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Differential features of burden between spouse and adult-child caregivers of patients with Alzheimer's disease: An exploratory comparative design

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Abstract

Background: Research into burden among spouse and adult-child caregivers of patients with Alzheimer's disease has generated contradictory results as regards the group which suffers the greatest burden and the factors underlying any differences.

Objectives: The aim of the present study was to identify and compare the factors associated with caregiver burden among spouse and adult-child caregivers.

Design: Cross-sectional analytic study.

Settings: All clinical subjects had been referred on an out-patient basis to the Memory and Dementia Assessment Unit of the Santa Caterina Hospital in Girona (Spain).

Participants: Data were collected from 251 patients and their caregivers, 112 with spouse and 139 with adult-child caregivers.

Methods: The association between caregiver burden and the socio-demographic and clinical variables of both patients and caregivers was analysed, the results being compared for spouse vs. adult-child caregivers. Burden was analysed using a multivariate linear regression including all the variables for the two groups of caregivers.

Results: The results show greater burden among adult-child caregivers ($p < .05$), who experience more feelings of guilt ($p < .001$). In both groups the behavioural and psychological symptoms of patients were correlated with burden ($p < .001$). Living with the patient has a notable influence on burden among adult children ($p < .001$). Husbands, wives, daughters and sons, in this order, showed increasing levels of burden ($p <.05$) and progressively worse mental health ($p <.01$). However, the correlations between burden and mental health were strongest in daughters ($p < .001$).

Conclusion: The differences in burden between spouse and adult-child caregivers were not associated with age, physical health or clinical factors of the patients. Overall burden was greater among adult-child caregivers, especially those who lived with the patient and who had other family duties. Feelings of guilt were associated with not living with the patient, and there was a strong correlation between burden and mental health. These results support the hypothesis that spouses regard caregiving as part of their marital duties, whereas for adult children such tasks imply an important change in their lifestyle.

Key words: Caregiver burden, spouse caregivers, adult-child caregivers, Alzheimer’s Disease, mental health.

Number of words: 5947

What is already known about this topic?

- The findings regarding levels of burden and the factors that influence it in spouse and adult-child caregivers are divergent and contradictory.
- In contrast to adult-child caregivers, spouses report greater burden when the patient enters institutional care.
- Feelings of guilt are more acute among adult-child caregivers, who are more likely to make use of community or institutional resources.

What this paper adds

- The greater burden of adult-child caregivers is associated with living with the patient. Guilt feelings are stronger among those who do not live with the patient.
- Husbands, wives, daughters and sons, in this order, show increasing levels of burden and progressively worse mental health.
- The differences between spouse and adult-child caregivers are not attributable to age or physical health, but rather to the nature of the family relationship. It is argued that educational and emotional support should therefore be tailored to the different needs of caregivers.

1. Introduction

1.1. Empirical research

A review of the literature on differential factors in the burden experienced by spouses and adult children reveals notable differences. Some studies report that adult children show the highest levels of burden (Coen et al., 2002; Andrén and Elmståhl, 2007; Molyneux et al., 2008), whereas other state that the greatest burden is that experienced by spouse caregivers (Montgomery and Kosloski, 1994; Rinaldi et al., 2005; Serrano-Aguilar et al., 2006). Conversely, some authors have found no significant differences overall (Ferrario et al., 2003; Ankri et al., 2005; Turró-Garriga et al., 2008).

This diversity of findings as regards differences in the burden felt by spouse and adult-child caregivers could be due to numerous factors, such as the way caregivers react to a given point in the disease evolution. Marwit and Meuser (2002) described three different stages in the patient's evolution, considered according to the Clinical Dementia Rating (CDR) Scale (Berg, 1988). The suffering of adult-child caregivers followed a curved line in the form of an inverted U, i.e. of low intensity in mild dementia (CDR 0.5-1), very intense in moderate dementia (CDR 2) and of moderate intensity in severe dementia (CDR 3), coinciding with institutionalisation. In contrast, the suffering of spouse caregivers was depicted by an ascending line, where the greatest intensity coincided with the patient entering institutional care.

Regarding specific features of the burden experienced by spouse and adult-child caregivers, some authors have analysed the internal factors of the Caregiver Burden Interview (CBI) (Zarit et al., 1986), reporting that adult children experienced stronger feelings of guilt (Ankri et al., 2005; Turró-Garriga et al., 2008; Sanders et al., 2008).

Social isolation has been reported to be more common among spouses than adult children, with the latter being more involved in various activities and settings (Rinaldi et al., 2005; Ott et al., 2007; Sanders et al., 2008).

As regards the use of external resources, adult-child caregivers receive more help from other people (Lawton et al., 1991), show a greater tendency to make use of community resources (Winslow, 1997; Robinson et al., 2005; Sanders et al., 2008), and are more likely to place the patient in institutional care (Montgomery and Kosloski, 1994; Winslow, 1997; Zhu et al., 2008).

