# Health Economic Analysis on a Psychosocial Intervention for Family Caregivers of Persons with Dementia.

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# Health economic analysis on a psychosocial intervention for family caregivers of persons with dementia

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**Keywords**

Cost-effectiveness, dementia, family caregiver, HRQoL, intervention.

## Abstract

**Background/Aims:** Psychosocial intervention has shown positive effects on caregiver's burden and satisfaction. The aims of this study were to describe the cost and cost-effectiveness of such intervention. **Methods:** We analysed resource use and costs of formal care for 308 persons with dementia and their caregivers' health related quality of life (HRQoL). **Results:** The costs of home help services were lower in the subgroup of spouse caregivers in the intervention group and the cost of nursing home placement was lower in the intervention group. While the person with dementia lived at home, caregivers in the intervention group rated higher HRQoL ($p<0.01$). After the person with dementia had moved to nursing home, spouses in the control group rated a lower HRQoL ($p<0.001$).**Conclusion**: The result can be interpreted as a positive effect of the intervention focusing on the identified specific needs of the family caregivers.

## Introduction

The majority of persons with dementia in industrialized countries have an informal caregiver i.e. family caregiver. Both the person with dementia and the family caregiver are in need of support and help during this, often lengthy period of disease.

Every municipality in Sweden has the responsibility to offer services to residents, including personal care and practical assistance based on the needs of the individual, whether the person lives at home or in a nursing home. This care is almost exclusively financed by taxes. The limited amount the person in need of care has to pay is based on his or her taxable income. Since 2009 the Social Service Act has stated that the municipality is also responsible for providing support and help to the family caregiver [1].

The costs related to dementia disorders depend on the extent of responsibility taken by society in terms of formal care and by the amount of informal care provided by family caregivers. An estimation of the worldwide costs of dementia in 2009 was $ 422 billion of which $ 142 billion was considered the cost of informal care. The figures are based on the assumption that time spent for informal care is 1.6 hours per day and include only basic Activities of Daily Living (ADL). If time spent for assisting with instrumental ADL is included, costs for informal care increase to $329 and the total societal costs to $608 billion [2]. In a recently published study from the US, total costs for 2010 were estimated to $157-215 billion. The estimates were based on self-reported spending and the utilization of nursing home care. The costs for informal care were based on either estimated wages or the cost of equivalent formal care [3].

Caring for a person with dementia can be stressful and burdensome with economical, physical, psychological, and social consequences for the family caregiver [4, 5]. A wide range of interventions to support family caregivers have been reported but the results should be interpreted with caution, mainly due to differences in intervention and study design [6-10].

Furthermore, it is probably difficult to find a method of intervention for family caregivers that suits everyone regardless of relationship, age, course of disease or cultural setting.

We have in previous studies on family caregivers to persons with dementia, evaluated a controlled, longitudinal psychosocial intervention, consisting of a five week program followed by a three month conversation group. With this intervention we have demonstrated reduced caregiver burden using a novel caregiver burden scale [11, 12], prolonged time to nursing home placement [13], and a better interpretation and understanding of the symptoms and behaviors of the person with dementia disorders [14].

The implications for resource use and costs in the two study groups (intervention group n=153, control group n=155) have not been analyzed previously. Costs and cost-effectiveness of psychosocial interventions is sparsely described. A recently published review on this topic points out the difficulty of establishing evidence for cost-effectiveness of interventions due to lack of detailed data on both costs and outcome measures [15]. Our study has data on both the actual annual costs of formal care for specific care units, and the resource use for each person with dementia. This together with the family caregivers' health related quality of life (HRQoL) during a five year follow-up period, gives us the ability to examine the costs and cost-effectiveness of a psychosocial intervention including five weekly counselling sessions and a three-month conversation group.

Providing cost-effective formal care to persons with dementia and effective support to their family caregivers is an important issue in all societies, regardless of whether funding comes from taxes or private insurance, or whether care is provided by public or private enterprises.

The aims of this study were to

- Describe the total costs of formal care for persons with dementia at home and in the first year after nursing home placement during a five year follow-up period.

- Study the family caregivers’ HRQoL.
- Perform a health economic evaluation of a psychosocial intervention consisting of educating and informing the family caregiver.

## Materials and methods

The study design was quasi-experimental and part of a longitudinal cohort study entitled the Malmo Intervention study of family caregivers to persons with Dementia (MIND). Of the ten districts from the municipality of Malmö in southern Sweden (population: 260.000 inhabitants; National Bureau of Statistics, 2004), two were chosen to ensure similar socio demographic structures and similar levels of public service. The proportion of elderly (over 80 years of age) living alone in the two districts was 59% in the intervention group and 45% in the control group, and the majority were women, 72% intervention 68% control. Of the elderly in the intervention group, 97% lived in rented housing compared to 94% among the controls. The proportion of married subjects was 29% in the intervention group and 32% among the controls and the proportion of persons who were widowed was 51% in the intervention group and 54% in the control group. The number of staff employed in formal care for the elderly in both public and private settings was 105 per 1000 inhabitants in the chosen districts [11].

A letter was sent to 2721 persons over 70 years of age who received social services in the two districts, inviting them and their family caregiver to participate in the study. Home visits for the persons who responded (n=1656) were carried out by a registered nurse (RN) who performed an interview and assessed cognition of the person participating using the Mini-Mental State Examination (MMSE). The maximum score on MMSE is 30 and scores <24 are considered to indicate cognitive impairment [16, 17]. If the assessed person had symptoms of cognitive impairment and/or MMSE <24, the person was invited to a medical examination by a physician and an additional interview by a RN. The family caregiver, who accompanied the person at this occasion, was also interviewed by both a RN and a physician. The medical examination and interview took place at the university hospital or in the home of the person with symptoms of cognitive impairment. In total, 571 persons underwent clinical examination. The diagnosis of dementia, according to the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV), was established in 415 persons [18]. The person with dementia and his or her family caregiver formed a dyad and 308 dyads were available for this study (Table 1). The dyads from one district comprised the intervention group (n=153) and the dyads from the other district comprised the controls (n=155). Informed consent was obtained from all participants prior to the home visit and it was clearly stated that they had the right to refuse participation at any time without explanation.

