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How Do Officially Organized Services Meet the Needs of Elderly Caregivers and Their Spouses With Alzheimer's Disease?

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The caregiving situation among caregivers and their spouses with Alzheimer's disease, the support and services received, the unmet needs, and the caregivers' satisfaction with the services are examined. The study included a survey of a random sample of 1943 caregivers of persons with Alzheimer's disease in Finland. Mean age of the caregivers was 78.2 years, and 35% had poor subjective health. Disabilities and behavioral symptoms were common among the spouses with Alzheimer's disease. The services most often offered were financial support (36%), technical devices (33%), physiotherapy (32%), and respite care in nursing homes (31%). Most often needed services were physiotherapy for the spouse with dementia (56%), financial support (50%), housecleaning (41%), and home respite (40%). Only 39% of the caregivers were satisfied with the services, and 69% felt they did not have any influence on what services were offered. It was concluded that official services poorly meet the needs of these caregivers.

Keywords: dementia; Alzheimer; caregiver; services; needs

Many studies have shown that the caregivers' burden is quite heavy in the care of a person with dementia.[1-3] They have a great need for support and services. Some studies have suggested, however, that services do not meet caregivers' needs properly.[2,4]

Although caregiving entails strain and burden, families of dementia patients are often reluctant to use the services offered.[2,4-7] Formal services are typically engaged when informal services are not available or only if a crisis arises.[7] Caregiving literature has suggested several reasons for this. First, families are often unaware of available services, and they have a great need for information.[2,4] Second, caregivers may have had previous disappointing experiences with staff insufficiently trained to cope with patients with Alzheimer's disease (AD) or with high staff turnover.[2] Third, families seek greater flexibility and the ability to influence service packages.[8] Fourth, caregivers have a strong moral commitment related to their spousal relationship, and they often feel that they have a duty not to entrust their spouse to others.[6,9] Finally, these families value their autonomy, privacy, and dignity even in very stressful situations and therefore they are reluctant to use the services.[7,9] Thus, there is friction between the service system and the caregiving families.

Although some qualitative and small descriptive studies have suggested that there are problems between the caregiving families and the service system, no large epidemiological studies have described the extent of these problems. In addition, there are only a few large-scale studies on how caregiving families use services in different countries, which services they prefer or would consider using if available, and how satisfied they are with the services. An Italian study reported the service use of 60 family supporters and found that 59% were dissatisfied with their services. They also expressed a need for specifically trained operators or more tailored intervention.[2] An Australian study of 67 carer dyads found a large number of various unmet service needs, respite care being the most wanted.[7]

Unmet needs are particularly common among supporters of demented people compared with caregivers of nondemented people.[10] According to the EUROCARE cross-national survey (ie, a study of co-resident spouse carers for people with Alzheimer's disease, N = 280), the burden of the caregiver was not predicted by the formal home care received or financial support.[11] In a recent US large-scale study of 4761 dementia families, early community-based service utilization was shown to be cost-effective and to delay institutionalization.[12] In an 18-month longitudinal design of 5831 dementia families, unmet needs predicted nursing home placements, death of care recipients, and loss to follow-up.[13] To our knowledge, this is the only large-scale epidemiological study investigating the predictive value of unmet needs on the use of health services among dementia families.

The aims of this study were

1. to describe the caregiving situation among older couples, of which one suffers from AD and the other acts as the caregiver,
2. to examine how the spousal caregivers of home-dwelling patients with AD receive official support and use services; to clarify the unmet needs among these couples, and
3. to investigate the spousal caregivers' satisfaction with these services.

Methods

Sample

A random sample for this survey was gathered from the Alzheimer drug users' register of the Social Insurance Institution of Finland. In Finland, the Ministry of Social and Health Care has obliged the Social Insurance Institution to consider all grounds for the compensation of medication for AD (donepezil, galantamine, rivastigmine, and memantine). To receive the benefit for AD drugs in Finland, every patient needs a statement from a specialist doctor (neurologist, geriatrician, or psychogeriatrician) for the Social Insurance Institution. The compensation of drug costs is approved only if AD has been properly diagnosed. Thus, each patient receiving this benefit has undergone thorough diagnostics, which include cognitive tests, for example, the Mini-Mental State Examination,[14] laboratory tests, and a computed tomography (CT) or magnetic resonance imaging (MRI) scan of the brain. Because the long-term use of these medications is expensive for the family, most individuals use their legal right to receive compensation for drug costs from the state. Thus, our random sample from the AD drug users' register of the Social Insurance Institution consisted of patients with probable AD. In addition, the requirement of sampling included that they had a spouse living at the same address.