Adult children are also more likely to benefit from educational interventions, partly due to their higher level of education (Lavoie et al., 2005). In contrast, spouse caregivers have greater experience of caring (Sörensen et al., 2002) and take more advantage of peer support (Lavoie et al., 2005), being more assiduous in their attendance at support groups (Ott et al., 2007).

Finally, some studies coincide in reporting worse physical health among spouse caregivers, this being related to their own advanced age (Ott et al., 2007; Sanders et al., 2008).

1.2. Theoretical framework of analysis and interventions

The main theoretical model used in analysing both the factors involved in caregiving and interventions designed to reduce negative symptoms is the stress process model (Pearlin et al., 1990; Schulz and Martire, 2004). Figure 1 is a complementary adaptation of the models developed by these authors. The figure aims to highlight the multi-dimensional nature not only of stress factors (context, patients and caregivers) but also of interventions. It is neither possible nor advisable to consider the problems faced by caregivers as being homogeneous or uniform, and this applies both to caregiver factors (relationship with the patient, gender, living with the patient, etc.) and to patient factors (behaviour, disease stage, etc.). Although social support may be of greater importance at the outset, and help to reduce anxiety about the situation, the point at which other resources are introduced will depend on the specific needs of the patient/caregiver in question.

Current research with caregivers supports the need to take into account not only the primary stressors (associated with the patient) but also, and especially, the caregiver-associated variables, the latter having a more decisive influence on burden. In this regard it is important to consider differences between caregivers according to their relationship to the patient, their gender or their ethnicity, etc., and to cease treating them as a uniform and homogenous group (Gallagher-Thompson and Coon, 2007). Furthermore, the scant findings regarding how to reduce caregiver burden suggest the need for interventions that are as personalised as possible and which include various kinds of support.

Zabalegui et al. (2008), in a review of fifteen studies with an experimental and control group, reported that interventions with caregivers had a significant but moderate effect on burden (40%), anxiety (50%) and depression (90%). They agreed with other authors that burden was the most difficult aspect to modify, since it is a stressor that remains present throughout the period in which care has to be provided. The review of 44 studies by Thompson et al. (2007) offers a more pessimistic analysis and concludes that there is little evidence to support the general efficacy of interventions designed to support and/or provide information to the caregivers of dementia sufferers.

The review by Gallagher-Thompson and Coon (2007) states that the various categories of interventions (psychoeducational programmes, psychotherapy and multicomponent interventions) aimed at caregivers have shown moderate efficacy with respect to the symptoms of anxiety, depression or burden. However, they also highlight a number of questions about intervention programmes that need to be addressed (the differences between spouse and adult-child caregivers, the differences between male and female caregivers, the different degrees of deterioration in the patient, and ethnicity) in order to evaluate the effectiveness of interventions with each of the groups.

1.3 Aims of the study

The aim of the present study was to identify the differential factors affecting burden in a sample of spouses and adult children who were caring for non-institutionalised patients with mild or moderate Alzheimer's disease (AD). Inter-group and intra-group differences were analysed. The study also examined the extent to which patient factors and caregiver factors contributed to caregiver burden. Finally, we sought to determine which relatives had the greatest overall burden and to identify the most important circumstances in each group of caregivers (spouses and adult children), distinguishing more specifically between husbands, wives, sons and daughters.

The study fills an important gap in the research on caregiver burden, since the role of the family relationship between patient and caregiver and its influence on caregiver burden has yet to be explored in any depth. The nature of this relationship (spouse vs. adult child) has important repercussions for caregivers in terms of, for example, the way in which they deal with the patient's behavioural disorders, their own mental health in the context of burden, the degree to which social relationships are affected, the presence of guilt feelings, and their overall experience of the situation. A further contribution of the present study is that it goes on to argue that these specific features of the patient-caregiver relationship mean that interventions should be tailored to the distinct needs of spouse and adult-child caregivers.

2. Method

2.1 Design and sample

The design is a cross-sectional analytic study. The sample comprised 251 patients diagnosed with AD according to DSM-IV criteria (Diagnostic and Statistical Manual of Mental Disorders) (American Psychiatric Association [APA], 2001), or probable AD according to NINCDS-ADRDA criteria (National Institute of Neurological and Communicative Disorders and Stroke/Alzheimer's Disease and Related Disorders Associations) (McKhann et al., 1984), as well as their respective caregiver relatives (N = 251; Spouse, n = 112; Adult child, n = 139).

All clinical subjects had been referred on an out-patient basis to the Memory and Dementia Assessment Unit of the Santa Caterina Hospital in Girona (Spain) and formed part of the SIDEA project (Comprehensive Follow-up of Alzheimer's Disease). The present study was approved by the Clinical Research Ethics Committee of the local healthcare board.

The inclusion criteria were: informed consent of the patient and main caregiver, clinical diagnosis of probable Alzheimer's disease, Mini Mental State Examination (MMSE) score between 10 and 28, and the presence of a reliable and trustworthy caregiver who could accompany the patient to all the research interviews.

2.2. Procedure

The initial interview was used to explain the objectives of the study to patients and caregivers. Once informed consent had been obtained the research protocol was applied to both groups. Patients and caregivers were interviewed separately and the assessment instruments were administered in the hospital by a team of clinical psychologists with neuropsychological training.