The RN together with the family caregiver assessed the severity of dementia by describing the person's social dependency using the Berger scale and the person's social dependency due to functional disabilities with the Katz Index of activities of daily living (ADL). In this study the scores were dichotomized in to low (classes1-2) and high severity of dementia (classes 3-6) for the Berger scale and in to low (classes A-B) and high social dependence as a result of functional disabilities (classes C-G) for the Katz index. Another instrument used in the study initially at baseline and then every six month, is the Gottfries-Bråne-Steen-scale (GBS-scale). The GBS-scale is constructed for rating dementia syndrome and the changes of symptoms over time by observing and/or interviewing the person with dementia. The GBS-scale is comprised of three subscales measuring intellectual (GBS-I), emotional (GBS-E) and motor functions (GBS-ADL). All instruments with the exception of MMSE, were used in assessing the cognitive and functional status at baseline (Table 2) and at follow-ups, and the results has been published previously [14]. The study was completed in 2010.

**Table 1 approx here**

**Table 2 approx here**

*Participants*

A total of 308 family caregivers were followed for up to five years (60 months) after inclusion in the study. Family caregivers included persons with a family relationship to the person with dementia and persons with a network association without immediate family relationship. For this analysis, we used three categories: a) spouses and individuals cohabitating with the person with dementia**;** b) children, children's' spouses, grandchildren and siblings**;** and c) others, i.e. indirect family members, including friends and neighbours. Family caregivers remained in the study until the person with dementia had lived at home for five years, lived in a nursing home for one year, or died; or until the caregiver declined further participation**.**

As expected, the study design and the natural history of dementia implied that the panel of participants diminished over time. Halfway through the study, at 30 months, 21 % of the dyads (39 intervention and 26 control subjects) remained in the study (Table 3). In both groups, approximately 30 percent of the persons with dementia died, and 56% in the intervention group and 50% among the controls moved to a nursing home during follow-up. The drop-out was 11% in the intervention group and 19% among the controls. Only a few percentages (2 and 4 respectively) remained in the study during the total follow-up of 60 months.

Table 3 approx here

*Intervention*

A psychosocial intervention consisting of two components, education and provision of a support group for the family caregivers was conducted from September 1999 to January 2004. The intervention started approximately one month after the person was diagnosed with dementia. Each group comprised about eight family caregivers, mainly spouses and adult children. The program led by an RN and a counsellor, consisted of both an educational and a social part were the family caregivers in a relaxed and social setting could discuss the topics and share their experiences. The five sessions included information and education about dementia disorders, depression, and symptoms of delirium, handling behavioural symptoms, medication, legislation, and available services in the community. The groups met two hours weekly for five weeks, and each meeting was followed by group discussion. Among the 153 family caregivers in the intervention group, approximately 20 were unable to join the groups and chose individual meetings with the RN and the counsellor for a total of four hours/person. The family caregivers were then invited to continue with support groups under the supervision of the counsellor, and these groups met twice every month during three months [11, 13]. Of the family caregivers, 71/153 (46%) chose this opportunity. The main purpose of the support groups was to more deeply discuss feelings and emotions among the family caregivers. The counsellor chose an ego-supportive therapy to support and develop resources within the individuals, i.e. the family caregivers. Accepting help from others, different types of coping strategies, feelings of loss and anger, are examples of topics discussed in the support group. A follow-up led by the RN and the counsellor, were conducted for each group approximately 12 month after the fifth educational session. This concluded the support group. During the intervention period (0-60 months), the family caregivers in the intervention group had the opportunity to contact the physician, the RN and/or the counsellor for further advice. Telephone interviews with the family caregivers in both groups were carried out every six month during the whole study period and scheduled between the postal questionnaires. On these occasions, the RN was able to further inform and give advice to the family caregiver.

### *Procedures*

Baseline data were collected between January 1999 and April 2003 for the intervention group and from January 2000 to May 2005 for the controls. A questionnaire was sent by mail at baseline and every six months thereafter to the family caregivers regarding socio demographic data, type and cost of care provided by the municipality and the kind of help provided by the family caregivers. The questionnaire also contained a diversity of instruments assessing caregivers' perception of the present situation and HRQoL. Telephone interviews with the family caregivers were carried out every six month and scheduled between the postal questionnaires to update possible changes in care provided by the municipality and/or the family caregivers.

### *Resource use and costs*

Resource use in terms of home help service, adult day care service and the specific nursing home placement were collected annually from the municipal administrative office in the two districts during the study. To value the resource use, we used the Malmo municipality five-level tariff for home help services and adult day care. The tariff for home help services included provision of security alarm, meals on wheels and other services to support the person with dementia and/or the family caregiver. Resource use and costs were obtained annually from municipality registers for each participant. Additional information on resource use was obtained from family caregivers' self-reports by telephone interviews, and questionnaires every third month. Nursing home costs were derived from residency specific monthly tariffs. The intervention consisted of groups of approximately eight family caregivers led by an RN and a counsellor who met two hours weekly for five weeks. In a follow-up period, caregivers were invited to join a conversation group with six 90 minute meetings. The intervention was valued using a marginal cost approach considering labour costs (per hour RN =26 EUR, counsellor = 31 EUR). We did not include opportunity cost of the group meeting premises or private costs.

All nominal tariffs and costs for the intervention were indexed to 2010 price levels using consumer price index from Statistics Sweden (www.scb.se) to obtain comparable costs and reduce the impact of differential timing due to the longitudinal design of the study. All costs were expressed in EUR using the average exchange rate for 2010 reported by the Swedish Central Bank (1 EUR = SEK 9.5413; www.riksbanken.se).

### *Instrument*

Earlier publications [5, 11], from the intervention study have reported family caregiver outcomes using two instruments; the Caregiver Burden Scale [12] and the Nottingham Health Profile [19]. This report uses a third instrument in the intervention study; the generic EQ-5D [20, 21]. Based on preferences elicited from a general UK population, EQ-5D health states can be converted into utility scores referred to as the EQ-5D index.

### *Analysis*

We compared resource use, costs and family caregivers' HRQoL in the intervention and control groups using all within study measurements. The intervention was intended to support the family caregiver in his or her daily life with the person with dementia and as such could improve the caregiver wellbeing. The first narrow perspective cost-effectiveness analysis compared the costs of intervention to the difference in family caregiver utility in two study frames: 1.while the person with dementia lived at home: and 2. after the person with dementia moved to a nursing home or died. The second broader costs and outcome analyses compared resource use and costs related to formal care used by the person with dementia. In particular, the intervention directed at family caregivers was hypothesised to influence the family caregivers' interaction with formal care decision makers. Volumes of formal care in terms of home help service and adult care could vary and there was a potential trade-off between formal and informal care as well as between the time at home with intensive home help services and moving to a nursing home.

