, is tax-free, and independent of income. It can be obtained by submitting a certificate from a physician attesting that the patient requires help on a regular basis in order to be able to live at home. All patients with a dementing disease requiring regular care are eligible for the payment. Eligible patients had no other severe diseases (i.e., severe stroke or cancer) which could possibly lead to institutionalization in the near future. Patients were excluded if they and their caregivers were not able to participate in annual rehabilitation courses.

Altogether, 141 eligible patients were identified for the primary Kuopio Dementia Study (Substudy I) (Figure 1). In October 1993, the first round produced a total of 86 patients. In order to attain the originally planned 100 study patients, a second cohort of patients was added in January 1995. This time, all demented patients in the municipality of Kuopio listed in the register of the Social Insurance Institution were examined. This round produced another 14 patients for inclusion. All of the study patients (n=100) were diagnosed by a neurologist according to DSM-III-R criteria for dementia (American Psychiatric Association 1987), and were randomly allocated to either the intervention group or the control group. For the randomization, the NCM had prepared 100 sealed non-transparent envelopes, of which 53 indicated allocation to the intervention group and 47 to the control group. Allocation to the groups was made by each patient (or her/ his caregiver if the patient was unable) drawing one envelope.

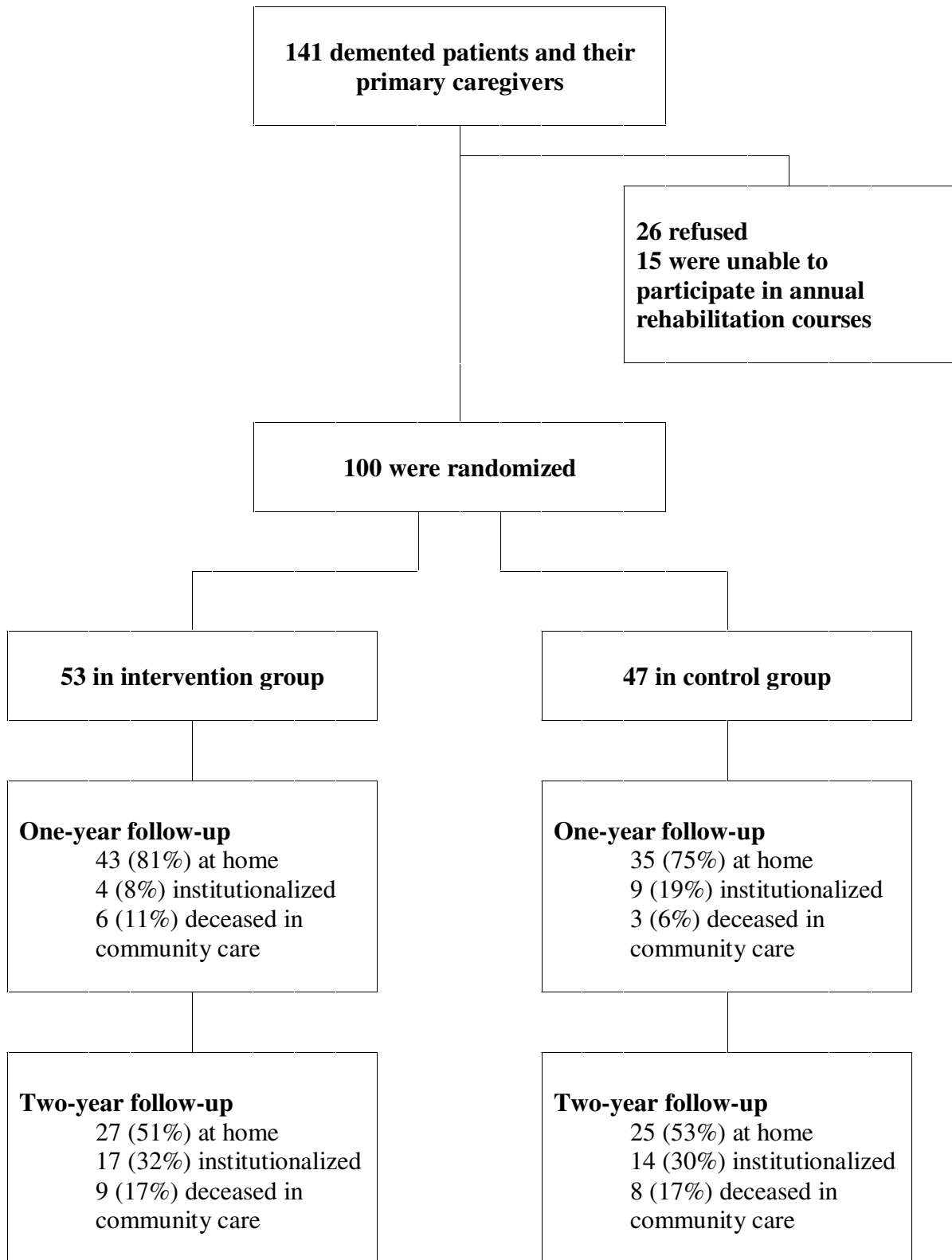


Figure 1. Study profile for the Kuopio Dementia Study

The Mini-Mental State Examination (MMSE) (Folstein et al. 1975) was used to assess the severity of dementia on a 30-point scale. Severe dementia is defined as a score of 0-11, moderate 12-17, and mild 18-23.

Out of 100 study patients, 56 patients had spouse caregivers. All these 56 couples were included into the study examining the influence of dementia on marriage (Substudy II) (Publication V). The final sample consisted of 42 (75%) spouse caregivers since 14 spouses could not be interviewed. Non-respondents were due to caregivers' death (n=4), inability to participate because of severe health problems (n=7) or refusal (n=3). At the time of the interviews, 13 (31%) demented patients were still living at home. The remaining 29 (69%) were either in long-term institutional care (n=11, 26%) or had died (n=18, 43%). The mean time from the end of home care was 1.1 ± 1.1 year, range 0-4 years.

In February of 1999, all the available caregivers from the original intervention study were contacted by the telephone in order to study life changes and emotional responses of caregivers after the cessation of caregiving (Substudy III) (Publication VI). By that time, 80 caregivers had experienced the cessation of caregiving, either due to death or permanent institutionalization of the patient. Of these, 16 could not be interviewed due to the caregiver's death (n=6), severe illness (n=2), refusal (n=2) or inability to be reached (n=6). Thus, the final sample consisted of 64 (80%) caregivers who had ceased caregiving. No significant differences in the sociodemographic characteristics (gender, age, kinship, duration of caregiving, reason for cessation, or time elapsed since cessation) of the caregivers were detected between the 64 respondents and the 16 non-respondents.

4.1.2. The Kuopio Delirium Study

In the Delirium Study, the intervention patients (n=51) were people living in the community, aged 65 or over, admitted consecutively to hospital with a delirious state based on the DSM-III-R criteria (American Psychiatric Association 1987) between May 1st, 1994, and October 31st, 1996 in the city of Kuopio (Publication II, III). The patients were restricted to healthy elderly people without any serious predisposing disorders such as cancer, hip fracture, serious stroke or moderate to severe dementia. However, it was decided to include individuals with possible mild cognitive impairment because of the difficulties in differentiating delirium and the early stages of dementia in a short period of time.