A postal questionnaire was sent to a random sample of 1943 such spouses of persons with AD in 5 urban or nonurban regions in Finland to get a representative picture of the whole situation in Finland (Helsinki, Tampere, Middle Finland, Northern Karelia, and Lapland with Northern Ostrobothnia). Our sample of 1943 Alzheimer patients consisted of 13% of the background population receiving compensation for Alzheimer drugs in Finland. There was no age criteria for inclusion in the survey. Before gathering the sample, the ethics committee of the Helsinki University Hospital approved the study.

Procedures

For security reasons, the Social Insurance Institution posted the questionnaire to the caregivers, who

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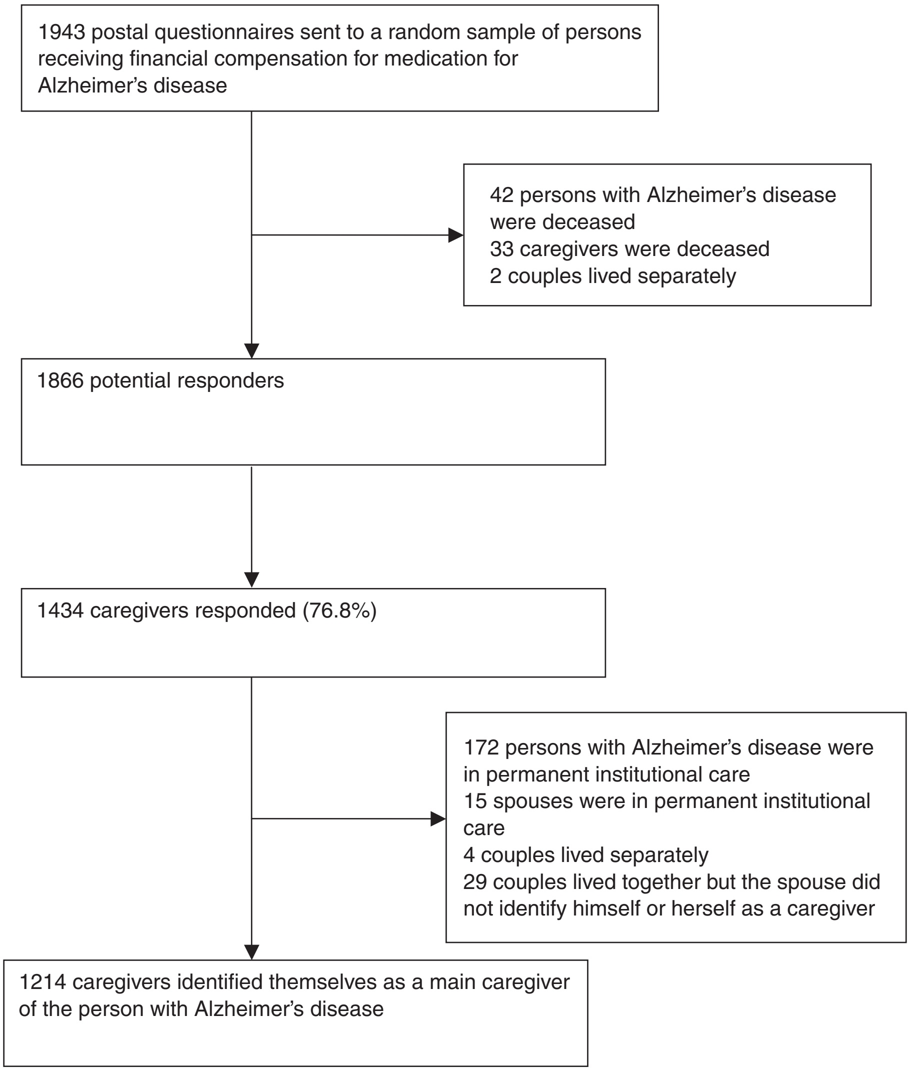

Figure 1. Data collection of the postal survey of Finnish spouse caregivers of persons with Alzheimer's disease in autumn 2005.

returned them to the researchers anonymously. Thus, the researchers did not have an access to the register of the Social Insurance Institution containing any personal data or medical records. The researchers received only code numbers of each participant. Of the original random sample, mortality registers were used by the Social Insurance Institution to remove participants no longer living (n = 77), and 2 couples lived separately according to current address information. Questionnaires were sent in September 2005 and were resent in November 2005 to the spouses who had not responded. In all, 77% (n = 1434/1866) returned the questionnaire. Altogether 1214 spouses identified themselves as the main caregiver of the spouse with AD. Of the other respondents (n = 220), a majority had already admitted their spouse to permanent institutional care (n = 172) (Figure 1). A total of 15 potential caregivers had themselves been admitted to permanent institutional care, and 4 couples announced that they lived separately. The rest (n = 29) did not identify themselves as caregivers. The majority of these spouses (n = 27) were in even poorer health condition than the person with AD.