### *Statistical methods*

Data were analysed using descriptive statistical methods, Student's-T-test, Mann-Whitney U and Kaplan-Meier stratified survival analysis and longitudinal regression analysis [22]. All analyses were done using statistical package Stata version 11.0 [23]. A p value $\leq 0.05$ was considered significant.

## Ethical aspects

Ethical approval was obtained prior to the data collection from the Ethical Committee of Lund University, Sweden (LU-1997-573). Permission to perform the studies was also obtained from the board of municipality in each of the two districts.

Informed consent was obtained from all subjects and their family caregivers.

## Results

The results on resource use and costs depend on the proportion of participants alive at different points in time and on their need for formal care. Survival is therefore an important component of the cost results. This section presents results organised under separate subsections including survival, resource use and costs.

### *Survival*

Dementia is a severe disease and approximately 75 % of persons with dementia died within five years of the study start date (intervention 116/153 and control 114/155). Survival did not differ significantly between the intervention and the control group ($p = 0.15$) in the total study sample.

### *Time before moving to a nursing home*

We found no overall difference between the intervention group and controls in time before the person with dementia moved to a nursing home, using Kaplan-Meier analysis and accounting for censoring due to death (Figure 1, panel A; $p = 0.86$). Persons with dementia who died before moving to a nursing home were censored in the Kaplan-Meier analysis (intervention n=31, control n=33). Overall, among persons with dementia who moved to a nursing home during the five-year study period, the average number of days at home was higher in the intervention group (487 vs. 434 days) but not significant ($p$ =0.32).

Nevertheless, the intervention group and controls differed in stratified analysis of subgroups based on type of family caregiver.

There was a tendency for persons with dementia to move earlier to a nursing home if their caregivers were spouses and cohabitants in the intervention group rather than the control group (Figure 1, panel B spouses; (*p*<0.01) where 35/70 persons with dementia moved; mean 486 days vs. 678 days in the control group *p* =0.09).

For children and grandchildren caregivers, the reverse was true and persons with dementia remained home significantly longer in the intervention group (mean 529 days vs. control group 394 days *p* =0.03 and Kaplan-Meier curve Figure 1, panel C, p=0.06). In this group of persons with dementia, 139 out of 204 moved to a nursing home,

Other caregivers, including neighbours and friends, composed the smallest group (n=34) Figure 1, panel D others; *p* = 0.07. While 23 persons (68%) with dementia moved to a nursing home earlier in the intervention group (367 days vs. 491 days in the control group) the difference was not significant (*p* =0.43).

**Fig 1 approx here**

We found no significant differences between the intervention group and controls regarding severity of dementia and/or functional status. The results at the 6, 12 and 18 month follow-up, showed a progression of the disease in both groups according to the Berger scale (at six months both group scored 3-6 ) and an increasing social dependency due to functional disabilities according to the Katz Index. The results of the GBS-scale showed that family caregivers who underwent psychosocial intervention rated both the intellectual and emotional symptoms in the person with dementia, higher compared to controls. These results have been published previously [14].

### *Family caregiver HRQoL*

Caregiver quality of life was analyzed in two different subsets: 1) while person with dementia lived at home was analyzed using the GEE population-averaged generalized linear model to account for repeated measurements; and 2) using linear regression analysis for the last measurement after the person with dementia moved to nursing home [23]. Missing data were treated as missing and no imputation or extrapolating strategies were applied**.**

Person with dementia lives at home

We had 795 observations (n= 286) of which 436 were of family caregivers in the intervention group while the person with dementia was living at home and 404 observations of family caregivers in the controls. As shown in Figure 2 (left panel) family caregivers in the intervention group rated higher EQ-5D index value (interquartile range, IQR) 0.848 (0.725-1) compared to controls 0.796 (0.725-1). The difference in EQ-5D index value was 0.052 ($p<0.01$) and did not account for confounders or for the fact that we had several measurements on several individuals. Family caregivers in the intervention group who were children or grandchildren, reported higher HRQoL compared to their counterparts among the controls when other factors were controlled for including the age, gender and employment status of family caregivers; the study group or category, and patient demographics. The estimated mean difference in EQ-5D index value compared to controls in the same position was 0.065 (95% CI 0.012 - 0.118; $p = 0.02$). In addition, female family caregivers in both the intervention and control groups reported significantly lower HRQoL than male caregivers -0.08 (95% CI -0.04 - -0.13; $p<0.01$).

Person with dementia moved to a nursing home

Figure 2 (right panel) shows HRQoL by EQ-5D value at last measurement when the person with dementia had moved to a nursing home. Median (IQR) for the intervention group was 0.866 (0.725–1) and for controls 0.796 (0.725–1) ($p=0.16$).

Among the family caregivers who reported HRQoL once the person with dementia had moved to a nursing home, spouses and cohabitants in the control group were significantly worse off. After controlling for patient demographics and for caregiver factors including age, gender, employment status and study group or category, the EQ-5D index value for control group spouses was –0.363 (95% CI -0.567 – -0.159; $p<0.001$). There was also an indication that family caregivers who were children or grandchildren in the intervention group were slightly better off; EQ-5D index value 0.076 (95% CI –0.003 - 0.156; $p=0.06$).

**Fig 2 approx here**

EQ-5D-values were reported for 292/308 caregivers at 840/865 (97%) of measurements in the first subset consisting of observations before the person with dementia moved to nursing home or died (intervention 436/444, 98%; control 404/421, 96%). The response rate in the second subset was lower, 172/308 (56%) as questionnaires were not distributed to caregivers where the person with dementia died before moving to nursing home.

### *Resource use*

Persons with dementia from the intervention group remained longer in the study, median (IQR) for intervention was 20.9 months (14.2–34.0) and for control 18.9 (10.8–29.5) ($p$ 0.06). Persons with dementia from the intervention group had longer median times with home help services and in nursing homes, although these differences were not significant.

### *Costs*

The following paragraphs report the full study period costs for home help services, nursing home care, the study intervention and total costs. As the length of the study period differed between individuals in the intervention group and controls, all costs except costs of the intervention are weighted by length of observation.