The age- and gender-matched controls were collected using the same inclusion and exclusion criteria from the list of preceding patients admitted to the same hospital between January 1st, 1990 and April 30th, 1994, and thereafter discharged to the community.

4.1.3. Study of Respite Care in special care units

The study of Respite Care in special care units (SCU) included 85 community-living demented patients who had been referred to two SCUs for institutionalized respite care by professionals in the social or health care system. One SCU was located in the city of Helsinki and the other in the city of Vaasa. Both SCUs provided short-term as well as long-term institutional care. SCU 1 in Helsinki was founded in 1989, and SCU 2 in Vaasa in 1995. In SCU 1, the patients consisted of 53 consecutive demented patients referred to the unit during 1989-1991 for whom information was available concerning their MMSE scores (Folstein et al.1975) both before and after the respite care period. In SCU 2, the same criteria was used to obtain a total of 32 patients. These patients were referred to respite care during 1995-1996.

4.2. Methods

4.2.1. The intervention procedure in the Kuopio Dementia Study and in the Kuopio Delirium Study

In the Kuopio Dementia Study (Substudy I), the patients in the intervention group and their caregivers were enrolled in a two-year support program. The program involved systematic and comprehensive support for the patients and their caregivers during community care by a NCM who had access to the physician. Annual rehabilitation courses (eight to ten patients with their caregivers in each course) provided the educational part of the intervention program. At baseline, the rehabilitation period lasted for ten days, whereas the courses one year and two years later lasted for five days. Based on individualized needs and wishes, the patients in the control groups received the usual services provided for geriatric patients in community care from the municipal social and health care system or from the private sector.

In the Kuopio Delirium study, the three-year intervention consisted of (1) continuous and systematic support of the patient by the NCM after providing the standard treatment for delirium, and (2) one in-patient rehabilitation period each year in the Brain Research and Rehabilitation Center "Neuron". The mean duration of the rehabilitation period at baseline was 13.7 days (range 7 to 25 days). The periods in the following years were shorter, on average 4 days per patient (range 1 to 9 days).

4.2.1.1. Nurse case manager

Both intervention studies had one NCM. The NCMs were registered nurses with a public health nurse background and a special interest in geriatric nursing. In both studies, the NCMs were located in the city of Kuopio. At the beginning and throughout the study, they underwent a wide range of training in geriatrics and the care of the elderly, with an emphasis on dementia and delirium. The primary goal of the NCMs was to assume comprehensive responsibility for providing the patients with support that would allow the patient to continue in community care. Table 5 lists the pre-planned guidelines for the work of the NCM intervention at the beginning of both studies.

Table 5. Pre-planned guidelines for the work of the nurse case managers (NCM) at the beginning of the intervention studies.

-
- Follow-up contacts with patients and their caregivers
 - 24-hour daily availability by mobile telephone
 - Arranging individually planned social and health care services at the patient's expense with the goal of "one-stop shopping"¹
 - Psychological support for patients, their caregivers and relatives
 - Advocacy for patients and their caregivers
 - Problem solving in crises threatening community care
 - Working as a primary nurse during the annual rehabilitation periods
-

¹ NCM assumed comprehensive responsibility for arranging all the needed services on behalf of patients and their caregivers

4.2.1.2. Rehabilitation courses

The patients were admitted each year to the Brain Research and Rehabilitation Center "Neuron" for one rehabilitation course in which the NCMs acted as primary nurses.

The primary aim of the rehabilitation courses was to provide educational information and to support the functional abilities and adaptation of both the patients and their caregivers. Possibly undiagnosed diseases were detected and treated and appropriate medication and care were arranged. Community care was planned carefully and arranged together with the patients and their caregivers or relatives. In the patients with delirium, close collaboration with the professionals in the formal service system was usually needed since the most of these patients lived without a caregiver.

The rehabilitation courses included a medical check-up and psychological assessment of the patients, lectures, separate group meetings for patients and caregivers, as well as various kinds of physical, mental and social activities.

4.2.1.3. Assessment of the patients

The study physician carried out medical examinations of the intervention patients at the baseline and then annually during the two-year follow-up (Dementia Study) and the three-year follow-up (Delirium Study). Similarly, the NCMs obtained data on the patients'

cognitive and functional capacity, psychosocial situation, and use of formal services. The Barthel Index was used to assess physical function (Mahoney and Barthel 1965) and MMSE (Folstein et al. 1975) to assess cognitive capacity. In the Kuopio Dementia Study, the control patients also participated in the annual follow-up procedures.

4.2.1.4. End points and main outcome measure

Follow-up time for each patient was two years in the Kuopio Dementia Study and three years in the Kuopio Delirium Study. The end points were (1) placement in long-term institutional care or (2) death during community care. The main outcome measure in the study was the time elapsed until institutionalization, i.e. the period in community care, from the enrolment of patients in the study to their placement in long-term institutional care. The occurrence of long-term institutionalization was defined as the point when a patient had permanently moved to an institution with night-time supervising personnel.

Data concerning the end points and the outcome measure for the Kuopio Dementia Study were received from the register of the Social Insurance Institution. In the Finnish local social and health care system, a group of experts (usually a chief physician, head nurse and social worker) make the decision to permanently institutionalize patients when they or their caregivers have expressed the need for institutionalization. These groups of experts were blind to the allocation, and most often unaware that a patient was even participating in the study. In the Kuopio Delirium Study, the data regarding the end points and the outcome measure were obtained from the registers provided by the Kuopio Health and Social Service and by the National Death Register.

4.2.1.5. Evaluation of the measures delivered to the patients and their caregivers

The NCM documented in detail the planned and arranged services, as well as contacts with the patients, their caregivers and relatives, and with the social and health care professionals. She documented any problems interfering with the patients' ability to continue in community care, and the measures taken to resolve them. All documents produced by the NCM for these studies were evaluated in order to describe the measures provided by the NCM in supporting the continuity of community care. The problems and measures were analyzed and categorized.

4.2.2. The study examining the influence of dementia on marriage

The data were collected using semi-structured telephone interviews with the spouse caregivers of the demented patients from the Kuopio Dementia Study between June and August 1997.

The questionnaire consisted of questions covering two areas of marriage: (1) the general atmosphere, happiness and relations, and (2) the sexual side of the marriage. For both areas, the questions inquired about the time before the onset of dementia symptoms and the time after those symptoms had appeared. At the beginning of the interview, the caregivers were informed what was meant by the time before and after the onset of their spouses' dementia. The caregivers were also reminded of these concepts during the interview. The time before dementia was the time from the beginning of the marriage to the time when the dementia symptoms appeared. Accordingly, the time after the onset of dementia was the time of community care with dementia until the interview, or until community care had ended due to long-term institutional care or death of the demented patient.

4.2.3. The study examining the effects of cessation of caregiving

The data were collected using semi-structured telephone interviews with the caregivers (n=64) from the Kuopio Dementia Study in February 1999. The telephone interviews lasted between 10 minutes and one hour, though averaged 20 minutes.

