

# **Family Care as Collaboration: The Effectiveness of a Support Model for Elderly Families with Dementia**

## **A randomised controlled intervention study and qualitative process research**

Research and Development Project on Geriatric Rehabilitation  
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## **Summary**

### *Background*

Illnesses causing dementia are the most significant reason for elderly people's need of social and health care services. Spouses are often very committed to care at home for even their severely demented partner, even if the burden of caring for a demented person has been linked in particular to his/her functional disabilities and behavioural and psychological symptoms. Results of earlier randomised controlled studies have been promising in terms of the possibility of supporting family carers' well-being and coping at home of demented people. The existing service system in Finland is very complicated and responds poorly to the needs of family caregiving. According to a national survey of spousal carers of demented people carried out in Finland, only half of the caregiving families received help when they needed it. Over two thirds of the carers considered themselves unable to have an influence on what services they received, and only a third were happy with their services. Diagnosis and medication of dementia have improved in Finland during recent years, but after receiving diagnosis demented people and their families are often left without the support they need. Thus, support of home care requires new models of action that would respond better to the needs of family caregiving.

### *Objectives*

The objectives of the intervention study Family Care as Collaboration were to find out whether it is possible to

- promote living at home of demented spouses and postpone their long-term institutional care with a versatile, family-focused and individually tailored support model
- enhance demented spouses' psychological and physical well-being, and
- support spousal family carers' psychological well-being and quality of life.

Additionally, the effects of the intervention on total usage and expenses of social and health care services were analysed.

### *Research setting*

A randomised controlled intervention study and qualitative process research.

### *Data*

The intervention involved 125 caregiving families living in Helsinki (Finland), in which one spouse was caring for her/his demented partner at home. The families were recruited by newspaper announcements and from a compensation register for Alzheimer's disease medication of the Social Insurance Institution of Finland. The accuracy of dementia criteria used in initial diagnosis was confirmed from relevant patient registers before the families were randomised into an intervention group (n = 63) and a control group (n = 62). The intervention involved primarily families in which the demented spouse suffered from at least moderate dementia.

### *Intervention*

The intervention procedure was a combination of earlier research results, systematic work of the multidisciplinary and multiprofessional research team, and feedback received from the involved families during the intervention. In putting into practice the core functions of the intervention, the following principles were followed:

- Supporting the family as the whole
- Flexibility and immediate action when needed
- Recognising and accepting different micro cultures
- Respecting the families' autonomy and developing collaboration
- Supporting family life
- Optimism and support of resources

The core functions of the intervention consisted of a family care coordinator's actions, a geriatrician's medical investigations and treatments, and goal-oriented peer support group meetings. The family care coordinator was responsible for carrying out the versatile, individually tailored and need-based support activities. The geriatrician operated in partnership with the coordinator, and the intervention families had her medical expertise at their use. Seven goal-oriented peer support groups met five times during the first follow-up year. On the basis of individual assessment, some families were also involved in dementia rehabilitation (physiotherapy), dementia information sessions, and group meetings dealing with difficult situations at home. The family care coordinator was a trained public-health nurse and, together with the geriatrician, had a broad expertise in dementia care, as well as good knowledge and level of experience of the public social and health care service system. The longest possible duration of the intervention was two years, but each family's involvement with the intervention varied between 20 and 24 months due to the phased recruitment and randomisation of the participants.

### *Methods*

The intervention families took part in research nurses' interviews and examinations before randomisation, as well as at six and 12 months into the intervention. They also received a survey questionnaire evaluating the peer support group activities, and another survey after the intervention had ended assessing family carers' experiences of the intervention and the services received in it. Institutional care placements and deaths of demented spouses as well as services used during the intervention were also investigated. The average expenses of the intervention and other services were estimated per person year. The qualitative data of the research consisted of discussions in family carers' goal-oriented peer support groups (saved on audio disks), written responses to the group survey, diaries of and feedback from group instructors, descriptions of group processes, interviews with the family carers and the family care coordinator, and the coordinator's case files.