### *Total median monthly costs*

During the five year follow-up, the median total costs weighted for study length did not differ between groups, although there were substantial individual variations. The median (IQR) total cost per month was; EUR 1926 (1043-2588) in the intervention group and EUR 1860 (864-2577); ($p$ =0.47) in the controls. The only significant difference was found in the subgroup of persons with dementia who had a non-family caregiver ("Other") in the intervention group (Table 4).

**Table 4 approx here**

### *Monthly costs of home help services*

When the costs of home help services were weighted by the time the person with dementia remained at home during the study period, no differences in costs were noted in the total studied population. The subsample with spouses and cohabitants as family caregivers in the intervention had lower costs for home help services with median cost (IQR) of home help services of EUR 355 (201-927) compared to EUR 718 (511-1203) in the controls ($p$ = 0.01). Most participants had at least some home help during the study but the level of home help services ranged from once a month to several times daily.

### *Monthly costs of nursing home care*

When the costs of nursing home care were weighted by the length of stay in months during the study period, we found lower costs in the intervention group compared to the control; the median (IQR)for the intervention group was EUR 4125 (3870-4274) versus EUR 4334 (4057-4473) for the control group ($p<0.01$). The lower costs for nursing home placement in the intervention group were noted for both spouses and children or grandchildren as family caregivers (Table 4).

*Total costs of psychosocial intervention*

The total costs for providing psychosocial education and support are estimated to be EUR 107 per family caregiver, based on average hourly wages for the RN and the counsellor, multiplied by the number of hours provided for education and support.

## Discussion

To our knowledge, this is the first study describing the actual costs for home help services, nursing home placement and the costs of a psychosocial intervention, as well as the effect of the intervention on the family caregivers HRQoL.

Total costs did not differ between the intervention and control groups, although costs for nursing home placement were lower in the former group and with substantially higher HRQoL for subgroup of children and grandchildren family caregivers in the intervention group.

The higher costs for home help services in the control group for the subsample with spouses as family caregivers might reflect the progression of dementia resulting in an increased burden on the family caregiver. In contrast, persons with dementia in the intervention group and with spouses as family caregivers had lower costs for home help services. This result can be interpreted as a positive effect of the intervention with its psychosocial approach, including information, education, and social support, which puts focus on the identified specific needs of the family caregiver, and helps him or her to cope with the situation in a new and different way.

Furthermore, we found no overall difference between the intervention group and controls in time before moving to a nursing home, but the intervention and control groups differed when stratified by family caregiver subgroup. Persons with dementia in the intervention group with spouses and cohabitants as family caregivers, moved earlier to a nursing home and the reverse was true for persons with dementia with children or grandchildren as family caregivers. In a previous study based on the same population, a significantly longer time at home was noted for persons suffering from dementia with children as family caregivers; 605 days in the intervention group compared to 425 days among controls (p=0.018) after taking into account covariates such as age, gender, caregiver burden, dementia severity and subjective health [13].

Whether this is an effect of the intervention that causes the family caregivers to identify medical needs at an earlier stage needs to be explored.

The reduced risk of nursing home placement in this study, contradicts findings by Wattmo et al. [24], who aimed to identify risk factors for nursing home placement. Among other predictors, they found that solitary living was a significant risk factor for nursing home placement. Similar findings were established in a study by Luppa et al. [25].

The intervention might have given the spouse caregivers in our study the incentive to consider the possibility of nursing home placement at an earlier stage. Gaugler et al. [26] described that one predictor of nursing home placement was the family caregivers' desire to institutionalize; these thoughts might have been encouraged by the design of the intervention, which gave family caregivers the opportunity to support each other during the group meetings. Gaugler at al. also identified that emotional stress and the feelings of isolation or "being trapped", as factors that predicted nursing home placement and suggested that those factors could be more important in predicting nursing home placements than the symptoms of dementia in the person with the disease [26]. Similarly, a study by Annerstedt et al.[27], identifying the breaking point at which home care no longer is adequate, shows that especially among spouses, the feeling of isolation is an important factor in total burden and a strong predictor of nursing home placement.

Being a spouse or cohabitant often imposes heavier burden on the family caregiver. It is important both to help the caregiver identify the time when transitioning to a nursing home is the most appropriate choice and to support him or her during this often very stressful and difficult decision.

The fact that children and grandchildren in the intervention group reported significantly higher HRQoL when the person with dementia lived at home indicates that this group may have benefited most from the psychosocial intervention and this can be a possible explanation for the prolonged stay at home for the persons with dementia in this subgroup. This is in accordance with findings by Sörensen et al. [6]. Their review of 78 intervention studies, suggested that spouses generally benefits less from intervention than adult children, mainly because the information provided is often more novel to adult children and therefore has a greater effect on their situation as family caregivers.

We also noted that spouses and cohabitating caregivers in the control group were significantly worse off in their ratings of HRQoL after the person with dementia moved to a nursing home. The fact that the persons with dementia who were cared for by spouses or cohabitants in the control group stayed at home longer could have caused increased caregiver burden and affected the HRQoL. Also, spouses and cohabitants in general might not be as psychologically relieved when the person they care for moves to a nursing home. A study by Schultz et al. [28], with data collected before and after nursing home placement, demonstrated that for some family caregivers, symptoms of anxiety and depression did not decrease when the person with dementia moved to nursing home. Furthermore these effects were most pronounced among family caregivers who were spouses. Bruvik et al. [29] demonstrates in a study using QoL-Alzheimer's Disease Scale that family caregivers cohabiting with the person with dementia had lower score than non-cohabiting caregivers. Findings by Gaugler et al. [30] revealed that female family caregivers such as wives and daughters were most likely to experience burden after nursing home placement, findings similar to this study in which female caregivers reported lower HRQoL than male caregivers.

It is reasonable to assume that the above described results also should influence the organization of interventions and support. The findings suggest it is important to individualize support, and when group support is planned, to consider the composition of the group in order to offer the best possible conditions for the participants. This is consistent with a meta-analysis by Pinquart and Sörensen [31] on 168 studies including large subgroups of spouses (n=28.980), adult children (n=30.739) and children-in-law (n= 4.627). Their results suggest that an intervention might be more effective if it addresses the specific issues faced by the different subgroups of family caregivers. Studies looking at subgroups of family caregivers and the intervention outcome of HRQoL are few, and more research is needed to reveal which characteristics in both the person in need of care and the family caregiver, affect the family caregiving situation.