The semi-structured questionnaire was constructed based on the results of previous studies (Gold et al. 1995, Almqvist et al. 1997, Matsuda et al. 1997, Elmståhl et al. 1998). It contained three parts, with the initial section covering sociodemographic data. The second part focused on the emotional reactions the caregivers recalled from the point of cessation. It sought to detect the presence or absence of loneliness, depressive feelings, sorrow, relief and guilt. The third part of the questionnaire focused on determining life changes occurring after the cessation of caregiving. The caregivers were asked whether they had experienced in their lives any positive or negative changes, and whether any changes had occurred in the amount of their leisure activities, in their social life, or quality of life. Open questions were used to describe what kind of positive and negative life changes had occurred during the period after

the cessation of caregiving. Classification of the answers to the open questions was done at the time as the data were analyzed.

4.2.4. The study examining the effects of institutional respite care on functional capacity

4.2.4.1. Intervention measures

The intervention measures in the SCUs were based on the therapeutic community model with emphasis on ward atmosphere, support of active participation, and recognition of the impact of all members of the community (i.e. patients, nurses and family members) (Isohanni 1990). The model was modified to meet the special needs of demented patients (Table 6).

Table 6. Intervention measures to support patients in institutional respite care

-
- Good medical evaluation and care, with accurate diagnoses of the dementing disease
 - Treatment of secondary disorders affecting the functional capacity of patients
 - Family involvement
 - Staff is provided with extensive training and counseling in dementia care from dementia specialists
 - Emphasis on the 24-hour ward atmosphere, not on scheduled activities
 - directed by ideology, not by rules, schedules or hierarchy
 - normal home life, focused on resources of each member of the therapeutic community
 - stimuli and activities are a natural part of everyday life
 - provides feelings of freedom, space, security and approval for both the patients and nurses
 - gives respect and positive feedback to both the patients and nurses
-

4.2.4.2. Primary efficacy parameters

MMSE (Folstein et al 1975) and CGIC (Clinical General Impression of Change) (Guy 1976) were the primary efficacy parameters. MMSE was used before and after the intervention to measure the patients' cognitive symptoms. CGIC was used to assess whether changes in the mood and functional capacity of the patients had occurred during the respite care period. The

CGIC questionnaires were filled out by both the nurses in the SCUs and the primary informal caregivers.

4.3. Statistical methods

Statistical analyses in the present study were performed with SPSS for Windows. All statistical tests were two-sided, with $p < 0.05$ as the criterion indicating statistical significance.

Statistical testing of group differences was done with the Pearson chi-square test, Fisher's exact test for categorical variables, the paired t-test, two sample t-test or Kruskal-Wallis test for continuous variables and the McNemar test for binary measures, as appropriate. Multi-categorical matched variables were compared with the Wilcoxon signed ranks test or marginal homogeneity test.

The Kaplan-Meier method was used to estimate probabilities of survival in community care without institutionalization. In the survival analyses, the times were censored at death if the patient died in community care before institutionalization. Differences between the curves were evaluated with the log rank test. The time-dependent Cox regression analysis was used to assess the significance of the difference between the survival curves of the two groups in the Kuopio Dementia Substudy I (Publication I) since the assumption of the proportional hazards was not met in the data.

In the Kuopio Dementia Substudy III (Publication VI), the multiple logistic regression analysis was used to identify the best predictors of emotional reactions at the point of cessation and of life changes occurring after the cessation. All sociodemographic factors (gender, kinship, duration of caregiving, reason for the cessation of caregiving, and time elapsing until the cessation) were included in the models. The multiple regression was used to test whether the change in MMSE (Folstein et al. 1975) could be explained by age, gender, diagnosis, severity of dementia or time in respite care (Publication IV).

4.4. Ethical considerations

Informed consent was obtained from the patients and/or their caregivers and relatives for the intervention studies. The Dementia Study was approved by the Ethics Committee of the Social Insurance Institution and the local boards of the social and health authorities in the home municipalities of the patients. The Delirium Study was approved by the Ethics Committee of the Kuopio University Hospital and the Health Centre of Kuopio, and the Social and Health Ministry of Finland.

In both telephone interview studies, the interviewer explained the purpose of the interview to the caregivers on the phone. The caregivers provided oral approval to participate in the study.

5.RESULTS

5.1.Effects of supporting community care

5.1.1. Survival in community care (I, II)

In the Kuopio Dementia Study (Substudy I), the systematic intervention deferred placement in long-term institutional care of demented patients during the two-year follow-up. During the first months, the rate of institutionalization was significantly lower in the intervention group than in the control group ($p=0.042$), though the benefit of the intervention decreased with time ($p=0.028$). The survival curves suggested that severely demented subjects benefited the most from the intervention (median time of staying in community care 647 days in the intervention group vs 396 days in the control group). Among the severely demented with spouse caregivers, the mean time of community care in the intervention group ($n=9$) was 698 days compared with 292 days in the control group ($n=5$) ($p=0.010$).

In the Kuopio Delirium Study, the survival in community care without institutionalization was significantly longer in the intervention than in the control patients at the end of the three-year follow-up ($p=0.025$).

The control patients were institutionalized at the earlier phase of the study. However, at the end of the follow-up, in neither study significant differences were found between the intervention and the control group in the number of deaths or in the number of patients having moved to long-term institutional care.

5.1.2. Measures delivered by the NCMs in community care (III)

In the Kuopio Dementia Study, the NCM delivered 595 telephone contacts and 91 in-home visits during the two-year support program, whereas in the Kuopio Delirium Study in-home visits were common ($n=392$ during the three-year follow-up). The occurrence of problematic situations at home accounted for a great variability in the number of contacts in both studies. In such problematic situations and crises that threatened the continuity of community care, the NCMs were persistent in trying to find solutions.

Table 7 presents the number of patients with problematic situations and the intervention measures delivered by the NCMs. When needed, the NCMs contacted the physician in the study for consultation and medical care.

In the Kuopio Dementia Study, the patients and their caregivers frequently needed “one-stop shopping” services (n=340) in which the NCM assumed comprehensive responsibility for arranging all the needed services on behalf of the patients and their caregivers. The caregivers and relatives contacted each of the NCMs only five to six times per year outside working hours, even though the NCMs could be reached 24 hours a day via a mobile telephone.

Table 7. Number of patients (%) with problematic situations and the measures provided by NCMs during the follow-up.