The main caregiver was defined as the person responsible for helping the patient with basic and instrumental needs of daily living, as well as for providing supervision in the home. The study data correspond to those obtained in the initial interview.

2.3. Measures

Socio-demographic analysis. The socio-demographic characteristics of patients and caregivers (age, gender, marital status, level of education, family relationship, living with or apart from the patient, employment status, other family burdens) were collected by means of a structured interview, the Cambridge Mental Disorders of the Elderly Examination Revised (CAMDEX-R) (Roth et al., 1998). Specifically, the Spanish adaptation of this instrument (Vilalta-Franch et al., 1990) was used.

Cognitive assessment. Cognitive assessment was based on two instruments:

Cambridge Cognitive Examination-Revised (CAMCOG-R). This forms part of the CAMDEX and assesses various cognitive functions, with scores ranging from 0 to 107. As regards the instrument's psychometric properties the total score has been shown to have excellent internal consistency (Cronbach's alpha 0.82-0.89) and test-retest reliability (0.86) (Vilalta-Franch et al., 1990). The cut-off score for the Spanish population is 68/69, with sensitivity of 93.7% and specificity of 71.8% (Llinás-Reglà et al., 1995).

Mini Mental State Examination (MMSE) (Folstein et al., 1975). This is a brief cognitive assessment tool whose scores range from 0 to 30, the cut-off point for cognitive impairment being 21/22. The internal consistency (Cronbach's alpha) varies widely (from 0.54 to 0.96) across studies, with lower values being found in populations of higher educational level (Jorm et al., 1988). The values obtained for test-retest (0.89) and inter-observer (0.82) reliability are good.

The instrument has high sensitivity (87%) and specificity (82%) in detecting dementia. Its concurrent validity has been demonstrated with respect to various neuropsychological tests and in longitudinal studies (Folstein et al., 1975).

Functional assessment. Functional assessment of the patient was based on the Disability Assessment for Dementia (DAD; Gélinas et al., 1999). This scale offers a broad assessment of daily living activities: basic, instrumental and leisure. It comprises forty items and scores range between 0 and 80 points, which are transformed into percentages. The scale has high internal consistency (Cronbach's alpha > 0.80) and both inter-examiner and test-retest reliability are excellent (ICC = 0.95. and 0.96, respectively). Its validity is supported by the strong correlation between the total score and the GDS (Reisberg et al., 1982), as well as with scores on the Mini-Mental State Examination.

Behavioural and psychological symptoms of dementia (BPSD). BPSD were assessed using the Spanish adaptation (Vilalta-Franch et al., 1999) of the Neuropsychiatric Inventory (NPI) (Cummings et al., 1994). This tool, which was administered to caregivers, comprises twelve subscales that assess the presence of delusions, hallucinations, agitation/aggression, depression, anxiety, euphoria, apathy, disinhibition, irritability, aberrant motor behaviour, sleep/night-time behaviour and appetite/eating disturbances. The overall score ranges between 0 and 144.

As regards the psychometric properties of the Spanish adaptation the inter-examiner/observer reliability ranges between 0.85 and 1. Concordance rates for the overall score on each subscale range between 0.96 and 1 (with the exception of 'irritability', which yielded a value of 0.63). The internal consistency (Cronbach's alpha) was 0.59 for exploratory questions, between 0.47 and 0.83 for the subscales and 0.85 for the total score. Sensitivity was 95.4% for the depression scale, 88.8% for hallucinations and 100% for the remainder. As regards specificity the values obtained ranged between 85.7% (apathy) and 100% (hallucinations). The concurrent validity with respect to the Behavioural Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD; Reisberg et al., 1987) gave a correlation of 0.66 for frequency and 0.71 for severity. The correlation coefficients with respect to the Hamilton Depression Scale were 0.70 and 0.59 for frequency and severity, respectively (Vilalta-Franch et al., 1999).

Severity of dementia. This was assessed according to the clinical criteria of the CAMDEX-R, which include cognitive and functional factors over four levels of intensity: minimal, mild, moderate and severe (Vilalta-Franch et al., 1990).

Physical and mental health of caregivers. This was assessed using the Spanish adaptation (Alonso et al., 1998) of the Health Survey (SF-12; Ware et al., 1996). This tool is a short form of the SF-36 Health Survey, which assesses subjective health status and any associated interference in daily living activities. It comprises twelve items and scores range between 12 and 28. Two global dimensions can be obtained from the direct scores: physical health and mental health. Here a specific analysis was conducted for the items that evaluate anxiety symptoms, depressive symptoms and difficulties in social relationships. The SF-12 items explained 91% of the variance in the components of the SF-36. The internal consistency (Cronbach's alpha) was 0.85 for the physical component and 0.78 for the mental component. Its validity was shown to be satisfactory when checked against population-based norms for age, sex, socio-economic status and body mass index (Vilagut et al., 2008).