The median total costs per month for formal care in the intervention group was EUR 1926 (Table 4), resulting in an annual cost of approximately EUR 23 100 per person with dementia. The total cost for intervention in this study based on wages for the RN and counsellor, was EUR 107 per family caregiver, less than one half percent of the total costs per person with dementia and could be considered a marginal cost.

## Methodological considerations

The two districts chosen for the recruitment of persons with dementia had similar socio demographic structures and levels of public services. All subjects in both the intervention group and control groups were classified and diagnosed after medical examination according to standardized DSM-IV criteria. Home visits were performed to avoid selection bias and reduced participation rate. Many previous studies are hampered by short-term follow-up in contrast to this study with up to five-year follow-up. Furthermore, specific annual costs were retrieved for the specific units and care, instead of estimations often used in previous studies. Only 21 percent of the dyads remained in the study at 30 months, and approximately three out of four persons with dementia died within five years from study start, demonstrating the severity and progression of the disease and the difficulty in conducting longitudinal studies on persons with dementia and their family caregivers. A smaller sample reduces the statistical power to detect potential systematic differences between the intervention group and controls.

It is also possible that the persons with dementia remaining in the study are less affected by the disease which may have affected the family caregiver's ratings of HRQoL. In analysing the costs, only formal care costs were considered in this study. Private costs and the possibility of a reduced degree of employment were not included in our analyses.

## Conclusions and applications

Our main findings are that there were no overall differences in costs between the intervention group and controls and significantly higher HRQoL in caregiving children and grandchildren receiving intervention.

Moreover, we observed between-subgroup differences with decreased costs of home help services and time to nursing home placement in the intervention group. This could be a result of the intervention focusing on the specific needs of individual patients once family caregivers became better informed about dementia, its consequences, and the municipalities' responsibility for dementia care. This may be interpreted as a support for implementing psychosocial intervention for family caregivers of person with dementia

Furthermore, the differences in HRQoL for various caregiver relationships might indicate that future psychosocial interventions should be targeted towards the specific needs of subgroups of family caregivers. In addition to these quality of life outcomes for the family caregiver, our data also indicates that potentially as a result of the intervention, the need for certain levels of care for the person with dementia may have been identified earlier.

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## Conflict of interests

The authors declare no conflicts of interest nor any affiliations with the industry related to this work.

## References

1. Ministry of Health and Social Affairs. The Social service act 2001:453 (Socialjänstlagen)
2. Wimo A, Winblad B, Jönsson L: The worldwide societal costs of dementia: Estimates for 2009. Alzheimers Dement 2010; 6:98-103.
3. Hurd MD, Martorell P, Delavande A, Mullen KJ, Langa KM. Monetary costs of dementia in the United States. N Engl Med; 2013 ; 368: 1326-34
4. Kraijo H, Brouwer W, de Leeuw R, Schrijvers G, van Exel J. Coping with caring: Profiles of caregiving by informal carers living with a loved one who has dementia. Dementia 2011; 11(1): 113-130.
5. Andrén S, Elmståhl S. The relationship between caregivers' perceived health and their sense of coherence in caring for elders with dementia. J C Nurs 2008; 17 (6):790-799.
6. Sörensen S, Pinguart M, Duberstein P. How effective are interventions with caregivers? An updated meta-analysis. Gerontologist 2002; 42 (3):356-372.
7. Brodaty H, Green A, Koschera. A. Meta-analysis of psychosocial interventions for caregivers of people with dementia. JAGS 2003; 51: 657-664.
8. Selwood A, Johnston K, Katona C, Lyketsos C, Livingston G. Systematic review of the effect of psychosocial interventions on family caregivers of people with dementia. J Affect Disord 2007; 101: 75-89.
9. Thompson C A, Spilsbury K, Hall J, Birks Y, Barnes C, Adamson J. Systematic review of information and support interventions for caregivers of people with dementia. BMC Geriatr 2007; (7)18.

**10.** Corbett A, Stevens J, Aarsland D, Day S, Moniz-Cook E, Woods R et al. Systematic review of services providing information and/or advice to people with dementia and/or their caregivers. Int J Geriatr Psychiatry 2012; 27:628-636.

**11.** Andrén S, Elmståhl S. Psychosocial intervention for family caregivers of people with dementia reduces caregiver's burden: development and effect after 6 and 12 months. Scand J Caring Sci 2008; 22: 98-109.

**12.** Elmståhl S, Malmberg B, Annerstedt L. Caregiver's burden of patients 3 years after stroke assessed by a novel caregiver burden scale. Arch Phys Med and Rehabil 1996; 77: 177-182.

**13.** Andrén S, Elmståhl S. Effective psychosocial intervention for family caregivers lengthens time elapsed before nursing home placement of individuals with dementia: a five year follow-up study. Int Psychogeriatr 2008; 20(6): 1177-1192.

**14.** Dahlrup B, Nordell E, Andrén S, Elmståhl S. Family caregivers' assessment of symptoms in persons with dementia using the GBS-scale, differences in rating after psychosocial intervention –an 18 month follow-up study. Clin Interv Aging 2011; 6: 9-18.

**15.** Jones C, Tudor Edwards R, Hounsome B. A systematic review of the cost-effectiveness of interventions for supporting informal caregivers of people with dementia residing in the community. Int Psychogeriatr 2012; 24(1):6-18.

**16.** Folstein MF, Folstein SE, McHugh PR."Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. J Psychiatr Res 1975; 12(3):189-198.

**17.** Tombaugh TN, McIntyre NJ. The mini-mental state examination: a comprehensive review. JAGS 1992; 40: 922-935.

**18.** Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV) Washington, DC: American Psychiatric Association; 1994.

**19.** Hunt SM, McEvan J, McKenna SP. Measuring health status: a new tool for clinicians and epidemiologists. J R Coll Gen Pract 1985; 35: 185-188.

**20.** Dolan, P. Modeling valuations for EuroQol Health States. Med Care 1997; 35 (11):1095-1108.

**21.** EuroQol Group. A standardised instrument for use as a measure of health outcome. 2012 (cited 2012; Available from: http://www.euroqol.org/).