Problematic situation	<u>Dementia Study</u> (n=53, 2-year program)	<u>Delirium Study</u> (n=51, 3-year program)	Measures
Health problems of patients Including acute decline in functional capacity, acute illness and medical problems	38 (72%)	38 (75%)	-Diagnosing the cause of the problem and implementing intervention accordingly -Consultation with the study physician (e.g., diagnosing the cause of the problem, medication for acute illness, re-evaluating medication) -Arranging other medical care (e.g., emergency admissions) -Arranging physiotherapy or other rehabilitative measures -Systematic support for the caregiver during the health problem
Behavioral and psychological symptoms of patients Including restlessness, anger and irritability, delusions, aggression, depression, feelings of loneliness	35 (66%)	25 (51%)	-Diagnosing the cause of the problem and implementing intervention accordingly -Consultation with the study physician in order to diagnose the causes of the problems and to find proper treatment -Systematic support of the caregiver during the problem-solving process -Counseling the caregiver to find ways of coping with problematic behavior -Arranging rest periods for the caregiver -Accompanying (e.g., during shopping and banking) -Recreational measures (e.g., visiting on birthdays, walking outdoors together)
Stress and burden on caregivers (Dementia Study) and relatives (Delirium Study)	44 (83%)	28 (55%)	-Systematic support in problematic situations -Arranging rest periods for the caregiver -Arranging support groups with co-caregivers -Emphatic listening, sharing the feelings of burden, showing respect and caring -Counseling, giving information about the patient's situation (with permission)
Health problems of caregivers Including medical problems, decline in functional capacity, surgery, depression	26 (49%)	3 (6%)	-Helping the caregiver to find proper medical care -Close follow-up of the situation -Consultation with the study physician -Arranging rehabilitation -Giving health advice

5.2. Influence of institutional respite care on demented patients (IV)

The average time in respite care was 2.9 weeks (range 1-8 weeks) in SCU 1 and 2.1 weeks (range 1-4 weeks) in SCU 2. MMSE scores significantly improved in both SCU 1 ($p=0.028$) and SCU 2 ($p=0.005$). Furthermore, the caregivers reported improvement in the functional capacity of 40% of the patients (SCU 1) or 26% of the patients (SCU 2). According to the caregivers, positive changes were common in the patients' mood (76% of the patients in SCU 1 and 68% of the patients in SCU 2), while a decline in functional capacity and in mood was rare.

5.3. Influence of dementia on marriage (V)

At the time of the onset of dementia, the mean age of both the caregivers and the patients was 72 years. The couples had been married before the onset of dementia for a mean of 39 years, ranging from two to 52 years. The mean duration of home care after the onset of dementia was 7.7 years, ranging from one to 14 years.

After the onset of dementia, the spouse caregivers reported a marked decline in happiness ($p=0.012$), equal relations of their marriage ($p=0.001$), and in the patients' abilities to fulfill expectations as spouses ($p<.001$). More of the demented patients expressed disturbing jealousy after the onset of dementia than before dementia ($p=0.021$). However, the caregivers felt that the general atmosphere of the marriage had not changed ($p= 0.782$) (Figure 3).

Expressions of tenderness had increased in 14 demented patients (33%) (Figure 4).

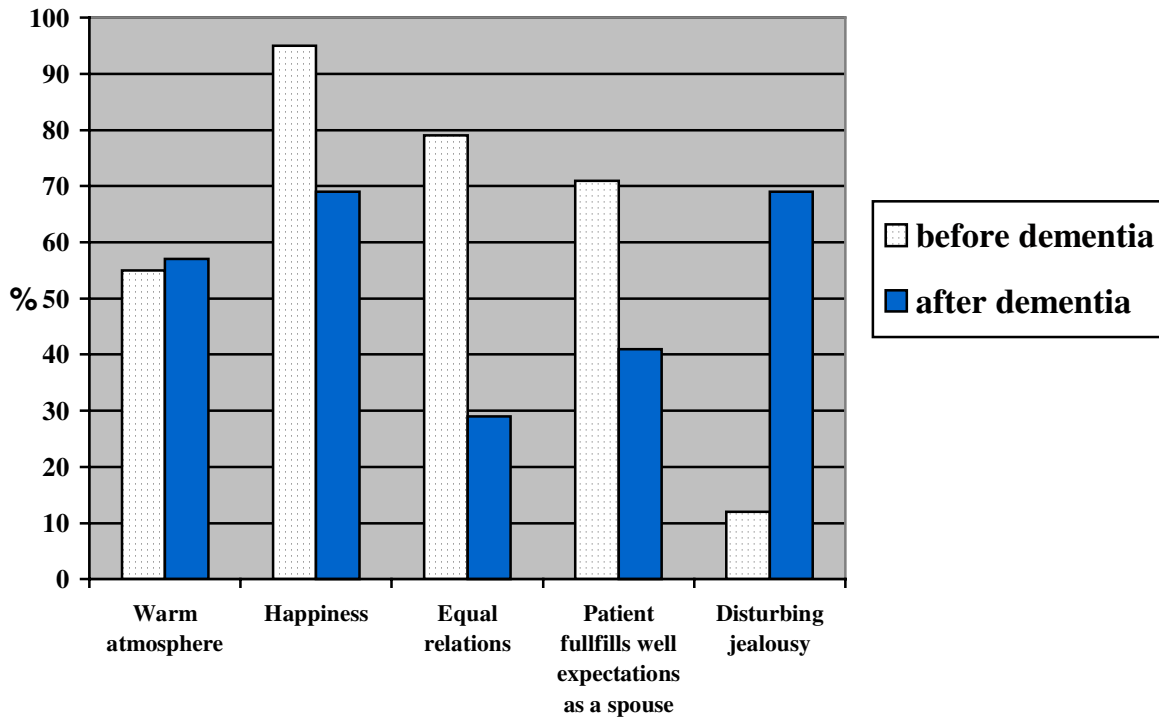


Figure 2. Characteristics of marriage before and after the onset of dementia.

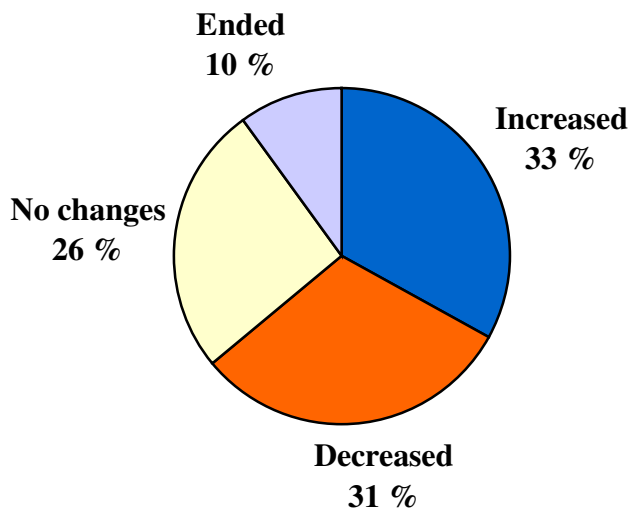


Figure 3. Changes in expressions of tenderness in demented patients before and after the onset of dementia.

During the time before dementia, 93% of the patients (n=39) used to express their sexual needs, while only 17% (n=7) did so after the onset of dementia ($p<.001$). The caregivers reported that the sexual relationship had become less important in the demented patients' life after the onset of dementia ($p<.001$). A longer duration of dementia was associated with a more negative attitude towards the importance of the sexual relationship ($p=0.025$). However, 41% of the patients (n=15) at five years and 28% (n=7) at seven years from the onset of dementia had continued to practice intercourse (Fig 4). The patient's gender and diagnosis of dementing illness did not have any impact on whether the couple continued to have intercourse.