## *Results*

About two thirds of the family carers in both the intervention and control groups were female. Family carers in the intervention group were somewhat older than those in the control group (mean age 76 yrs. vs. 74 yrs.,  $p = 0.02$ ). The mean age of demented spouses in the intervention group was 78 years and in the control group 77 years. The most common illness causing dementia was Alzheimer's disease or Alzheimer's disease combined with characters of dementia with Lewy bodies (intervention group 87 %, control group 84 %). According to the Clinical Dementia Rating (CDR) scale, the illness had advanced at least to moderate stage in three out of four demented spouses in both the intervention and control groups. The mean Mini-Mental State Examination (MMSE) score was 13.4 in the intervention group and 14.2 in the control group. According to the Barthel Index, the demented spouses in both groups had clear functional disabilities and need of help in their everyday activities. They also had a lot of behavioural and psychological symptoms estimated by the Neuropsychiatric Inventory (NPI). Differences between the groups were not statistically significant in relation to any other baseline variable except family carers' age.

In the intervention group, 5 % (95 % CI 2–14) of the demented spouses were in long-term institutional care at 12 months, while in the control group the proportion was 15 % (95 % CI 8–27). The difference was not statistically significant. At about one and a half years, 11 % of the demented spouses in the intervention group had ended up in long-term institutional care, while the proportion in the control group was 26 %. The difference between the groups was statistically significant ( $p = 0.027$ ). At the end of the intervention, the differences between the groups had disappeared.

The total cost of social and health care services for one follow-up year and one intervention family was approximately 15 568 euros and for one control family 23 553 euros. There was a statistically significant difference in the total cost of social and health care services for the benefit of the intervention families calculated per person year (-7 985 euros,  $p = 0.030$ ). After excluding the total expenses of the intervention from these figures, there was still a saving of 5 104 euros per family per year. About half of the savings were due to reduced expenses of institutional care and another half due to reduced expenses of community care. When the differences in expenses between the intervention and control groups are estimated for the whole duration of the follow-up and 63 persons, the numerical savings of public funds came to 855 000 euros.

The intervention had a considerable positive impact on the well-being of both the intervention and control families. Family carers in the intervention group expressed greater satisfaction with the services they had received than carers in the control group. They also had fewer unsatisfied service needs. According to the qualitative data, the most important aspects about the intervention were respecting the families' autonomy, psychological support, practical help and unobtrusive guidance, and continuity and reliability of the services. These activities were put into practice in the intervention by encountering people in their own unique situations, listening to and taking seriously people's own analyses and interpretations of their situation, acting appropriately on the basis of joint negotiations, and creating a sufficient service network also for future needs. By these means, the family carers' self-confidence was increased, their agency in relation to the service system got stronger, and their ability to care for their spouse was improved.

## *Conclusions*

By implementing the support model Family Care as Collaboration for families with dementia developed in this intervention, it is possible to extend demented people's living at home up to a year and a half. Well-being and quality of life of both the intervention and control families improved significantly. The family-focused tailoring of services responded to the needs of intervention families, and simultaneously produced significant savings in terms of service expenses. The

effectiveness of support activities required mapping each family's situation individually as a whole, as well as genuine collaboration with the families and valuing of their expertise. Taking anticipatory, prompt and adequate action was important for an optimally early recognition of risks for living at home. Adopting an optimistic attitude enabled the intervention staff to look for solutions even in very difficult situations, which gave families hope for the future. Besides professional training, expertise in dementia and knowledge of the service system, the intervention staff's experience-based knowledge and reflectivity in relation to their working methods emerged as important issues. Also work counselling received by the family care coordinator and the geriatrician throughout the intervention proved significant in managing stress and difficult situations. Directing the existing services in a family-focused and economic manner requires increasing flexibility of the established service system and granting responsibility, as well as strong professional support, for the partnership of a family care coordinator and a geriatrician.