Questionnaire

The questionnaire consisted of questions on demographic variables, the physical and psychological symptoms of the spouse with dementia, the support and services received by the family from the official service system, and the caregivers' subjective needs and satisfaction with these services. The questionnaire was piloted face to face on 10 elderly spousal caregivers to ensure that the questions were easy to understand for elderly people. It took about 30 minutes to fill in the questionnaire of 12 pages. A large proportion of the questions had been used and validated before in several large-scale epidemiological surveys of the elderly.[15-17]

Demographics and Need for Care and Services

The demographic variables consisted of questions concerning both the caregiver and spouse: their age, sex, duration of their marriage, education, and income. The subjective health of the caregiver was surveyed and divided into two categories: (1) good (subjective health good or fairly good) or (2) poor (subjective health poor or fairly poor).

The mobility of the spouse with AD was examined by asking whether he or she was able to walk indoors without difficulty, and the answers were categorized as "able to walk indoors without aid" (1 = yes) and "needs the aid when walking indoors" (2 = no, needs a stick or walking aid, 3 = no, needs aid of another person, 4 = no, cannot walk at all). The incontinence of the spouse with AD was elicited with the question "Does your spouse have urinary or bowel incontinence?" with a yes or no option. The need for a caregiver's assistance and continuous presence was elicited with the question "Does the care of your spouse require your continuous presence?" with a yes or no option. Questions concerning hallucinations, depression, and the agitation of the spouse with AD were retrieved from the internationally well-validated and widely used Neuropsychiatric Inventory (NPI)[18] assessing behavioral and psychological symptoms of dementia with yes or no answers.

Official Service System and Service Utilization

The use of various official services in Finland and the subjective need for them were elicited with yes or no questions. We also studied whether, according to the caregivers, it was easy to obtain information about the services. Finally, the caregivers' satisfaction with the services and their ability to influence what services they received were elicited with yes or no questions. In Finland, caregivers devoting significant hours of work to caregiving are legally entitled to financial support from the community after a home visit and evaluation by a social nurse. The services offered are dependent on the social worker's or health care worker's evaluation of the needs of the care recipient. The communal service system includes a large variety of services (skilled home nursing, domestic help, meals on wheels, physiotherapy, day care, respite care, etc). Transport services are offered by the communities to people unable to use public transportation. The charge for communal services is dependent on the income of the care recipient. Various technical devices are free of charge. Physiotherapy is offered yearly by the state for World War II veterans free of charge.

Analyses

Data were analyzed with the NCSS for Windows statistical program. The characteristics and well-being of the spouses with AD and their caregivers were cross-tabulated according to the caregivers' sex. The chi-square test was used to test differences between the categorical variables. The Mann-Whitney U test served for testing non-normally distributed variables. Logistic regression analysis was used to test how the determinants of health service use, known from the Andersen model,[19,20] predict the satisfaction of services among the caregivers. Age, sex, education <7 years, subjective health of the caregiver, disability, >2 physical and >2 psychological symptoms of the spouse with AD, income, experience of the care provider's emotional support, difficulties getting information about the available services, and the perceived control over what services the family was receiving were used as covariates.[19,20] P values <.05 were considered statistically significant.

Results

The response rate was 77%. The mean age of the caregivers of spouses with AD was 78.2 years, male caregivers being older than female caregivers (80.2 vs 76.7 years, $P < .001$). Most of these spousal caregivers were female, but the proportion of male caregivers was also high (37%), considering the high age of the respondents. All couples were married, and the mean duration of marriages was very long, among female and male caregivers, 52 and 54 years, respectively. Over half the caregivers and spouses

Table 1. Characteristics of the Spousal Caregivers and Their Home-Living Spouses With Alzheimer's Disease (AD) in Finland, 2005 (N = 1214)