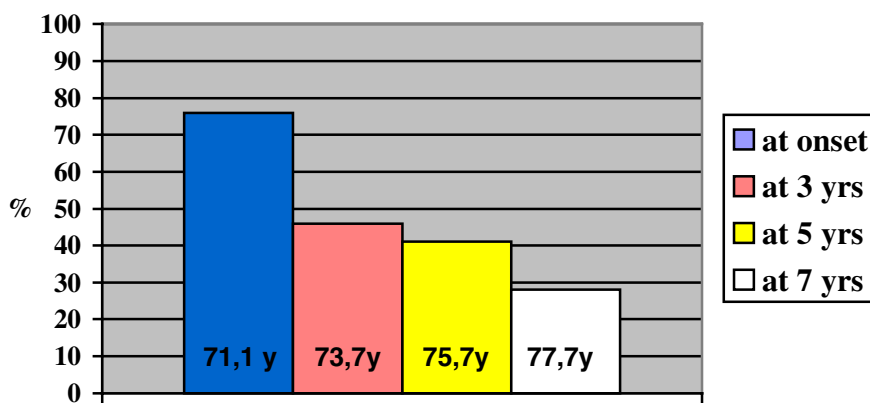


Figure 4. Percentages of demented patients practicing intercourse at 0, 3, 5 and 7 years from the onset of dementia (n=42). Mean ages of the patients at each time point are in the bars.

During the course of dementia, four caregivers (10%) had experienced that the demented patient had shown positive behavioral changes on the sexual side of the marriage. Negative behavioral changes had been experienced by 25 caregivers (60%). No significant association was found between the changes in sexual behavior and the patient's gender or diagnosis of dementing illness. The most common negative sexual behavioral change was the inability of the demented patient to pay attention to the spouse's sexual feelings and needs (n=19, 45%).

During the course of dementia, 24% of the male patients (n=7) had shown the behavioral symptom of constantly expressing a need for making love.

5.4. Effects of cessation of caregiving (VI)

The study sample consisted of 64 caregivers, of whom 47 (73 %) were female. Thirty six (56%) caregivers had belonged to the supported group during the intervention study. One half of the caregivers (n=31, 48 %) were spouses. The mean duration of caregiving after the onset of dementia was seven years, ranging from one to 16 years. In 48 (75%) cases, the caregiving had ended due to long-term institutional care of the patient, and in the rest of the cases, due to the death of the patient. The mean time elapsing since the cessation of caregiving at the time of the interview was 3.2 years, ranging from 0.1 to 5.3 years. In 60 cases (94%), the time period was more than one year.

The three most common emotions experienced by the caregivers at the time of the cessation of caregiving were relief (n=51, 80%), sorrow (n=39, 61%) and loneliness (n=30, 47%). Feelings of relief were associated with non-spouse caregiving (p=0.026). The spouse caregivers had a higher risk for loneliness (OR 276, 95% CI 9.50-8038) and sorrow (OR 4.84, 95% CI 1.24-18.92), as well as for depressive feelings (OR 6.10, 95% CI 1.65-22.61) than did the non-spouse caregivers.

The caregivers in the supported group had a lower risk for loneliness (OR 0.198, 95% CI 0.01-0.51), depressive feelings (OR 0.273, 95% CI 0.73-1.02) and sorrow (OR 0.242, 95% CI 0.07-0.90) compared with the caregivers in the control group.

Feelings of loneliness and sorrow were significantly associated with cases when death was the reason for ending caregiving. Depressive feelings were associated with a shorter period of time elapsing since the cessation of caregiving.

Positive life changes were experienced by 43 (67%) of the caregivers. The most common positive changes were increased leisure time (n=31, 48%) and a sense of freedom and relief (n=18, 28 %). Furthermore, 29 caregivers (45%) reported having experienced negative life changes, of which loneliness and (28%) increased health problems (20%) were the most

common. Negative life changes tended to be associated with spouse caregivers (OR 2.90, 95% CI 0.98-8.64) ($p=0.055$).

Over half of the caregivers (56%) reported that they had the increased amount of leisure activities after caregiving. A significant independent association was observed between increased leisure activities and being in the supported group (OR 5.06, 95% CI 1.63-15.70).

6.DISCUSSION

This thesis consists of three different study populations that have been used to investigate aspects of supporting the community care of demented patients from four different perspectives. The effects of nurse case manager (NCM) intervention were evaluated in two populations of cognitively impaired elderly. Moreover, two further studies were carried out on the population of the Kuopio Dementia Study. The influence of dementia on marriage was studied among those demented patients who had spouse caregivers. The impact of the NCM intervention was evaluated after the cessation of caregiving. The fourth aspect concerning community care was comprised of the study that assessed whether institutional respite care in two special care units would be possible without the deterioration of cognitive and functional capacity.

6.1.Intervention in supporting demented patients in community care

The Kuopio Dementia Study was a randomized controlled intervention study. The sample population was recruited from the register of the Social Insurance Institution in the city of Kuopio and its surroundings. All community-living demented patients requiring regular care are entitled to payments from the Social Insurance Institution. The study design increased the likelihood that the results could be fairly well generalized to reflect those Finnish community-living demented patients aged 65 years and over who have an informal caregiver as their primary support. Such intervention studies from a non-selected sample are needed in order to obtain evidence-based strategies for developing the community care of demented patients.

This study has some limitations. First, the small sample may give rise to a type two error: the erroneous acceptance of a false null hypothesis. It is likely that with a larger sample size, the intervention effect would have been stronger. The possibility also exists that the patients may not have fully represented all those community-living demented patients with informal caregivers, even though the sample was recruited from the register of the Social Insurance Institution. Although 141 patients were found eligible for the study, based on the prevalence of dementia, the cohort did obviously not constitute all eligible patients in the study area. If any possible eligible patients were omitted from the study, this was most likely due to either

improper diagnosis of the dementing illnesses by the health care system or to neglect in informing patients about their right to payments from the Social Insurance Institution. However, this potential bias would not have a critical effect on this study since a randomized controlled design was used.

Second, the allocation of the last 14 patients at a ratio of 2:1 could have led to bias in this study. This allocation was made since it was desired that as many patients as possible could benefit from the opportunity of receiving support from the NCM. With hindsight, a ratio of 1:1 should have been maintained throughout the study. However, it seems that the ratio used contributed no bias in favor of either the intervention or control patients. Analysis of the data for the first 86 patients (43 intervention and 43 control patients) showed that institutionalization and survival of the intervention patients were similar to that of the whole study population at the end of the second year.

Third, the annual assessments of the control patients with medical examinations and service counseling may also have had some support effect on the control group.

The main outcome measure of the study was the patients' survival in the community without institutionalization. The intervention deferred placement in long-term institutional care among the intervention patients. However, the effects of the intervention decreased with time, and inevitably long-term institutional care could not be prevented. This result supports previous findings that demented patients are very likely to end up in long-term institutional care at some point (Drachman et al. 1990). It is also possible that the intervention may have had some novelty effect among the caregivers.

Unfortunately, the sample size was too small to draw any far-reaching conclusions concerning which subgroups benefited the most from this intervention. However, some subgroup analyses were made for descriptive purposes. The analyses suggested that severely demented patients benefited the most from the intervention, and significantly so when they had spouse caregivers. These clinically important findings deserve some discussion.

