

## Research Article

# Alzheimer's Patients' Spouses Critiques of the Support Services

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*Introduction.* Caregiving families of patients with dementia are often reluctant to use support services. The aim of this study was to describe their subjective critiques of these services. *Material and Methods.* A cross-sectional questionnaire was sent to a random sample ( $N = 1943$ ) of Alzheimer's patients' spouses in Finland with an open-ended question: "What kind of problems have you faced with the services?" Their responses were analyzed with thematic content analysis. *Results.* Of the responders identifying themselves as caregivers ( $N = 1386$ ), 728 (mean age 77.8, 65.1% females) responded. Opinions could be divided into two categories: (1) problems with the service application process ( $N = 296$ ); (2) critiques of the services offered ( $N = 270$ ) including either problems with community care support services or institutional care. 74 indicated that they had no need for services, and 15 praised the services they had received. *Conclusions.* From the caregiver's perspective, the service system is complicated, bureaucratic and works organization centredly.

## 1. Introduction

Several investigations have studied caregivers' burden and need for support and services in the care of a person with dementia [1–7]. Caregivers require information on dementia and its consequences, training in coping strategies and stress management, financial support, communication assistance with a person with dementia and various professionals in the service system, legal advice, information on drug treatment, and help with end-of-life issues [8]. Although services have been developed to meet caregivers' needs, a number of studies have suggested that services fail to meet these needs adequately [2–9].

Although caregiving leads to strain and burden, families of dementia patients are often reluctant to use the services offered [2, 9–13]. Only one third of caregiving families use these services [10]. Barriers to service use include reluctance of the person with Alzheimer's disease (AD) or the caregiver, hassles for the caregiver, concerns over the quality of services, and concerns related to finances [14]. To succeed, both the

person with dementia and the caregiver should be involved in daily care decisions [15, 16].

Formal services are typically engaged when informal services are unavailable or only in moments of crisis [13]. The literature on caregiving has suggested several reasons for this. Families are often unaware of available service, and are in great need for information [2, 9]. 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]. Families seek greater flexibility to influence their service package [17]. Thus, a friction often exists between the service system and the caregiving families. However, few studies have reported on caregivers' experiences with the use of services, their critiques of those services, or their reasons for not using them.

The aim of this study was to describe the critiques of support services by the spouses of persons with Alzheimer's disease. The study is based on their responses to an open-ended question in our survey of Alzheimer's patients' spouses. This is the first large-scale study investigating

the critics of the caregivers of persons with Alzheimer's disease regarding the support services.

## 2. Patients and Methods

A random sample was gathered from the Alzheimer's drug users' register of the Social Insurance Institution of Finland. The Social Insurance Institution of Finland takes the responsibility of the implementation of all Finnish social services justified by law (e.g., drug reimbursements, pensions, and financial support for persons with disabilities). It works under straight supervision of the Finnish Government. Each person with Alzheimer's disease (AD) found in the register had been approved for compensation for AD drugs and had a spouse living at the same address. The gathering of the sample has been described in our previous study reporting on the quantitative findings of our survey of caregivers' satisfaction with these services [5]. We sent a postal questionnaire to a random sample of 1943 such spouses of persons with AD in five urban or nonurban regions in Finland to obtain a representative picture of the overall situation in Finland (Helsinki, Tampere, Central Finland, Northern Carelia, and Lapland with Northern Ostrobothnia). There were no age criteria for inclusion in the survey.

Of the original random sample, population and mortality registers served to remove participants no longer living or living separately according to current address information. Questionnaires were sent on September 2005 and were resent on November 2005 to those spouses who had failed to respond to the initial questionnaire. Of the remaining potential respondents ( $N = 1866$ ), 1434 responded (a 76.8% response rate). We excluded all caregivers who were themselves hospitalized in permanent institutional care ( $N = 15$ ), couples who lived separately ( $N = 4$ ), and spouses who did not identify themselves as caregivers ( $N = 29$ ). Of the remaining 1386, 728 (52.5%) provided written responses to the open-ended question (Figure 1). Of them, 566 (77.7%) directly criticized the current support services. Altogether, 74 indicated that they had no need for service, and 15 provided positive comments on the service system. The rest ( $N = 175$ ) described how their personal caregiving situation affected their choice of service use. In this paper, we report on the direct critiques of the service system.