Caregiver burden. Burden was assessed using the CBI, (Zarit et al., 1986), which was validated for the Spanish population by Martín et al. (1996). Scores range from 22 to 110, and the higher the score the greater the perceived burden of the caregiver. Caregivers are asked to indicate how often they experience the feelings described by each item statement using a five-point Likert scale: never (1), rarely (2), sometimes (3),often (4), almost always (5). The Spanish adaptation established cut-off points of 22-46 for no burden, 47-56 for moderate burden and 56-110 for intense burden.

For the internal analysis of the CBI we used the subscales indicated by a previous factor analysis (Turró-Garriga et al., 2008): Factor 1, Social burden; Factor 2, Psychological stress; Factor 3, Feelings of guilt; Factor 4, Emotional pressure; and Factor 5, Relationship of dependency.

The test of internal consistency gave Cronbach's alpha of 0.91, while test-retest reliability was 0.86. The correlation with Goldberg's General Health Questionnaire (GHQ) was 0.63 (Martin et al., 1996).

2.4. Statistical analysis

The relationships between the scores of patients and caregivers on the CBI and the respective socio-demographic and clinical factors were analysed by means of the non-parametric Mann-Whitney (*U*) and Kruskal-Wallis (x^2) tests. When significant differences were observed in the comparison of two means, Cohen's d was then calculated (*d*) as a measure of effect size. The correlations between CBI scores and the other variables were analysed by means of the Pearson coefficient (*r*) for continuous variables and the Spearman coefficient (r_s) for ordinal variables and those with a non-normal distribution.

In order to determine the effect of the variables on caregiver burden a multivariate linear regression analysis, including both patient and caregiver factors, was performed in each group of caregivers, i.e. spouses and adult children. The dependent variables were the CBI scores of spouse and adult child caregivers, while the independent variables were all those from the bivariate analysis.

The level of significance was set at .05 for all hypothesis contrasts. Data were processed and analysed by means of SPSS, version 17.0 for Windows.

3. Results

3.1. Description of the sample

The sample comprised 251 patients and their main caregivers. The subgroup of spouse caregivers corresponded to 112 patients, while the remaining 139 patients had adult-child caregivers. The global data for caregivers as regards gender (male, 34.0%; female, 66.0%) and family relationship (spouses, 44.5%; adult children, 55.5%) were very similar to those reported in the studies conducted by Alzheimer Europe (Georges et al., 2008).

Adult-child caregivers had a higher level of education, more additional family burdens (children or dependents) and were more likely to be in employment than were spouse caregivers.

All the spouse caregivers lived with the patient, whereas in the group of adult-child caregivers only 55 (39.6%) lived with the patient. The complete socio-demographic data are shown in Table 1.

3.2. Clinical factors for patients and caregivers in the spouse and adult-child caregiver groups

There were no significant differences between the two groups of patients (i.e. cared for by spouses vs. adult children) in terms of functional capacities, behavioural and psychological symptoms (except for delusions, with a very low effect size), cognitive functioning, time since symptom onset, or the frequency distribution in the clinical evaluation of dementia. Therefore, any differences in the burden experienced by spouse versus adult-child caregivers could not be attributed to differences in the clinical characteristics of the patients in the two groups (Table 2).

The differences were mainly observed in caregiver factors. Adult-child caregivers had better physical health (with a notable effect size), while spouse caregivers had better mental health. Burden was greater among adult children, as was the frequency distribution in levels of burden. In the factor distribution of the CBI, adult children showed greater burden on F1: Social burden, F2: Psychological stress and F3: Feelings of guilt, the latter factor yielding the most significant differences. These feelings of guilt were stronger in the sub-group of adult children who did not live with the patient (n = 84), in comparison to those caregivers who did (n = 167), ($U = -3.93$, $p < .001$, $d = 0.47$).

No differences between spouses and adult children were observed as regards the time spent on helping with daily living activities.

3.3. *Caregiver burden and the relationship with patient factors*

The analysis of results included evaluating caregiver burden with respect to the socio-demographic and clinical characteristics of patients, as well as in relation to these same factors in caregivers themselves. The significant results for both aspects are shown in Table 3.

Socio-demographic characteristics. Among spouse caregivers there were differences as regards the patient's gender: male patients produced a greater burden for female caregivers than did female patients cared for by a male. As regards female patients, these produced a greater burden among adult-child caregivers than in their spouses. The patient's age ($r = .11$, $p = .209$ vs. $r = .14$, $p = .085$) and level of education ($x^2 = 0.59$, $p = .743$ vs. $x^2 = 0.93$, $p = .627$) showed no significant associations.

Clinical factors. This factor was more strongly associated with caregiver burden. Among spouse caregivers, burden increased progressively with time since the onset of symptoms, although the burden experienced by adult children was greater during the first year. In the group of adult-child caregivers the greatest burden was associated with greater severity in the clinical evaluation of dementia, whereas this variable was not significant for spouses. The effect sizes on these measures were notable.