Several previous studies have confirmed that the severity of dementia is one important risk factor for institutionalization (Brodaty et al. 1993, Severson et al. 1994, Gold et al. 1995, Knopman et al. 1999). In the study of Mittelman et al. (1996), patients with mild and

moderate dementia benefited the most from the intervention program of training and counseling for the spouse caregivers and families. In the study of Brodaty et al. (1997), no severely demented patients were included, thus preventing comparison with the present study. One explanation for the results of the present study is that the primary focus in the study was on those patient variables that have been reported to predict long-term institutionalization, such as BPSD, co-morbidity and functional disabilities (Ouslander et al. 1990, Severson et al. 1994, Osterweil et al. 1995, Juva et al. 1997, Hope et al. 1998). The need of the NCM to intervene was markedly related to these patient problems. The prevalence of these problems increases with the severity of dementia (Nagaratnam et al. 1998). Cohen and Pushkar (1999) suggested that recognition of problems in community care and crisis intervention are needed to provide support to demented patients and their caregivers.

In the present study, psychosocial support and education were provided to the caregivers during the rehabilitation courses, and when the NCM delivered her services to the patients. However, the caregiver support was not as systematic and intensive as in other studies focusing on caregiver variables (Mittelman et al. 1996, Brodaty et al. 1997), which may explain differences in the results for patients with mild or moderate dementia. On the other hand, these groups of patients are less likely to end up in long-term institutional care. In the present study, it was unlikely for intervention to have a strong effect on mildly demented patients because of the very low rate of institutionalization among patients in this group.

The finding in severely demented with spouse caregivers may be explained by two factors. First, the spouse caregivers are committed to providing caregiving for a longer period of time, and also tolerate disabilities in a patient better than would non-spouse caregivers (Pruchno and Potashnik 1989, Hope et al. 1998, Pot et al. 2001). Second, it can be speculated that the problem-solving approach had an additional support effect on the committed spouse caregivers. This is consistent with the findings of Kramer (1997) who reported that among 74 husbands caring for their wives with dementia, problem-focused coping predicted positive appraisals.

The intervention also had long-term effects on the caregivers in the intervention group after the cessation of caregiving. The long-term effect of intensive family training on prolonging the community care of demented patients has been reported by Brodaty et al. (1997). In the present study, the caregivers in the intervention group had a lower risk for experiencing

loneliness, depressive feelings and sorrow at the point when ending caregiving than did those caregivers in the control group. Furthermore, the caregivers in the intervention group were more likely to return to a normal life with increased leisure activities after the cessation of caregiving. These results could be explained by the prolonged period of community care that gave the caregivers a longer opportunity to process their feelings through psychosocial support. Furthermore, they may have felt that everything possible had been done to help the demented patient.

This study also supports other previous findings on spouse caregivers. First, it confirms that the cessation of caregiving may not necessarily lead to a decrease in the emotional strain felt by spouse caregivers. Indeed, previous studies show that many spouses may even have difficulties in coping with the new situation (Gold et al. 1995, Kaplan and Boss 1999, Rudd et al. 1999). At the point when ending caregiving, the emotional reactions of spouse caregivers differed considerably from those of non-spouse caregivers. The cessation provided less relief, and even tended to give rise to negative life changes, including increased health problems, as has been reported in the study of Kiecolt-Glaser et al. (1991). Second, the experiences reported after cessation may support the hypothesis that caregiving also provides satisfaction, not only distress. The present study also reveals some positive aspects that remain preserved in marriages with a demented patient. In one third of the patients, expressions of tenderness towards the caregiver had increased. Dementia seemed to have had surprisingly little impact on whether the couple continued to have sexual intercourse, as compared with the aging population in general (Kivelä et al. 1986, Bergström-Walan and Nielsen 1990, Kontula and Haavio-Mannila 1995, Matthias et al. 1997). Even though dementia had a major impact on many dimensions of marriage, it did not significantly affect the general atmosphere of the marriage. This finding can be interpreted similar to that of Gallagher-Thompson et al. (2001). In their study, they compared the interpersonal interaction of Alzheimer disease caregiving and non-caregiving wives (n=54), and found that dementia had not affected the shared values and closeness of the couples.

A similar intervention by NCM was used in the Kuopio Delirium Study. At the beginning of the NCM intervention, 14 patients (27%) had a mild dementia disorder that was diagnosed after delirium symptoms had subsided. During the three-year follow-up, 67% of the elderly were diagnosed as having dementia (Rahkonen 2001). Most of these lived without a

caregiver. The intervention based on CM significantly prolonged community care as compared with the matched controls.

6.2. Nurse case manager supporting the community care of elderly people with cognitive impairment

The NCMs were the coordinators of care and support for the intervention patients. These studies have showed their work to be effective in prolonging the community care of the patients. The amount of NCM time was increased when a problematic situation arose, a finding similar to that of Diwan and Phillip (2001). Thus, the NCMs acted also as coordinators in the problem-solving process. The most frequent problems comprised stress and burden in the caregivers, and health problems and BPSD in the patients. However, health problems were also common in the caregivers of the demented patients. The NCMs delivered measures after diagnosing the cause of the problem, often requiring consultation with the study physician in this problem solving process.

The sample size was relatively small in this study analyzing the measures delivered by NCMs. Furthermore, no standardized, structured questionnaire was used for collecting the data of this study. However, the dementia group consisted of a population-based sample of demented patients, and the delirium patients were consecutive admissions to a district general hospital. Throughout the follow-up period, the NCMs documented in detail the problems and the measures taken in solving each problem, the planned and arranged services, and contacts with both patients and their caregivers or relatives as well as with formal service providers.

The NCMs were the primary nurses for the patients during the rehabilitation periods. These periods helped in obtaining a comprehensive overview of the patients' and their caregivers' situations. Furthermore, they provided the opportunity to create good personal relationships between the patients and their caregivers. However, the experiences of the present study, similar to those of Mittelman et al. (1996), indicate that the continuous, comprehensive intervention by the NCM in community care was the most important factor affecting the success of this intervention. The rehabilitation periods alone would not have provided sufficient support for the patients and their caregivers.

The NCM's primarily focused on those patient variables causing risks for institutionalization in elderly people with cognitive impairment. These risks are likely to occur with increasing severity of dementia, as stated in Nagaratnam (1998). The results of the present study support the feasibility of providing successful interventions in response to BPSD manifestations and the functional disabilities of demented patients, as previously reported by Hinchliffe et al. (1995) and Rosewarne et al. (1997). In the systematic review and meta-analysis of home visits to prevent institutionalization in elderly people, Stuck et al. (2002) concluded that identifying risks and dealing with them is an essential component of effective care of elderly people. This component is similar to the NCM intervention in the present study.

“One-stop-shopping services” were very common among caregivers of demented patients. A possible explanation for this may be that this type of service is especially valuable for overburdened caregivers of demented patients, as stated by Brodaty et al. (1989). The municipal health and social service system is often complicated with overly bureaucratic procedures and caregivers may have difficulties in finding the correct services.

In-home visits were more common in the Delirium Study than in the Dementia Study, which can be explained by the fact that 82% of the patients in the Delirium Study lived alone. A similar need for frequent in-home visits is very likely to occur when supporting demented patients living without a primary informal caregiver.