	Female Caregivers (n = 762)	Male Caregivers (n = 452)	*P*
Caregiver			
Mean age, years (range)	76.7 (50-93)	80.2 (45-95)	<.001[a]
Education <7 years (%)	57.1	56.1	.73[b] *df* 1
Poor subjective health	34.9	35.3	.92[b] *df* 1
Spouse with AD			
Mean age, years (range)	81.1 (67-97)	80.1 (54-91)	<.001[a]
Education <7 years	61.6	63.9	.42[b] *df* 1
Couple			
Mean years of marriage (range)	51.9 (6-67)	53.9 (2-68)	<.001[a]
Income (%)			
Good	19.2	19.6	
Moderate	77.9	78.0	
Poor	2.9	2.4	.89[b] *df* 2

[a] Differences between non-normally distributed continuous variables were tested with the Mann-Whitney *U* test.
[b] Differences between proportions were tested with the chi-square test.

Table 2. Prevalence of Symptoms and Care Needs of Finnish Home-Dwelling Persons With Alzheimer's Disease (AD) According to Their Spousal Caregiver (N = 1214)

	Female Spouses With AD (n = 452)	Male Spouses With AD (n = 762)	*P*[a]
Symptoms of hallucinations	42.3	44.6	.44
Symptoms of depression	51.5	53.7	.48
Symptoms of agitation	68.3	73.5	.06
Needs aid when walking indoors	33.3	36.2	.31
Urinary or bowel incontinence	40.0	48.9	.002
Needs the caregivers' continuous presence	39.3	40.1	.77

[a] Differences between proportions were tested with the chi-square test, *df* 1.

with dementia had an education of less than 7 years. Most families regarded their income as moderate. One-third (35.1%) of the caregivers had poor subjective health (Table 1).

Of the care recipients, 40% needed continuous support from their caregiver. Half had symptoms of depression, more than two-thirds had symptoms of agitation, and 44% had hallucinations. Urinary or bowel incontinence was very common (46%) among these home-living spouses with AD, and 1 in 3 care recipients was not able to move indoors without aid (Table 2).

The services most often received by these couples were the community's financial support for the caregiver (35.9%), various technical devices (33.4%), physiotherapy for the Alzheimer patient (32.4%), and a respite care in a local nursing home for the care recipient (31.1%) (Figure 2). Most of the physiotherapy received by the care recipients was the yearly rehabilitation for World War II veterans, which is fixed by law in Finland. Only every tenth of those with AD who were not war veterans had physiotherapy. Skilled home nursing was offered to 26% of the families and domestic help to only 15% of families. Among those not receiving the service in question, the most desired services were physiotherapy for the person with AD (56.4%), community's financial support for the caregiver (50.0%), housecleaning (40.8%), and home respite to give a few hours free time to the caregiver (39.9%) (Figure 3). Among those already receiving services, 16.1% to 30.8% had an extra need for the same service received. Sex differences appeared in the services received and needed so that male caregivers were offered more skilled home nursing, domestic help, housecleaning, and meals on wheels, whereas female caregivers were offered more financial support, physiotherapy, transport services, and respite care in a nursing home for the spouse with AD (Figure 2).

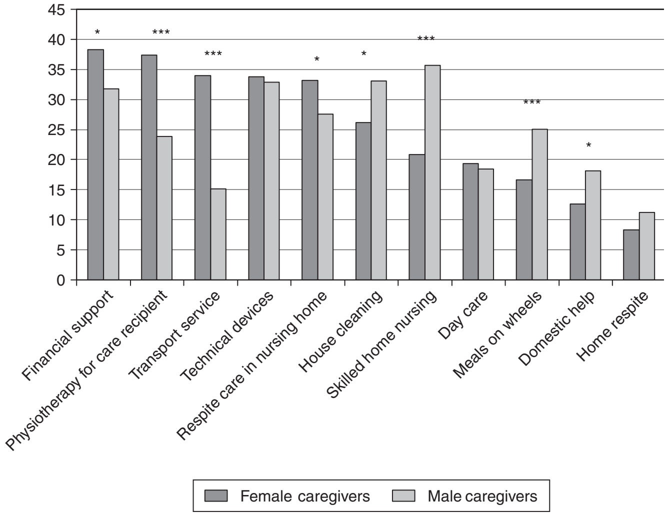

Figure 2. Proportions (%) among female and male caregivers of spouses with Alzheimer's disease receiving official services. *, Difference in the proportions between sexes, $P < .05$ (chi-square test, *df* 1); **$P < .01$; ***$P < .001$.