The questionnaire consisted of questions on demographic variables, the physical and psychological symptoms of the spouse with dementia, the support and services the family received from the official service system, and the caregivers' subjective needs and satisfaction with these services. In our previous paper, we reported on the quantitative findings [5]. At the end of the questionnaire, we provided an open-ended question: "What kind of problems have you faced with the services?"

The Helsinki University Hospital ethics committee approved the research protocol.

## 3. Data Analysis

We used thematic content analysis to analyze the responses of the open-ended question. The answers to the open-ended

question concerning the difficulties the caregivers of spouses with AD experienced with the services were systemically examined several times to identify different themes. The data were organized into codes and further into broader categories encompassing the initial codes. Each item was compared to the rest of the data to establish analytical categories (constant comparison) [18, 19]. The data were reviewed and coded independently by two authors to ensure reliability. In some cases, the authors had discussions to reach a consensus on different items. Tabulations served to determine frequencies in the categories [19]. Attention also focused on deviating phenomena.

## 4. Results

The mean age of the respondents ( $N = 728$ ) was 77.8 years (SD 6.1), and 65.1% were females. The mean age of the persons with dementia was 80.8 years (SD 3.9). The mean duration of marriages was 51.8 years (SD 9.6). Over half of the caregivers (53.3%) and spouses with dementia had an education of less than eight years. Most families regarded their income as at least moderate. Over one third (41.0%) of the caregivers had poor subjective health. Of the care recipients, 41.5% needed continuous support from their caregiver. Over half of them (56.8%) had had symptoms of depression, more than two thirds (76.2%) had had symptoms of agitation, and 48.5% had had hallucinations. Urinary or bowel incontinence was very common (49.6%) among these home-living spouses with AD. Almost half (43.5%) was not able to move indoors without aid.

The caregivers' critiques of the service system could be categorized into two major groups: (1) problems with the service application process ( $N = 296$ ) and (2) criticism on the services offered ( $N = 270$ ). In addition, 74 caregivers indicated that they had no need for services and 15 had positive views about the services (Figure 2).

*4.1. Problems with the Service Application and Delivery Process* ( $N = 296$ ). Caregivers described a diversity of problems with the service application process. They especially complained about difficulties obtaining information about services ( $N = 106$ ), the bureaucracy ( $N = 83$ ), delays in receiving services ( $N = 42$ ), dissatisfaction with service decisions ( $N = 143$ ), and secrecy in decision-making process ( $N = 7$ ). Some also felt that health and social care workers behaved impolitely or even rudely towards them ( $N = 47$ ).

*4.1.1. Difficulties Obtaining Information about Services* ( $N = 106$ ). Caregivers found that obtaining information about services was very difficult and that the service system was very complicated and difficult to comprehend:

*"I did not get any information about what kind of support I am entitled to receive."*

Several caregivers suggested that there should be one person to contact or one place where they could obtain information:

*"...even one appointment; then all the matters could be discussed. It would help so much."*