**22.** Altman D. Practical statistics for medical research 1991, London: Chapman & Hill.

**23.** StataCorp, Stata: Release 11. Statistical Software 2009, College Station, TX: StataCorp LP.

**24.** Wattmo C, Wallin ÅK, Londos E, Minthon L. Risk Factors for Nursing Home Placement in Alzheimer's Disease: A Longitudinal Study of Cognition; ADL, Service Utilization, and Cholinesterase Inhibitor Treatment. Gerontologist 2011;51(1):17-27

**25.** Luppa M, Riedel-Heller S G, Stein J, Leicht H, König H-H, van den Bussche H, Maier W, Scherer M, Bickel H, Mösch E, Werle J, Pentzek M, Fuchs A, Eisele M, Jessen F, Tebarth F, Wiese B, Weyerer S. Predictors of Institutionalisation in Incident Dementia –Results of the German Study on Ageing, Cognition and Dementia in Primary Care Patients (AgeCoDe Study). Dement Geriatr Cogn Disord 2012;33:282-288.

**26.** Gaugler JE, Fang Y, Krichbaum K, Wyman J.F. Predictors of Nursing Home Admission for Persons with Dementia. Med Care 2009; 47(2):191-198.

**27.** Annerstedt L, Elmståhl S, Ingvad B, Samuelsson SM. Family caregiving in dementia An analysis of the caregiver's burden and the "breaking-point" when home care becomes inadequate. Scand J Public Health 2000; 28: 23-31.

**28.** Schultz R, Belle SH, Czaja S, McGinnis KA, Stevens A, Zhang S. Long-term Care Placement of Dementia Patients and Caregivers Health and Well-being. JAMA 2004; 292(8):961-967.

**29.** Bruvik FK, Ulstein ID, Hylen Ranhoff A, Engedal K. The Quality of Life of People with Dementia and The Family Carers. Dement Geriatr Cogn Disord 2012;34:7-14.

**30.** Gaugler JE, Mittelman MS, Hepburn K, Newcomer R. Clinically significant changes in burden and depression among dementia caregivers following nursing home admission. BMC Med 2010; 8(85):1-14.

**31.** Pinquart M, Sörenson S. Spouses, Adult Children, and Children-in-Law as Caregivers of Older Adults :A Meta-Analytic Comparison. Psychol Aging 2011; 26(1):1-14.

**Table 1. Overview of data collection**

| **Eligible subjects identified for the community survey** | **Case group N = 1694** | **Control group N = 1766** |
|---|---|---|
| **Excluded** | Moved to another community 10<br>Moved to a nursing home 145<br>Patient deceased 147<br>Could not be contacted 18 | Moved to another community 20<br>Moved to a nursing home 147<br>Patient deceased 236<br>Could not be contacted 16 |
| **Available for the study**<br>Postal information and invitation | **N = 1374**<br>Non-participating 475<br>No caregiver/caregiver deceased 26 | **N = 1347**<br>Non-participating 537<br>No caregiver/caregiver deceased 27 |
| **Agreed to a home visit**<br>Telephone call<br>Interview survey at home to gain idea of cognitive decline | **N = 873**<br>No cognitive decline 394<br>Light cognitive decline 67 (re-test later)<br>Moved to a nursing home 54<br>Patient deceased 44<br>Caregiver declined participation 4 | **N = 783**<br>No cognitive decline 407<br>Light cognitive decline 32 (re-test later)<br>Moved to a nursing home 41<br>Patient deceased 29<br>Caregiver decline participation 13 |
| **Agreed to a clinical examination**<br>Medical examination by a physician<br>Blood tests<br>Computed tomography, possibly<br>Cerebral blood flow, possibly | **N = 310**<br>No dementia diagnosis 49<br>New clinical examination later 21<br>Dementia diagnosis 207<br>Moved to a nursing home 15<br>Patient deceased 15<br>Caregiver declined participation 3 | **N = 261**<br>No dementia diagnosis 50<br>New clinical examination later 3<br>Dementia diagnosis 208<br>Moved to a nursing home 14<br>Patient deceased 12<br>Caregiver declined participation 12 |
| **Available to participate** | **N = 207**<br>Moved to a nursing home 28<br>Patient deceased 4<br>Caregiver declined participation 14<br>Caregiver deceased 2 | **N = 170**<br>Moved to a nursing home 6<br>Patient deceased 0<br>Caregiver declined participation 9<br>Caregiver deceased 0 |
| **Agreed to participate** | **N = 159**<br>Incomplete data in questionnaire 6 | **N = 155**<br>Incomplete data in questionnaire 0 |
| **Participating** | **N = 153** | **N = 155** |

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**Table 2 Demographic characteristic of persons with dementia and the family caregiver at baseline**

| | **Intervention group** | **Control group** |
|---|---|---|
| **Persons with dementia, n** | 153 | 155 |
| **Age (years)** | | |
| Mean, range | 84 (57-101) | 85 (66-95) |
| **Gender, number (%)** | | |
| men | 60 (39) | 53 (34) |
| women | 93 (61) | 102 (66) |
| **Living arrangements, number (%)** | | |
| Living together | 41 (27) | 35 (23) |
| Living apart | 112 (73) | 120 (77) |
| **Instruments** | | |
| MMSE[a], mean (range) | 19 (0-30) | 18 (7-28) |
| Berger scale | | |
| Low severity of dementia % | 75 | 48 |
| High severity of dementia % | 25 | 52 |
| Katz index of ADL[b] | | |
| Low dependency % | 80 | 76 |
| High dependency % | 20 | 24 |
| GBS subscales[c], mean scores (SD) | | |
| Intellectual | 16.5 (9.1) | 22.5 (10.7) |
| Emotional | 2.3 (2.3) | 4.1 (3.3) |
| ADL[b] | 5.6 (6.0) | 6.1 (5.4) |
| **Family caregivers, n** | 153 | 155 |
| **Age (years)** | | |
| Mean, range | 62 (27-90) | 62 (38-95) |
| **Gender, number (%)** | | |
| men | 60 (39) | 53 (34) |
| women | 93 (61) | 102 (66) |
| **Relationship, number (%)** | | |
| spouse/partner | 38 (24.8) | 32 (20.6) |
| adult children | 91 (59.5) | 101 (65.2) |
| grandchildren | 1 (0.7) | 2 (1.2) |
| daughters and sons in law | 3 (2.0) | 1 (0.6) |
| siblings | 1 (0.7) | 4 (2.5) |
| others | 19 (12.4)* | 15 (9.7)* |