The qualifications of the NCM may also be a very important predictor of efficiency in a NCM's work. This assumption is supported by previous studies. Lauri and Salanterä (1995) reported that experience is one of the most important factors affecting nurses' decision-making abilities. Soini and Välimäki (2002) emphasized the need of training in supporting nurses to identify the problems of patients and to deliver appropriate interventions. Few studies have highlighted the need for specific education and training of case managers (CM) (Bernabei et al. 1998, Stuck et al. 2000, Diwan and Phillips 2001). Stuck et al. (2000) indicated that the impact of a support program is likely to be affected by the nurse's or home visitor's performance in conducting the program. Diwan and Phillips (2001) investigated the impact of the BPSD on the use of CM time in 73 demented patients. They concluded that qualified CMs are needed in order to focus on direct attempts to address the management of BPSD instead of only dealing with the consequences of problems. Based on experiences in the present study, it is suggested that the NCM for demented patients should be a registered

nurse qualified to work with this patient group. Problem solving abilities, initiative and a high capacity for responsible and independent work are required from NCMs. Furthermore, the NCM needs to be able to collaborate well with a physician who knows the patient.

The approachability of the NCM and her availability by mobile telephone were probably very valuable to the success of the intervention, and the patients and their caregivers could rely on the help and support of the NCM in any situation. In the study of MaloneBeach et al. (1992), 46 caregivers of demented patients were interviewed to explore the use of case-managed services. In this study, the CMs were from different professional backgrounds. Counseling, arranging services and information about services were the main tasks of the CMs. The caregivers appreciated that a CM arranged services, but they wanted to be involved in planning these services. They appreciated the flexibility and reliability of the CM's work, such as when and by whom the care is provided, and that visits and calls are delivered as promised. The importance of the CM being a sympathetic person was also emphasized.

Based on the experiences in the present study, one NCM is capable of taking responsibility for the care of approximately 50 demented patients and their caregivers at the same time, especially if the patients live within 30 minutes' travel distance from the NCM's office. However, the exact number of patients each NCM can handle depends greatly on the problems threatening the community care of the patients, and whether the patients live alone or with a caregiver.

6.3. Intervention in institutional respite care

This pilot study in two special care units supports the feasibility of providing institutional respite care to demented patients without deterioration in the cognitive and functional capacity of demented patients.

In this pilot study, the small number of study subjects and the absence of a control group limit the ability to generalize these findings. However, the similar results obtained from two SCUs may provide some evidence suggesting that respite care program targeted at demented patients' needs may have a positive effect. It can be assumed that SCUs provide the ideal foundation for respite care because they are designed for demented patients and are intended to meet the special needs of this patient group. However, SCUs are not always able to provide efficient respite care, as supported by the findings of Larkin and Hopcroft (1993), who suggested that future respite research should delineate the dementia program in order to ascertain whether such factors as staff training programs, staffing requirements, and physical environments could have an impact on outcomes.

In this study, the intervention measures in both SCUs were based on the therapeutic community model. Other variables in these two units differed substantially, including the staffing, professional background of staff members, environmental design and location in Finland. It can be assumed that the style of nursing care most likely explains these suggestive positive results, a speculation similar to that presented earlier by Homer and Gilleard (1994).

Institutional respite care is needed to support demented patients and their caregivers. So far, studies examining the effects of institutional respite care have relied on small, non-representative samples, mostly using pre- and post-test design. Randomized controlled trials are needed to provide evidence-based institutional respite care for demented patients. Such studies, should clearly define the interventions as well as the style of respite care in terms of the frequency, duration and at what point of the disease process respite care should be provided, as suggested by Gräsel (1997).

7.CONCLUSIONS

1. The placement of demented patients in long-term institutional care can be deferred through NCM intervention, in which the primary focus is on those patients with characteristics that may threaten the continuity of community care. The target groups for NCM intervention are demented patients with behavioral problems, functional disabilities or serious health problems; those with severe dementia; and those with spouse caregivers. The results from the delirium study indicate that one other target group may also be those patients with milder dementia who live without a caregiver.
2. The intervention also had long-term effects on the caregivers of demented patients and helped them to return to a normal life with an increased amount of leisure activities.
3. A good choice for the NCM is a registered nurse qualified in working with cognitively impaired elderly. The NCM should be capable of working in close collaboration with not only the social and health care system but also a physician, such as a general practitioner, who knows the patient.
4. Institutional respite care provided in SCUs designed for the care of demented patients may have positive effects on patients. Effective institutional respite care requires well-trained staff and a care environment targeted to the needs of demented people.
5. The cessation of caregiving caused significantly more negative feelings in spouse caregivers than in non-spouse caregivers.
6. Dementia had a major negative impact on many dimensions of marriage. However, positive changes and preserved aspects of marriage were also found, which may explain why spouse caregivers are especially committed to continue in caregiving, even at more advanced stages of dementia.

8. CLINICAL RECOMMENDATIONS

The measures provided by the present social and health care system are not effective enough in supporting the continuity of the community care of demented patients. The results of the present study indicate that nurse case managers (NCM) can be implemented within the formal care system in order to prolong the community care of demented patients. The NCM intervention should be well targeted in order to be effective. The ideal target groups are demented patients with behavioral problems, functional disabilities or serious health problems, those with severe dementia, and those with spouse caregivers. One target group may also be those patients with milder dementia living without a caregiver.

To be effective, the NCM intervention requires (1) a registered nurse qualified in working with demented patients, (2) close collaboration between the NCM and a physician, e.g. a general practitioner who knows the patient, (3) close co-operation with the social and health care system, and (4) approachability and availability of the NCM on a 24-hour basis. Furthermore, a NCM needs to have problem solving abilities, initiative, and a high capacity for responsible and independent work.

One NCM is capable of assuming responsibility for the care of approximately 50 demented patients and their caregivers at the same time, especially if the patients live within 30 minutes' travel distance from the NCM's office. The exact number of patients is determined by the amount of problems threatening the community care of the patients, and whether the patients live alone or with a caregiver.

Institutional respite care tends to deteriorate the capacity of demented patients to perform daily functions, thus leading to long-term institutionalization. Therefore, the institutional respite care should be primarily provided in highly qualified special care units (SCU) that may be able to provide care without deterioration of the demented patient's functional capacity. The social and health care system with a NCM and a highly qualified SCU could provide the facilities to deliver comprehensive, flexible and well-targeted community care support to demented patients.

Spouse caregivers are a very important resource in the community care of demented patients. They are often committed to continue with community care even when problems arise. Appropriate and effective interventions should be provided when problems arise. Furthermore, at the time of cessation of caregiving, spouse caregivers need support in coping with their new life situation. After cessation, spouse caregivers may be more prone to developing health problems, and these should be properly treated.

9. SUMMARY IN FINNISH – SUOMENKIELINEN YHTEENVETO

Suomessa on noin 100 000 dementiapotilaasta, joista 40-50% on pitkäaikaisessa laitostasoisessa hoitopaikassa. Dementoituneiden määrän nousu 128 000:een vuoteen 2030 mennessä lisää painetta kehittää heidän kotona selviämisen mahdollisuuksiaan. Dementiapotilaiden kotona asuminen on suurelta osin omaishoitajien varassa. Erityisesti puolisoitajat ovat usein sitoutuneita hoitamaan vaikeastikin dementoituneita tai käyttöoireista kärsiviä. Eräänä kotihoidon tukimuotona käytetään ympärivuorokautista lyhytaikaishoitoa, joka kuitenkin usein heikentää potilaan toimintakykyä ja osaltaan edistää hänen pitkäaikaiseen laitostasoiseen hoitoon joutumistaan.