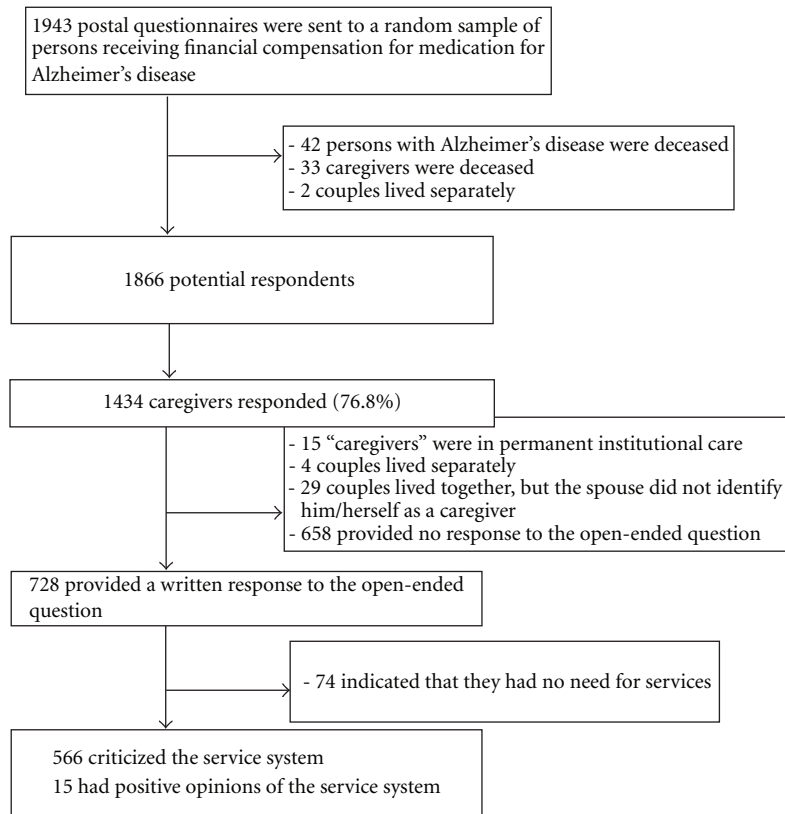


FIGURE 1: Data collection of the postal survey of Finnish spousal caregivers of persons with Alzheimer’s disease in autumn 2005.

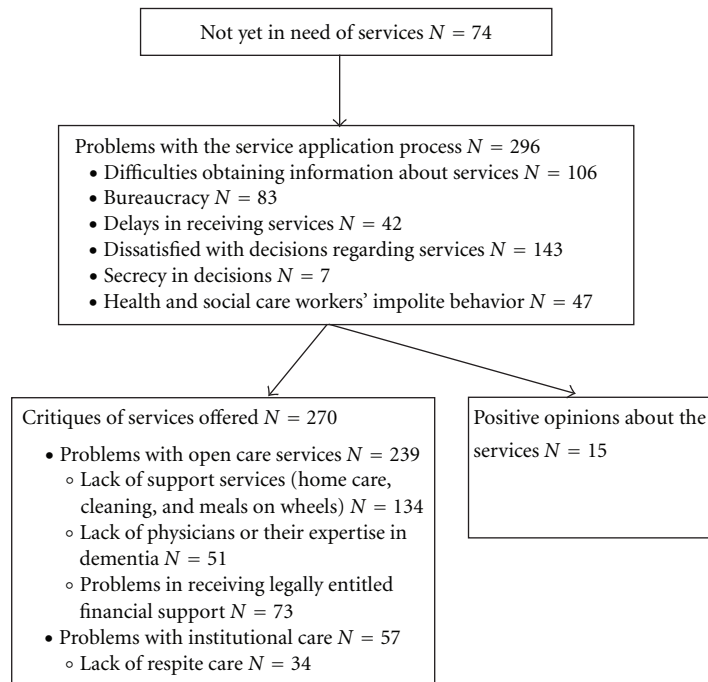


FIGURE 2: The caregivers’ feedback on the service system.

The caregivers felt that the service system is complicated even for the authorities.

*"I always call the wrong place, even if I have received instructions. They do not seem to know themselves how to manage the system."*

Several responses included constructive suggestions for improving the availability of information about the official service system:

*"One single counselling coordinator, would make it unnecessary to go to many different professionals. She or he could even come to our home once a month to ask how we are managing and what we need: Do we need a house cleaning, milk from the store or sticks of wood?"*

4.1.2. *Bureaucracy* ( $N = 83$ ). Many caregivers felt that a lot of bureaucracy surrounded decision making concerning support services:

*"It requires a lot of things...they always need more and more information. It is difficult to understand what kind of information is really needed. They suspect our needs..."*

*"The red tape is enormous...There are a thousand different people taking care of things..."*

4.1.3. *Secrecy in Decision Process* ( $N = 7$ ). Some respondents complained of secrecy behind decisions to give support services and that the grounds for decisions are often unclear:

*"They do not tell about the services available to those who might need them. The only way to get information is through the grapevine."*

4.1.4. *Delays in Obtaining Services* ( $N = 42$ ). In addition to the bureaucratic application process, delays in receiving services worsened caregiving situations:

*"The situations change while waiting for the decisions and may already be different by the time we get help."*

4.1.5. *Dissatisfaction with Service Decisions* ( $N = 143$ ). Many caregivers were dissatisfied with the rejections related to financial support. Many small communities lack the funds to support dementia families, which leads to rejections of the communal support service:

*"The war veteran rehabilitation application was rejected, and they could not tell why. They also rejected the caregiver's request for financial support. They could not offer us home help while I was undergoing surgery at the hospital, so our daughter took a day off from her work to take care of her father."*

*"A poor municipality can offer nothing."*

4.1.6. *Impolite Behavior of Health and Social Care Workers* ( $N = 47$ ). In particular, these families having to face difficult behavioral disturbances and needing emotional support require healthcare and social care professionals to possess not only clinical but also good communicational skills. The caregivers offered their critiques:

*"I was even advised to divorce my husband because of his Alzheimer's disease."*

*"When I inquire about services I often become so sad and angry; everyone is so dismissive and superficial."*

4.2. *Critiques of the Services Offered* ( $N = 270$ ). The caregivers experienced various problems with both open care services ( $N = 239$ ) and institutional care ( $N = 57$ ). The caregivers complained about the lack of support services (e.g., home care, cleaning, meals on wheels) ( $N = 134$ ), as well as the lack of physicians' services or expertise in dementia care ( $N = 51$ ), and often mentioned that they had problems obtaining their legally entitled financial support ( $N = 73$ ). The problems with institutional care usually involved a lack of respite care (short-term institutional care) ( $N = 34$ ) and long delays in securing permanent institutional care for their spouses ( $N = 24$ ).

#### 4.2.1. *Problems with Open Care Services*

*Lack of Offered Support Services.* The spouses felt that obtaining the services was difficult even when they really needed them:

*"It was so difficult to get help. I grew exhausted and my husband had to be admitted to hospital."*

*"When I fell ill and the ambulance came for me, I could not go to the hospital because nobody would take care of my wife. This has happened three times."*

Many respondents complained of receiving the wrong services or of receiving inadequate services:

*"When I requested someone to take care of him so that I could go walking outside a couple of times a week, they asked if half an hour a week is enough...I lost my confidence that someone (from service system) could understand these things."*

*Lack of Physicians' Knowledge of Services or Expertise in Dementia Care.* Some caregivers felt that health care workers lacked sufficient expertise in dementia:

*"They (physicians and nurses) did not take us seriously... we received no referral for further investigations."*

*"The doctors in primary care change often. They do not have enough time to familiarize themselves with the patient's situation."*

*Problems in Obtaining Legally Entitled Financial Support.* In Finland, caregivers are legally entitled to financial support "Caregiver's financial support" when they care for a person with a chronic disability. The application process and the financial support itself raised many feelings:

*"The caregiver's financial support should be easier to obtain: it should not be like begging for mercy."*

*"What is such financial support? 100 euros per month for a caregiver who is 86 years old? And in addition, they take away 28% in taxes."*

#### 4.2.2. *Problems with Respite Care or Having Permanent Institutional Care*

*Lack of Respite Care.* Respite service is one of the most common services offered to caregiving families, because the law stipulates that those caregivers who are officially entitled to receive caregiver's financial support are also entitled to receive three days off per month. Respite service is often



organized by offering respite in a nursing home for the person with dementia, although demand for this service often exceeds availability:

*“We very seldom receive respite services. I have to be really exhausted to receive one week of respite (for my spouse).”*

Many caregivers reported having lack of confidence in the quality of respite care:

*“When my spouse returns from respite care, his health is often worse since they have no time to go out with him.”*

Many caregivers reported in their open responses that they would have needed a few hours of home respite instead of overnight respite care:

*“I have to take him with me every time I go to my dentist or physician, and this is not easy. I asked for home respite, but could not receive it.”*

*Delays in Obtaining Permanent Institutional Care.* Of the 24 comments related to institutional care, most ( $N = 18$ ) described the difficulties in securing a permanent place in a nursing home:

*“I had to submit a claim to the state authorities before we secured a permanent place in an institution. I was so exhausted that I almost needed a place in a nursing home for myself.”*

*“It took a long time to secure a place in a nursing home; it required a lot of my activity on my part. . . I had to struggle for it; it was not easy for an old invalid.”*

Caregivers also had other concerns about their spouse's nursing home being too far from their own home, problems with professionals caring for their spouse, or repeated transfers from one institutional place to another.

## 5. Discussion

To our knowledge, this is the first large-scale study to explore in-depth the critiques of support services by spousal caregivers of persons with AD. Even though the spousal caregivers were very old themselves, they were nonetheless eager to respond to our open-ended question about problems with the service system: over half of them provided responses. Their critiques were diversely directed at problems with the service application and delivery process as well as various open care and institutional health and social services. The friction and problems between the families and the service system are familiar from previous literature, but the new contribution of our study is that our results reflect openly on the caregivers' own voices, feelings, and reasoning. Caregivers often feel alone with their difficulties or misunderstood. Some feel that they are battling their situation from one professional to another, while nobody takes responsibility. Their many questions concerned ethical issues, which have been acknowledged in a recent European report guiding dementia care [20].