Greater functional autonomy was negatively correlated with burden among both spouse and adult-child caregivers. As regards the behavioural and psychological symptoms of the patient, both the spouse and adult-child caregiver groups yielded significant correlations between burden and total NPI score, apathy, appetite/eating disturbances, agitation/aggression and irritability. Only among adult-child caregivers were there specific correlations with delusions, disinhibition and euphoria. The NPI subscales hallucinations ($r_s = .06$, $p = .474$ vs. $r_s = .11$, $p = .171$), depression ($r_s = .07$, $p = .436$ vs. $r_s = .11$, $p = .178$), anxiety ($r_s = .11$, $p = .227$ vs. $r_s = .10$, $p = .229$), aberrant motor behaviour ($r_s = .18$, $p = .057$ vs. $r_s = .01$, $p = .904$) and sleep ($r_s = .15$, $p = .114$ vs. $r_s = .00$, $p = .927$) showed no significant correlations in either group.

No significant correlations were observed between burden and cognitive impairment on the MMSE ($r_s = .02$, p = .774 vs. $r_s = .07$, $p = .387$) or CAMCOG-R ($r_s = .13$, p = .167 vs. $r_s = .05$, $p = .534$) in either of the caregiver groups.

3.4. Caregiver burden and the relationship with caregiver factors

Socio-demographic characteristics. There was no significant correlation between burden and the age ($r = -.01$, $p = .894$ vs. $r = .02$, $p = .734$) or level of education of caregivers ($x^2 = 5.11$, $p = .078$ vs. $x^2 = 1.53$, $p = .465$) in either of the two groups.

As regards gender, wife caregivers showed greater burden than did husband caregivers, while sons also experienced greater burden than did husband caregivers, the effect size being notable. There were no significant differences between wife and daughter caregivers.

The most notable difference was observed when considering whether or not the caregiver lived with the patient. All spouse caregivers lived with the patient, and when comparing them only to those adult-child caregivers who also lived with the patient, the latter subgroup showed greater burden with an important effect size. This greater burden was also observed when comparing adult-child caregivers who lived with the patient with those who did not. When they were the sole caregiver, adult children also showed greater burden than did spouses (Table 3).

Having other family burdens (children, caring for a disabled person, etc.) did not produce significant differences in the two groups ($U = -0.54$, $p = .588$ vs. $U = -0.56$, $p = .574$). Likewise, employment status was not a source of significant differences between spouse and adult-child caregivers ($U = -0.27$, $p = .784$ vs. $U = -0.99$, $p = .320$).

Clinical factors. There are some significant differences of relevance in this aspect. The correlation between burden and time spent on helping with instrumental daily living activities was significant for both spouse and adult-child caregivers. However, for basic ADLs this correlation was only significant for adult children.

The physical health (SF-12) of spouse and adult-child caregivers was not significantly correlated with burden, despite the fact that spouse caregivers had poorer physical health. In contrast, among adult-child caregivers there were notable correlations between burden and global mental health, as well as with anxiety symptoms, depressive symptoms and difficulties in social relationships.

3.5. Caregiver burden and mental health in husbands, wives, sons and daughters

Husbands, wives, daughters and sons, in this order, showed increasing levels of burden and progressively worse mental health, with the effect size being notable for both burden and mental health. This confirms that spouses experience less burden and have better mental health compared to adult children.

Among the correlations between burden and mental health, anxiety symptoms were only reported by adult children, whereas depressive symptoms were present in all subgroups except that of husbands; in fact, there was no significant correlation between burden and mental health among husbands. The most significant correlations in this regard were observed among daughters, whose scores were the most negative (Table 4).

3.6. Multivariate linear regression analysis

Spouse caregivers. The linear regression analysis (Table 5) for the most relevant factors of the CBI revealed that the highest scores were associated with patient factors, especially behavioural and psychological symptoms of dementia such as apathy and irritability. The time dedicated by caregivers to instrumental daily living activities was also a relevant factor.

Adult-child caregivers. As regards the most relevant factors of the CBI, the scores for patient factors (disinhibition and irritability) were lower, while higher scores were observed for caregiver factors, especially living with the patient and the caregiver’s mental health. It should be noted that neither the bivariate nor the regression analysis revealed a significant relationship between burden and physical health among spouses, whereas such a relationship was observed in adult-child caregivers.

Including the age of patients and caregivers and cognitive tests in the regression analysis did not yield significant values for either group. Those variables which had been shown to be significant in the bivariate analysis (gender of patient and caregiver, level of education of patient and caregiver, time since symptom onset, severity of dementia, being the sole caregiver and employment status of caregivers, DAD-functional autonomy, NPI-delusions, NPI-agitation/aggressiveness and NPI-euphoria in patients) were not conserved in the linear regression.

Adult-child caregivers who live with the patient. A specific regression analysis was performed introducing all the variables for adult-child caregivers who lived with the patient (n = 55), as this was the sub-group with the highest level of burden. The significant variables were daughter caregivers ($\beta = -.32$, $p = .001$), mental health of caregivers ($\beta = -.56$, $p < .001$), having other family burdens ($\beta = -.28$, $p = .005$) and the NPI-Irritability score of the patient ($\beta = -.32$, $p = .001$).