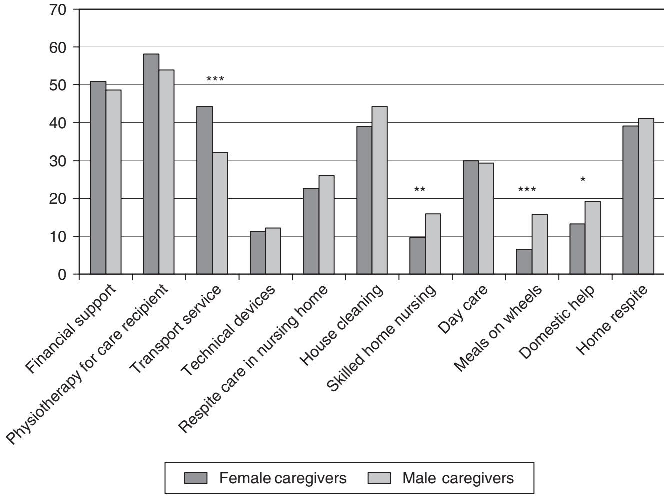

Figure 3. Proportions (%) among female and male caregivers of spouses with Alzheimer's disease having unmet needs and not receiving the service in question. *, Difference in the proportions between sexes, $P < .05$ (chi-square test, *df* 1); **$P < .01$; ***$P < .001$.

Only half (53.5%) the caregivers felt that they had been offered official services when they had needed them. Of these caregivers, 39.3% were satisfied with the services, and those feeling depressed were less often satisfied with the services (32.9%) compared to those not depressed (47.7%) ($P < .001$). Less than third (29%) of the caregivers found it easy to obtain information about available services. The majority of the caregivers (69.4%) felt that they had no influence on what services they received.

In logistic regression analysis testing the Andersen model on the determinants of service use,[19,20] experience of getting emotional support from the care provider (odds ratio [OR] = 5.8, 95% confidence interval [CI], 3.8-8.7) and disability of the spouse with AD (OR = 2.2, 95% CI, 1.6-3.1) were predictors for satisfaction with the received services. Poor perceived control over the received services (OR = 0.39, 95% CI, 0.29-0.54), difficulties getting information about the available services (0.40, 95% CI, 0.27-0.60), and caregiver's poor subjective health (OR = 0.58, 95% CI, 0.41-0.81) predicted being not satisfied with the services. Caregiver's age, sex, education, or income, and the physical or psychological symptoms of the spouse with AD did not predict satisfaction with the services.

Discussion

The spousal caregivers of individuals with AD were old, and many had poor subjective health. Spouses with AD had various neuropsychiatric symptoms and functional impairments, thus needing a great deal of help from their caregivers. According to our results, the support services poorly meet the needs of these families of Alzheimer patients. Only half the caregivers felt that they had been offered official services when they needed them, and only a third of the families were satisfied with these services. The caregivers' poor perceived control over the received services, their difficulties getting information about the services, and the poor subjective health of the caregiver predicted dissatisfaction with the services.

The mean age of both these spousal caregivers and the care recipients was high. They had long-lasting marriages. Most elderly people in this aged cohort had low education levels. Age, sex, education, or income did not predict satisfaction with the services.

The care of the home-dwelling persons with AD seems to lean on the shoulders of their aged spousal caregivers, who also are in poor health. One-third had poor subjective health—a proportion comparable to the Finnish aged population.[17] Our study finding confirms previous studies showing that the physical and emotional conditions of the caregiver[3,4,21-23] have an impact on the need for and use of services, as well as on the caregivers' satisfaction with services.[2] Their spouses with AD had various symptoms, and many needed their partners' constant support, help, or supervision. Physical impairments, incontinence, and behavioral symptoms among these home-dwelling persons with AD were surprisingly common, the last even higher than in some earlier population-based studies.[24] Some recent studies of home-dwelling persons with AD, however, support our results on the high prevalence of behavioral symptoms.[25,26] According to recent studies, the behavioral symptoms of dementia have increased the risk for permanent institutional care.[27,28] In our survey, the behavioral symptoms did not predict satisfaction with the services. The disability of the spouse with AD, however, was a significant predictor of satisfaction. This finding is well in line with previous studies.[29,30]

Our logistic regression model showed that psychosocial factors according to the Andersen model[19,20] were the strongest predictors of dissatisfaction with the services. Particularly, poor perceived control over the received services and difficulties getting information about the available services predicted dissatisfaction. According to our survey, these aged caregiving families of dementia patients seemed to be quite low-compensated resources for our service system because only one-third felt that they were able to influence what services they were offered, and only one-third were truly satisfied with the services. Dissatisfaction has been reported to be very common; for example, in an Italian study (N = 120), only 40% of caregivers were satisfied with services,[2] a proportion very similar to ours. Caregiving families have been shown to look for opportunities to influence the services they receive.[8] The families have experienced difficulties finding appropriate and good-quality services, whereas official workers have expressed concern that families do not want to use the services offered.