One limitation of our study is that we only inquired about problems with the support service system. Consequently, we cannot draw the conclusion that the entire service system is problematic. Most caregivers provided criticism because the questionnaire inquired about problems. However, that nearly a half of our large sample had

disappointing experiences with the service system and also wanted to share them was surprising. It is unlikely that the problems the caregivers described could be culturally specific or related only to Finland, as several international studies have also described these same problems [2, 3, 8, 14, 21, 22]. However, these studies have been smaller-scale qualitative studies or exploring the problems of services. It must be emphasized that the caregivers' opinions reflect not only the poor quality of the service system, but also caregivers' own stress, burden, anxiety, and feelings of loneliness related to their life situation [2, 23].

In addition, these findings represent the situation in Finland in 2005. Some changes have taken place since then: several communities are going to apply dementia care coordinator programmes after we published the positive findings of our previous study. The strength of this study is its large sample covering all of Finland. All caregivers are spouses of real AD patients because the random sample was retrieved from the AD drug register. Therefore, the caregivers are truly involved with the everyday problems of dementia. However, this sample represents the more fortunate persons with AD in Finland, because in real life many persons with AD go undiagnosed or live alone with no support. Consequently, we have no data on those with perhaps the more challenging problems. The caregivers' open-ended responses were detailed and descriptive of the life and needs of AD caregiving.

The caregivers described the problems related to the service application and delivery process in detail. The service system seems very complicated and bureaucratic, and the caregivers have a great need for information related to their rights. These issues have also been noted in many previous studies [5, 8, 24]. Since over half of the caregivers had an education less than eight years, which is typical to their cohort, these elderly people have even greater need for tailored information regarding available services. The complexity of the present service system is illustrated in Figure 3. In our previous project, we showed that about 25 different authorities and professionals are responsible for delivering services to AD families (Figure 3) [25]. Thus, it may be very time consuming and needs much patience from the 80-year-old caregiver to comprehend this jungle to have access to the services they need. As a consequence, we developed a successful care coordinator programme which proved effective in delaying institutional care for dementia patients [7]. Many caregivers in the present study also suggested the same kind of “single-person” counselling service.

The responses reflect a great need for information about services, disappointments with the service decisions, and delays in the application process. Professionals ought to take the initiative to provide information and to take comprehensive responsibility for dementia families [1, 7, 26]. The responses seem to indicate, however, that some professionals have instead taken on the role of a gatekeeper rather than a client-centered approach. Lack of services was also common complaint. Many caregivers were aware and understood that their municipalities have lack of funds and resources. However, it is surprising how large proportion of