4. Discussion

4.1. Caregiver burden and disease course

The present study confirms the hypothesis of Marwit and Meuser (2002) as regards spouse caregivers, in that this group showed a linear increase in caregiver burden with respect to time since symptom onset and severity of dementia. However, our findings do not support the hypothesis for adult-child caregivers, which stated that suffering and burden would be less intense in the early stages and then increase in the context of moderately severe dementia. As in the case of spouse caregivers the present results show a linear increase in burden with respect to the severity of dementia and time since onset, with a greater burden at symptom onset, a reduction over the subsequent two years and, finally, rising burden from the third year on. This discrepancy in the group of adult-child caregivers could be due to contextual factors. The fact that more information is now available about the disease may mean that the diagnosis has a greater impact on adult children, leaving them more aware of the consequences and making it more difficult to resort to denial, an aspect that was pointed out by Marwit and Meuser.

4.2. Overall burden and differences between spouses and adult children

Overall, the levels of burden observed here were greater among adult-child caregivers, and this was even the case when comparing spouses with adult-child caregivers who lived with the patient. These findings are consistent with previous reports (Coen et al., 2002; Andrén and Elmståhl, 2007; Molyneux et al., 2008).

As has been suggested by various authors (Skaff and Pearlin, 1992; Montgomery and Koloski, 1994; Roig et al., 1998) the observed differences between spouse and adult-child caregivers could be related to the different nature of the relationship involved. In the case of spouses, caregiving tasks would be regarded as part and parcel of the marital commitment, whereas for adult-child caregivers such tasks may be felt to have an important and disruptive effect on their lifestyle. This disruption would be especially noted when the ill father or mother lives with the adult-child caregiver, and could produce important correlations between burden and mental health, both generally and in terms of specific symptoms such as anxiety, depression and difficulties in social relationships. The sense of “moral obligation” and the fact of not being able to do more for a parent could lead to feelings of guilt, which are especially intense among adult-child caregivers. In this regard it should be noted that the factor “physical health”, which was objectively worse for spouse caregivers due to their advanced age, was not significantly correlated with the burden they experienced. In contrast, the regression analysis yielded a significant correlation between burden and physical health for adult-child caregivers, which would rest on their sense of a greater "subjective" burden.

4.3. Specific factors of burden and differences between spouses and adult children

In line with that reported by numerous authors the analysis of specific factors revealed the important contribution to caregiver burden of the behavioural and psychological symptoms of patients (Fuh et al., 2001; Coen et al., 2002; Garre-Olmo et al., 2000), as well as that of functional disability (Garre-Olmo et al., 2002). These factors were distributed generally across both groups of caregivers, although the regression analysis indicated that they had a greater effect on spouses, probably due to their living in closer contact with the patient. In contrast, cognitive factors showed no relationship with burden in either group of caregivers.

Most of the caregiver factors were associated with the burden experienced by adult-child caregivers, this being especially the case for living with the patient, being the sole caregiver and physical and mental health. This supports the idea that the burden of adult-child caregivers has less to do with the patient's behaviour than with their own difficulties in assimilating and managing the situation.

As regards the variables 'gender' and 'family tie' and their relationship to burden the most favourable situation of less burden and better mental health followed the same descending order: husbands, wives, daughters and sons. In contrast, the order for adult children was reversed in the correlations between the two variables. Although sons scored higher on burden, daughters showed a stronger correlation between burden and mental health, which suggests that it is they who are at greatest risk from an emotional point of view. The data confirm that the overall burden experienced by adult children is greater than that among spouses.

4.4. Therapeutic implications

Very few interventions designed to reduce burden in caregivers of dementia sufferers have produced significantly favourable outcomes. Nevertheless, it is worth noting some of the positive findings. Teri et al. (2005) described an intervention carried out by previously-trained professionals that aimed to improve mood, burden, the response to behavioural problems and caregiving skills. The eight individualised sessions were conducted in the caregiver's home and a telephone follow up was performed over the subsequent four months. The positive effects on caregivers in terms of depression, burden, their response to the patient's behavioural problems and an improved perception of the patient's quality of life were all maintained six months after the intervention. The programme designed by Gitlin et al. (2001, 2003) was implemented by occupational therapists, again on an individualised basis and in the caregiver's home. The five, ninety-minute sessions, accompanied by telephone follow-up, sought to educate caregivers about dementia, to explain how the home environment might influence problem behaviour and deficits in ADL, and to provide training in problem-solving and caregiving skills. The overall aim was to improve the effectiveness of caregivers and reduce their burden. The outcomes at six months were favourable and significant in terms of reducing burden and upset among spouses and women.

Both these interventions were individualised and carried out in the caregiver's home. A further noteworthy aspect of the studies by Giltin et al. (2001, 2003) is that, in contrast to most research, their analysis took into account gender and the patient-caregiver relationship. In this regard, Gallagher-Thompson and Coon (2007) also stated the need to analyse which groups (spouses, adult children, men, women, etc.) would benefit most from a given intervention. All these conclusions would seem to be in line with the findings reported in the present study.