An Australian study (N = 134) showed that a large proportion of caregiving families had unmet needs for services: 20% had wished for skilled nursing, 33% for domestic help, 24% for home respite, 25% for meals on wheels, and 28% for respite care in a rest home.[10] These figures from a smaller study are fairly well in line with ours.

Male and female caregivers used and needed the services somewhat differently. Male caregivers had more housecleaning, skilled home nursing, meals on wheels, and domestic help, whereas female caregivers received more financial support and transport service, and their care recipients had more physiotherapy and respite care in nursing homes. The unmet needs had similar trends according to sex. These differences probably reflect traditional Western gender roles, where the wife has more responsibility for domestic work and the husband more responsibility for finances and issues related to transportation, such as driving.

Persons with dementia are at the highest risk of institutionalization, and at best, well-organized tailored services may postpone institutionalization and nursing home placement.[1,3,6] However, the services of our official system were poorly tailored to the needs of these families of Alzheimer patients. The community tends to offer mostly financial support, respite care in nursing homes, and various technical devices. The most often desired service was physiotherapy for the spouse with dementia, and this is rarely offered by the communal service system. Half the spouses with AD were veterans of World War II, and the physiotherapy offered to the persons with AD in our study was mainly the yearly rehabilitation for war veterans fixed by law in Finland. Those who were not war veterans, mostly women and younger men, had significantly fewer opportunities for physiotherapy. If this situation continues, almost all the physiotherapy offered to persons with AD will vanish from Finland when our war veterans pass away.

Strengths and Limitations of the Study

Some obvious limitations in our study should be considered when evaluating the results. The questions about behavioral symptoms were based on the well-validated and widely used NPI scale (inter-rater reliability of the severity of behavioral symptoms is 89.4%-100% and of the frequency of symptoms is 95.7%-100%, Cronbach's alpha = 0.88),[18] so our results may be considered reliable. However, the questions were asked without their usual time frame (4 weeks). Therefore, the prevalence of symptoms probably reflects their existence during a longer time period. Because of the cross-sectional design of our study, we were not able to evaluate the causal relationships or the time span of the needs and symptoms in these Alzheimer families. Neither do we know the severity of the dementia of the persons with AD because we did not have access to their medical records. The strength of our study was in having a large-scale sample of patients with a proper diagnosis of AD and a large response rate despite the caregivers' high age.

These care recipients in our sample who have been approved for the compensation of AD drugs and who have a spousal caregiver at home probably represent the most fortunate proportion of dementia patients. They belong to that minority (25%) of all those with dementia in Finland who have thoroughly undergone the diagnostic procedure, been offered and have started medication for AD, been given information about the disease from a specialist doctor, and been informed about the services available. At the end of the year 2005, there were 25 000 of this type of patients in Finland. About 65 000 home-dwelling persons with dementia are in a worse situation without a specific diagnosis or information about services.[31] Taking this into account, the results from our sample give a rather rosy picture of the services and health situation of those with AD and their spousal caregivers. In "real life," the situation may be even worse.

Conclusions and Implications

The needs of spouses with AD and their caregivers are poorly met by the official service system. Spousal caregivers of persons with AD are quite elderly, and many are in poor health. A large proportion of the home-dwelling persons with AD suffer from various behavioral symptoms and physical impairments and have a great need for their spouse's support. Our study showed that caregivers' poor perceived control over the received services and their difficulties getting information about the services predicted dissatisfaction, and that the experience of receiving emotional support from professionals was associated with satisfaction with the services. To help these caregiving families, the service system should focus on closer collaboration with the families. This means giving more systematic and detailed information about the services. In addition, the caregivers' needs and wishes should be taken into account when tailoring the services. Caregiver coordinator service is one example of a successful intervention[1,3] that meets these needs and gives personal emotional support for these families. Because there was a great need for physiotherapy among these families, future studies should focus on how effective physiotherapy and rehabilitation are among home-dwelling persons with dementia.

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