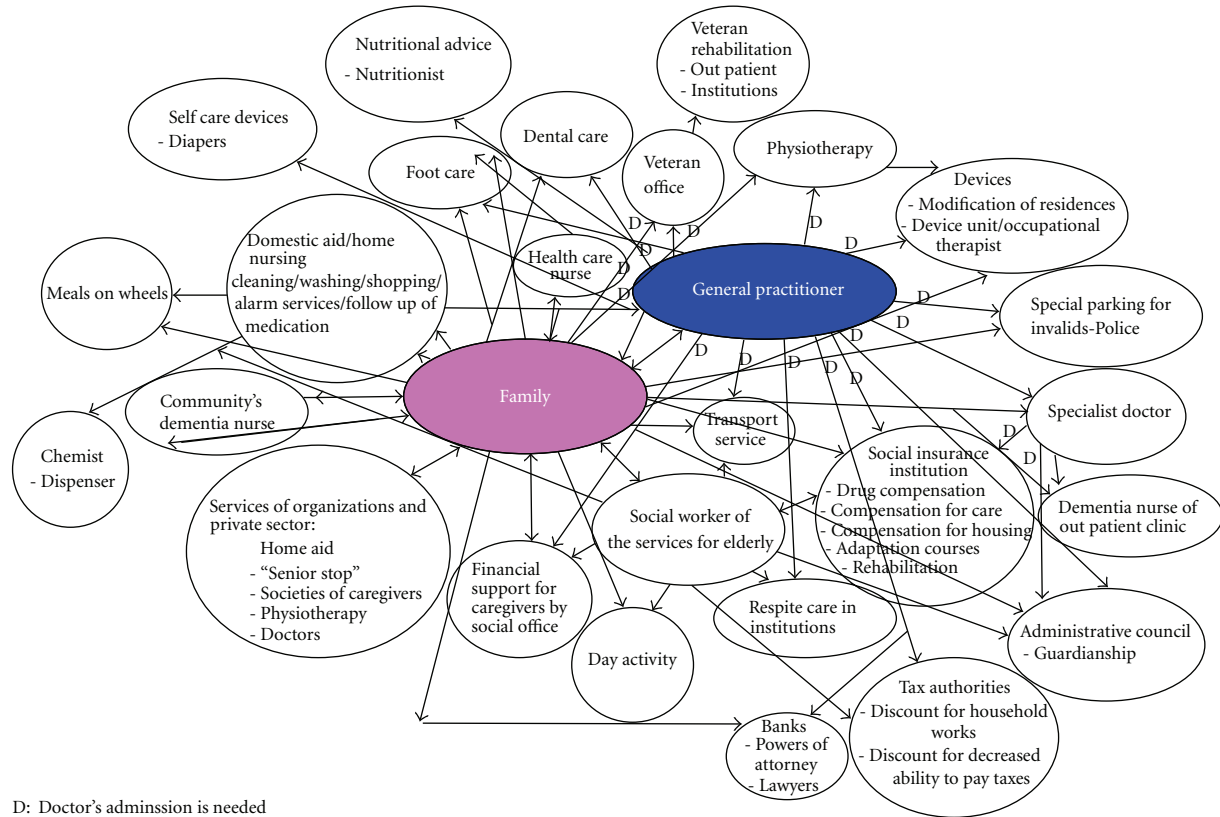


FIGURE 3: The Finnish service system for caregiving families with dementia patients (Eloniemi-Sulkava et al. 2006).

caregivers reported bureaucracy and professionals' inconsiderate behavior especially taking into account that these caregivers are elderly, stressed, and unable to defend themselves. Bureaucracy and secrecy around decisions regarding social benefits evoked suspiciousness and hopelessness among the caregivers. To our knowledge, no previous studies have examined this important issue. In this respect, these elderly people caring for their spouses with AD also benefit from the help of coordinators familiar with the needs of these families [7].

The caregivers also reported a lack of physicians' knowledge of services and expertise in dementia care. This result is in line with those of a recent Canadian qualitative study [27] in which 25 doctors were questioned about their knowledge of and interest in support services. They concluded in stating that physicians are poorly informed about the large array of available services and may even be perhaps uninterested in learning.

Problems related to outpatient health and social services were the most criticized issue. These elderly couples often feel abandoned with their difficulties, not even knowing what and whom to ask for help, and with nobody informing them about the services to which they may be entitled [8]. Problems related to respite and institutional care were also common. The caregivers reported difficulties in obtaining respite care, and after receiving such support, the care recipient may even return in worse condition than when they left home. Caregivers want these services not only to provide

them relief, but also to improve the care recipients' situation [14]. Providing caregivers emotional and ethical support and adequate knowledge about the disease may be one way of enhancing the coping skills of caregivers in their demanding situations [7, 28–30]. As in previous studies, [15, 16] the message from our caregiving families is that the voice of the entire family—caring team (both the care recipient and caregiver) should be heard when planning the service system to reduce the strain of caregiving.

## 6. Conclusion

When inquiring for problems about the service system, this study produced a surprisingly large number of criticism. Caregivers' own voices could be heard in their responses. In many cases, in describing their situations, their responses reflected their despair and loneliness. Officially organized services too often fail to meet the needs of spousal caregivers of demented individuals. The opinions and needs of caregivers and the equality of persons regardless their education or living area or caregiver strain should carry more weight in plans to improve the service system.

## Conflict of Interests

M. M. Raivio has been working part time for the Social Insurance Institution of Finland. All the other authors declare that they have no conflict of interests.

## Authors' Contribution

Details of the contributors: (1) conception and design (K. H. Pitkälä, M. M. Raivio, M. L. Laakkonen), (2) acquisition, statistical analysis, and interpretation of the data (K. H. Pitkälä, M. M. Raivio) (3) drafting or revising the manuscript critically for important intellectual content (K. H. Pitkälä, M. M. Raivio, M. L. Laakkonen), and (4) final approval of the version to be submitted (K. H. Pitkälä, M. M. Raivio, M. L. Laakkonen). M. M. Raivio is the guarantor.

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