Anxiety, depression, social isolation and burden may show different outcomes depending on the family relationship between patient and caregiver and/or the caregiver's gender.

Thus, the present results support the idea that interventions should be targeted differentially at caregivers. Indeed, it seems that the differences depend less on age or physical health than on the nature of the family relationship with the patient (i.e. spouses vs. adult children), and that this in itself would produce differences in lifestyle, burden, associated feelings, personal and social relationships, the perception of the situation and the use of external resources. In sum, the situation would be experienced in a different way. Presumably the generational factor would also affect the differences when it comes to possible ways of dealing with the disease, especially as regards the less negative view of external resources held by adult children.

Approaching these situations differentially would enable interventions to be targeted more effectively toward those aspects that could alleviate the symptoms of burden and poorer mental health. Support groups should also take into account the differences between spouses and adult children and address these caregivers independently. Adult-child caregivers are likely to need help with organising the use of external resources (such as day and residential centres), which could limit the disruption of their lifestyle and provide them with more individualised emotional support to reduce the impact of burden on their mental health. Spouses, especially wives, could benefit more from domiciliary care, particularly in terms of help with daily living activities. Furthermore, having more time available, as well as the fact that spouses are less involved in other contexts and social relationships, would enable them to obtain greater benefits from the relational and socialising aspects of support groups.

4.5. Limitations of the study

One of the most important limitations of the study is that the sample comprised patients and caregivers faced with mild and moderate Alzheimer's disease, and also that the patients were being cared for in their own home or that of a relative. Therefore, it would be useful to conduct a more comprehensive study that included advanced stages of the disease, in which the patient may have been placed in institutional care. This would enable the evolution of burden and mental health in both spouse and adult-child caregivers to be observed during these stages.

A second limitation concerns the degree of bias which may result from the use of a voluntary sample. The proportion of potential patients and caregivers who refused to take part was 10% (n = 32). The reasons given included transport difficulties among those who lived further from the city centre and a simple lack of willingness on the part of the patient and/or caregiver. A further 12% (n = 38) were not accepted by the research team as they did not fulfil the basic inclusion criteria: diagnosis of dementia, MMSE score of 10-28, and a clearly identified main caregiver. The refusal or non-inclusion rates are similar to those in other studies using convenience samples. It is difficult to speculate on the potential consequences of this bias for the results, although it is worth noting that overall the degree of non-participation did not substantially alter the proportions of spouse and adult-child caregivers.

5. Conclusions

Overall burden is greater among adult-child caregivers, especially those who live with the patient. In contrast, the strongest feelings of guilt are reported by adult children who do not live with the patient. There is a strong correlation between burden and mental health, and this is most notable among daughter caregivers.

The differences in burden between spouse and adult-child caregivers are not attributable to age, the physical health of caregivers or clinical factors of the patients, but rather to the different nature of the family relationship. Spouses regard caregiving as part of their marital duties and such tasks are thus assumed more naturally, without producing such high levels of burden. For adult-child caregivers, in contrast, caring for a parent implies an important change in their lifestyle, and it can be difficult to combine with other family responsibilities.

These differences suggest that educational and emotional support should be tailored to the needs of caregivers: for adult-child caregivers, this would mean better planning in the use of external resources and more individualised emotional support, while spouse caregivers could be offered more domiciliary care and group-based services to address relational deficits.

References

Alonso, J., Regidor, E., Barrio, G., Prieto, L., Rodríguez, C., de la Fuente, L., 1998. Valores poblacionales de referencia de la versión española del Cuestionario de Salud SF-36. Medicina Clínica (Barc) 111 (11), 410-416.

American Psychiatric Association., 2001. Manual diagnóstico y estadístico de los trastornos mentales (DSM-IV-TR) (4th. ed.). Masson, Barcelona.

Andrén, S., Elmståhl, S., 2007. Relationships between income, subjective health and caregiver burden in caregivers of people with dementia in group living care: a cross-sectional community-based study. International Journal of Nursing Studies 44 (3), 435-446.

Ankri, J., Andrieu, S., Beaufils, B., Grand, A., Henrard, J.C., 2005. Beyond the global score of the Zarit Burden Interview: useful dimensions for clinicians. International Journal of Geriatric Psychiatry 20 (3), 254-260.

Berg, L., 1988. Clinical dementia rating. Psychopharmacology Bulletin 24 (4), 637–639.

Coen, R.F., O'Boyle, C.A., Coakley, D., Lawlor, B.A., 2002. Individual quality of life factors distinguishing low-burden and high-burden caregivers of dementia patients. Dementia and Geriatric Cognitive Disorders 13 (3), 164-170.

Cummings, J.L., Mega, M., Gray, K., Rosemberg-Thompson, S., Carusi, D.A., Gornbein, J., 1994. The neuropsychiatric inventory. Comprehensive assessment of psychopathology in dementia. Neurology 44 (12), 2308-2314.