[a] MMSE=mini mental state examination
[b] ADL= Activity of Daily Living
[c] GBS=Gottfries-Bråne-Steen

* The sum of the percentages differ from 100% due to rounding

**Table 3. Participants (Family caregivers) included at 11 study measurements.**

| Month | Intervention | | Control | | Total | |
|---|---|---|---|---|---|---|
| | n | Percent | N | Percent | n | Percent |
| 0 | 153 | 100 | 155 | 100 | 308 | 100 |
| 6 | 134 | 88 | 123 | 79 | 257 | 83 |
| 12 | 110 | 72 | 103 | 66 | 213 | 69 |
| 18 | 74 | 48 | 80 | 52 | 154 | 50 |
| 24 | 52 | 34 | 53 | 34 | 105 | 34 |
| 30 | 39 | 25 | 26 | 17 | 65 | 21 |
| 36 | 26 | 17 | 18 | 12 | 44 | 14 |
| 42 | 20 | 13 | 11 | 7 | 31 | 10 |
| 48 | 7 | 5 | 11 | 7 | 18 | 6 |
| 54 | 2 | 1 | 11 | 7 | 13 | 4 |
| 60 | 2 | 1 | 3 | 2 | 5 | 2 |
| Total number of measurements | 619 | 51 | 594 | 49 | 1 213 | 100 |

**Table 4 Median (IQR) of total costs, cost of home help services and cost of nursing home per month during study in full sample and in three subsamples by caregiver category. All costs in EUR (Year 2010 average exchange rate EUR 1= SEK 9.5413).**

| | **Total** | | | **Home help service** | | | **Nursing home placement** | | |
|---|---|---|---|---|---|---|---|---|---|
| Sample | Intervention | Control | p | Intervention | Control | p | Intervention | Control | p |
| All (n=308) | 1926<br>(1043-2588) | 1860<br>(864-2577) | 0.47 | 951<br>(507-1237) | 880<br>(644-1140) | 0.59 | 4125<br>(3870-4274) | 4334<br>(4057-4473) | <0.01 |
| Caregiver category | | | | | | | | | |
| Spouses and cohabitants (n=70) | 1665<br>(448-2137) | 1076<br>(545-1921) | 0.35 | 355<br>(201-927) | 718<br>(511-1203) | 0.01 | 4136<br>(3854-4208) | 4401<br>(4392-4575) | 0.01 |
| Children and grandchildren (n=204) | 1940<br>(1039-2588) | 2003<br>(1028-2807) | 0.73 | 1025<br>(554-1364) | 880<br>(655-1140) | 0.28 | 4152<br>(4006-4226) | 4273<br>(4054-4486) | 0.03 |
| Other (n=34) | 2350<br>(1543-3028) | 1402<br>(987-2236) | 0.03 | 1036<br>(544-1088) | 942<br>(644-1071) | 0.69 | 4065<br>(3614-4353) | 4401<br>(4128-4401) | 0.08 |

**Figure legends**

Figure 1. Time before persons with dementia move to a nursing home. Kaplan-Meier curves where persons who died are censored. Results for all participants (panel A) and by subsamples for each caregiver category, spouse/cohabitant (panel B), child/grandchild (panel C), others (panel D).

Figure 2. Caregivers' self-reported quality of life by EQ-5D for intervention and control groups. Results while person with dementia lived at home (left panel) and after person with dementia moved to nursing home or died (right panel).

Figure 1.

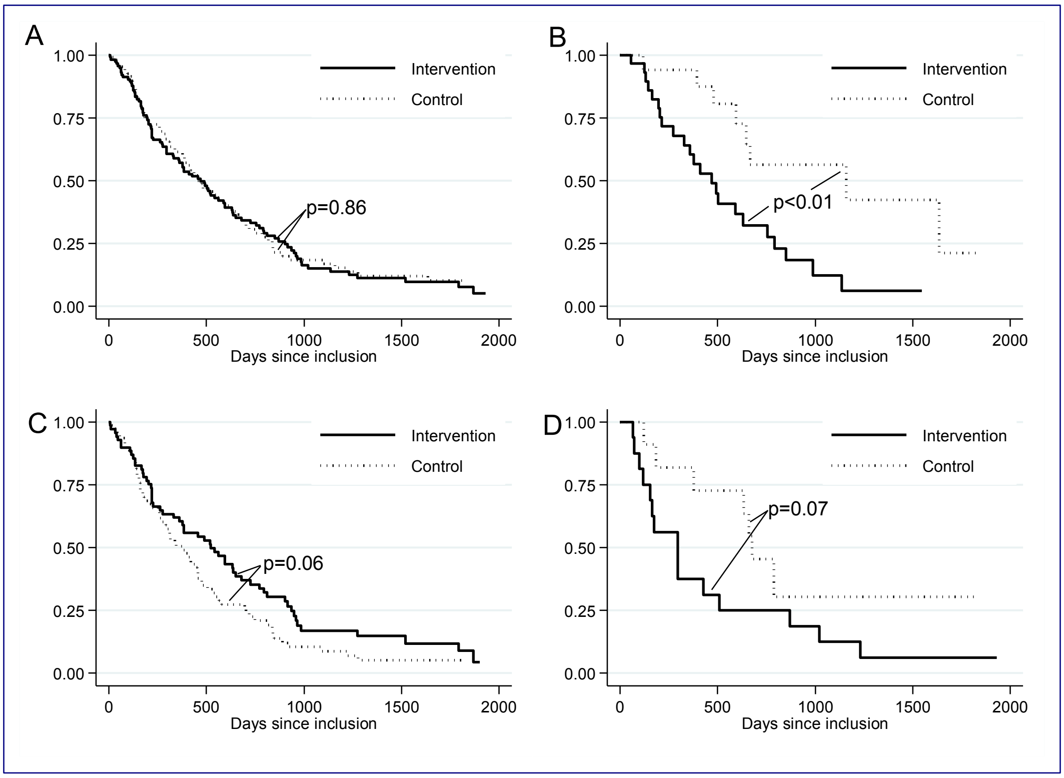
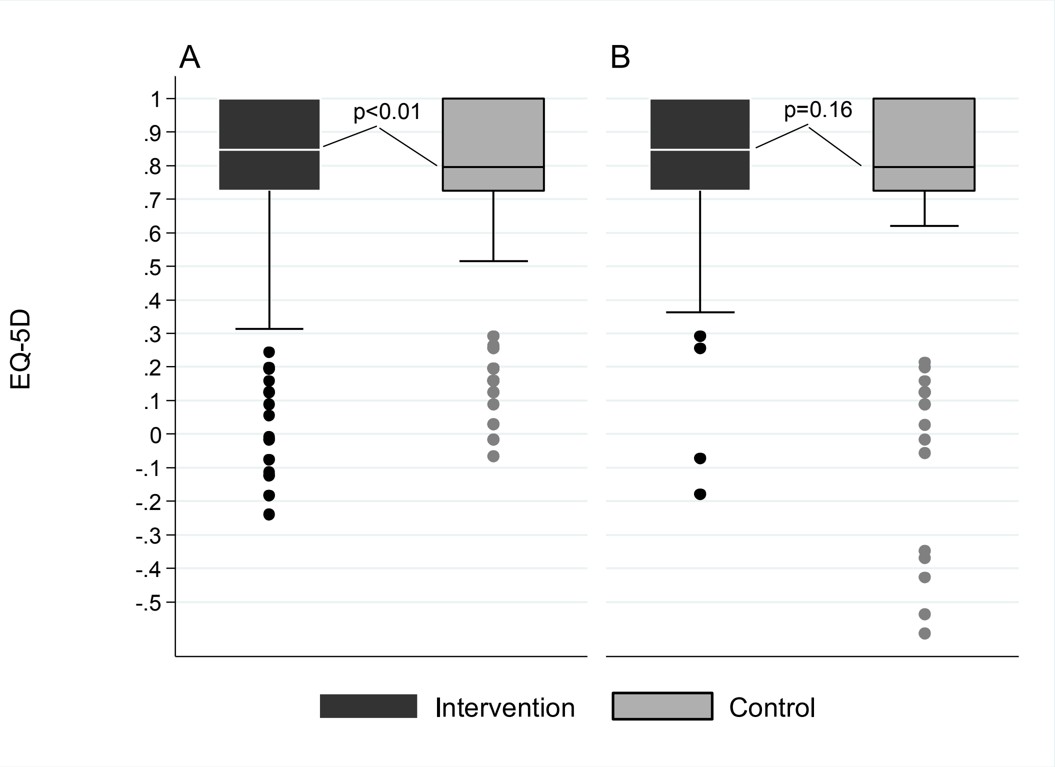