Käsillä oleva tutkimus tarkastelee dementiapotilaiden kotihoidon tukemisen mahdollisuuksia neljästä eri näkökulmasta. Dementiakoordinaattori-intervention vaikutusta kotihoidon kestoon arvioitiin kahdessa kognitiivisista ongelmista kärsivien iäkkäiden ryhmässä. Toiseksi intervention vaikutuksia omaishoitajan elämään arvioitiin kotihoidon päättymisen jälkeen. Kolmanneksi tutkittiin dementoitumisen myötä parisuhteessa tapahtuneita muutoksia. Neljänneksi selvitettiin, voidaanko lyhytaikaista ympärivuorokautista hoitoa toteuttaa ilman että dementiapotilaan toimintakyky heikkenee.

Dementiakoordinaattori-intervention vaikutuksia arvioitiin kaksivuotisessa Kuopion dementiatutkimuksessa ja kolmevuotisessa Kuopion deliriumtutkimuksessa. Kuopion dementiatutkimuksessa tutkittiin 100 kotihoidossa omaishoitajan tuella asuvaa dementiapotilasta. Nämä yli 65-vuotiaat potilaat otettiin Kansaneläkelaitoksen rekisteristä ja heidät satunnaistettiin tuettuun (n=53) ja kontrolliryhmään (n=47). Dementiakoordinaattori toimi tuettujen potilaiden ja heidän omaishoitajiensa vastuuhoidajana. Toteutettu interventio siirsi potilaiden pitkäaikaiseen laitostasoiseen hoitoon joutumista. Tulokset antoivat viitteitä siitä, että interventiosta hyötyisivät erityisesti vaikeasti dementoituneet sekä ne, joilla oli kotihoidon jatkumista uhkaavia tekijöitä. Dementiakoordinaattori-interventiota käytettiin myös Kuopio deliriumtutkimuksen tuettujen potilaiden (n=51) kotihoidon tukemisessa. Heistä 82% asui yksin. Näiden sairaalasta deliriumin jälkeen kotiutettujen yli 65-vuotiaiden kontrolliryhmänä käytettiin ikä- ja sukupuolivakioituja historiallisia verrokkeja. Kolmen vuoden seurannan aikana dementoiva sairaus voitiin diagnosoida 67%:lla tuetuista potilaista. Kotihoidon kesto oli merkitsevästi pidempi interventio- kuin kontrollipotilailla.

Dementiakoordinaattori oli tehtävänsä erityiskoulutettu sairaanhoitaja ja hän toimi tuettujen potilaiden hoidon ja palvelujen koordinoijana sekä ongelmatilanteiden ratkaisijana. Toiminnan tunnuspiirteitä olivat kokonaisvastuun ottaminen sekä sairaanhoitajan tavoitettavuus ja luotettavuus. Pääpaino oli nopea reagointi kotihoidon jatkumista uhkaaviin ongelmatilanteisiin.

Dementiakoordinaattori -intervention pitkäaikaisvaikutuksia arvioitiin jatkotutkimuksessa, missä kotihoidon päättymisen kokeneet omaishoitajat (n=64) puhelinhaastateltiin. Tuetun ryhmän omaishoitajilla oli merkitsevästi pienempi riski kokea yksinäisyyttä, mielialaongelmia ja surua kuin kontrolliryhmän omaishoitajilla. Heillä oli myös enemmän erilaisia harrastuksiin liittyviä aktiviteetteja. Kotihoidon päättymisen jälkeen puolisoitajilla oli merkitsevästi isompi riski negatiivisiin tunnekokemuksiin kuin muilla omaishoitajilla. Puolisohoitajat kokivat myös muita omaishoitajia vähemmän helpotusta, kun hoidon taakka poistui.

Parisuhteessa dementoitumisen myötä tapahtuneita muutoksia tutkittiin puhelinhaastattelemalla Kuopion dementiautkimuksen puoliso-omaishoitajat (n=42). Puolisohoitajat kokivat, että dementiaalla oli ollut huomattavia negatiivisia vaikutuksia moniin parisuhteen alueisiin. Tutkimus toi kuitenkin esiin myös parisuhteen positiivisia ja säilyneitä ulottuvuuksia. Dementia ei ollut merkittävästi vaikuttanut parisuhteen yleiseen ilmapiiriin. Joka kolmannella dementoituneista hellyyden osoitukset puolisoa kohtaan olivat lisääntyneet. Dementiaalla oli yllättävän vähän vaikutuksia yhdyntöjen jatkumiseen verrattuna samaa ikäluokkaa oleviin dementoitumattomiin pariskuntiin.

Ympäri vuorokautisen lyhytaikaishoidon vaikutuksia dementoituneiden kognitiiviseen ja fyysiseen toimintakykyyn sekä mielialaan arvioitiin kahdessa dementiayksikössä, joista toinen sijaitsi Helsingissä ja toinen Vaasassa. Hoito pohjautui terapeuttisen yhteisön malliin sekä potilaiden hyvään kokonaistilanteen arviointiin ja hoitoon, joka sisälsi dementoivan sairauden tarkan diagnosoinnin. Tulosten mukaan potilaiden kognitiivinen toimintakyky parani merkittävästi molemmissa yksiköissä. Lisäksi hoidolla oli positiivisia vaikutuksia potilaiden fyysiseen toimintakykyyn ja mielialaan.

Yhteenvedon voidaan todeta, että dementiakoordinaattori-interventio pitkitti erityisesti niiden kognitiivisista ongelmista kärsivien henkilöiden kotihoitoa, joilla oli kotihoidon päättymisen ennustekijöitä. Interventiolla oli myös pitkäaikaisvaikutuksia. Interventoryhmässä olevien dementiapotilaiden omaishoitajat selviytyivät kontrolliryhmää paremmin takaisin normaaliin elämään kotihoidon päätyttyä. Lisäksi tutkimus toi esille puoliso-omaishoitajien tilanteen erilaisuuden verrattuna muihin omaishoitajiin. Puolisohoitajat näyttivät tuen ansiosta voivan jatkaa kotihoitoa pidempään eikä kotihoidon päätyminen aina tuonut helpotusta heidän elämäänsä. Dementiaalla oli monia negatiivisia vaikutuksia parisuhteeseen. Kuitenkin parisuhteessa oli myös positiivisia ja säilyneitä ulottuvuuksia, jotka osaltaan saattavat selittää puoliso-omaishoitajien muita omaishoitajia suuremman sitoutumisen omaishoitajuuteen.

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11. ORIGINAL PUBLICATIONS

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- VI Eloniemi-Sulkava U, Rahkonen T, Suihkonen M, Hentinen M, Sulkava R. Emotional reactions and life changes of caregivers of demented patients when home caregiving ends. *Aging Ment Health*. Accepted for publication.