A
1.00
0.75
0.50
0.25
0.00
Intervention
Control
p=0.86
0
500
1000
1500
2000
Days since inclusion
B
1.00
0.75
0.50
0.25
0.00
Intervention
Control
p<0.01
0
500
1000
1500
2000
Days since inclusion
C
1.00
0.75
0.50
0.25
0.00
Intervention
Control
p=0.06
0
500
1000
1500
2000
Days since inclusion
D
1.00
0.75
0.50
0.25
0.00
Intervention
Control
p=0.07
0
500
1000
1500
2000
Days since inclusion

Figure 2.



## Supplementary Material

Person with dementia lives at home

**Table 1** Average difference in quality of life for intervention and control when person with dementia lived at home by regression analysis controlling for patient demographics and caregiver age, gender and employment status.

| EQ5D | Coefficient | p | 95% Conf.Interval | |
|---|---|---|---|---|
| Study group | | | | |
| Intervention & child/grand-child | 0.065 | 0.016 | 0.012 | 0.118 |
| Intervention & spouse | -0.063 | 0.273 | -0.175 | 0.050 |
| Intervention & friend/neighbour | 0.073 | 0.140 | -0.024 | 0.171 |
| Control & child/grand-child (reference) | | | | |
| Control & spouse | -0.051 | 0.380 | -0.164 | 0.062 |
| Control & friend/neighbour | 0.031 | 0.576 | -0.078 | 0.141 |
| Caregiver | | | | |
| Age | -0.002 | 0.247 | -0.005 | 0.001 |
| Woman | -0.084 | 0.001 | -0.132 | -0.036 |
| Patient | | | | |
| Age | <0.001 | 0.909 | -0.005 | 0.004 |
| Woman | 0.030 | 0.318 | -0.029 | 0.089 |
| Employment (caregiver) | | | | |
| Full-time (reference) | | | | |
| Part-time | -0.021 | 0.348 | -0.064 | 0.023 |
| Retired | -0.030 | 0.191 | -0.074 | 0.015 |
| Other | -0.033 | 0.315 | -0.097 | 0.031 |
| Regression constant | 0.969 | 0.000 | 0.609 | 1.330 |
| Number of observations | 795 | | | |
| Number of unique persons | 286 | | | |
| Average number of observations (min; max) per person | 2.8 | (1; 11) | | |

## Supplementary Material

### Person with dementia moved to nursing home or died

**Table 2**. Average difference in quality of life for intervention and control when person with dementia moved to nursing home or died by regression analysis controlling for patient demographics and caregiver age, gender and employment status.

| EQ5D | Coefficient | p | [95% Conf.Interval] | |
|---|---|---|---|---|
| Study group | | | | |
| Intervention & child/grand-child | 0.076 | 0.060 | -0.003 | 0.156 |
| Intervention & spouse | -0.021 | 0.796 | -0.183 | 0.141 |
| Intervention & friend/neighbour | 0.003 | 0.959 | -0.123 | 0.129 |
| Control & child/grand-child (reference) | | | | |
| Control & spouse | -0.363 | 0.001 | -0.567 | -0.159 |
| Control & friend/neighbour | 0.090 | 0.272 | -0.071 | 0.250 |
| Caregiver | | | | |
| Age | <0.001 | 0.951 | -0.005 | 0.006 |
| Woman | -0.025 | 0.495 | -0.096 | 0.047 |
| Patient | | | | |
| Age | 0.005 | 0.141 | -0.002 | 0.012 |
| Woman | 0.022 | 0.665 | -0.078 | 0.122 |
| Employment | | | | |
| Full-time (reference) | | | | |
| Part-time | -0.067 | 0.173 | -0.164 | 0.030 |
| Retired | -0.149 | 0.008 | -0.258 | -0.040 |
| Other | -0.129 | 0.094 | -0.281 | 0.022 |
| Regression constant | 0.433 | 0.161 | -0.175 | 1.040 |
| Number of observations | 165 | | | |
| R-squared | 0.259 | | | |

Note: 7 caregivers did not report employment status and were not included in the regression.