Ferrario, S.R., Vitaliano, P., Zotti, A.M., Galante, E., Fornara, R., 2003. Alzheimer's disease: usefulness of the Family Strain Questionnaire and the Screen for Caregiver Burden in the study of caregiving-related problems. International Journal of Geriatric Psychiatry 18 (12), 1110-1114.

Folstein, M.F., Folstein, S.E., McHugh, P.R., 1975. "Mini Mental State". A practical method for grading the cognitive state of patients for the clinician. Journal of Psychiatry Research 12 (3), 189-198.

Fuh, J.L., Liu, C.K., Mega, M.S., Wang, S.J., Cummings, J.L., 2001. Behavioral disorders and caregivers' reaction in Taiwanese patients with Alzheimer's disease. International Psychogeriatrics 13 (1), 121-128.

Gallagher-Thompson, D., Coon, D.W., 2007. Evidence-based psychological treatments for distress in family caregivers of older adults. Psychology and Aging 22(1), 37-51.

Garre-Olmo, J., Hernández-Ferrándiz, M., Lozano-Gallego, M., Vilalta-Franch, J., Turón-Estrada, A., Cruz-Reina, M.M., Camps-Rovira, G., López-Pousa, S., 2000. Carga y calidad de vida en cuidadores de pacientes con demencia tipo Alzheimer. Revista de Neurología 31 (6), 522-527.

Garre-Olmo, J., López-Pousa, S., Vilalta-Franch, J., Turón-Estrada, A., Hernández-Ferrándiz, M., Lozano-Gallego, M., Fajardo-Tibau, C., Puig-Vidal, O., Moriente-Muñoz, V., Cruz-Reina, M.M., 2002. Carga del cuidador y síntomas depresivos en pacientes con enfermedad de Alzheimer. Evolución a los 12 meses. Revista de Neurología 34 (7), 601-607.

Gélinas, I., Gauthier, L., McIntyre, M., Gauthier, S., 1999. Development of a functional measure for persons with Alzheimer's disease: the Disability Assessment for Dementia. American Journal of Occupational Therapy 53 (5), 471-481.

Georges, J., Jansen, S., Jackson, J., Meyrieux, A., Sadowska, A., Selmes, M., 2008. Alzheimer's disease in real life—the dementia carer's survey. International Journal of Geriatric Psychiatry 23 (5), 546-551.

Gitlin, L. N., Corcoran, M., Winteer, L., Boyce, A., Hauck, W., 2001. A randomized, controlled trial of a home environmental intervention: effect on efficacy and upset in caregivers and daily function of persons with dementia. Gerontologist 41(1), 4-14.

Gitlin, L.N., Winter, L., Corcoran, M., Dennis, M. P., Schinfeld, S, Hauck, W.W., 2003. Effects of the home environmental skill-building program on the caregiver-care recipient dyad: 6-month outcomes from the Philadelphia REACH Initiative. Gerontologist, 43(4), 532-546.

Jorm, A.F., Scott, R., Henderson, A.S., Kay, D.W.K., 1988. Educational level differences on the Mini-Mental State: the role of the test bias. Psychological Medicine 18 (3), 727-731.

Lavoie, J. P., Ducharme, F., Lévesque, L., Hébert, R., Vézina, J., Gendron, C., Préville, M., St-Laurent, C., Voyer, L., 2005. Understanding the outcomes of a psycho-educational group intervention for caregivers of persons with dementia living at home: a process evaluation. Aging & Mental Health 9 (1), 25-34.

Lawton, M.P., Moss, M., Kleban, M.H., Glicksman, A., Rovine M., 1991. A two-factor model of caregiving appraisal and psychological well-being. Journal of Gerontology: Psychological Sciences 46 (4), 181-189.

Llinás Regla J., López Pousa S., Vilalta Franch J., 1995. The efficiency of CAMDEX in the diagnosis of dementia and its sub-types. Neurología 10 (3), 133-138.

Martín, M., Salvadó, I., Nadal, S., Miji, L.C., Rico, J.M., 1996. Adaptación para nuestro medio de la Escala de Carga del Cuidador (Caregiver Burden Interview) de Zarit. Revista de Gerontología 6 (4), 338-346.

Marwit, S.J., Meuser, T.M., 2002. Development and initial validation of an inventory to assess grief in caregivers of persons with Alzheimer's disease. Gerontologist 42 (6), 751-765.

McKhann, G., Drachman, D., Folstein, M., Katzman, R., Price, D., Stadlan, E.M., 1984. Clinical diagnosis of Alzheimer’s disease: report of the NINCDS-ADRDA Work Group under the auspices of Department of Health and Human Services task force on Alzheimer’s disease. Neurology 34 (7), 939–944.

Molyneux, G.J., McCarthy, G.M., McEniff, S., Cryan, M., Conroy, R.M., 2008. Prevalence and predictors of carer burden and depression in carers of patients referred to an old age psychiatric service. International Psychogeriatrics 20 (6), 1193-1202.

Montgomery, R.J., Kosloski, K., 1994. A longitudinal analysis of nursing home placement for dependent elders cared for by spouses vs. adult children. Journal of Gerontology: Social Sciences 49 (2), S 62-74.

Ott, C.H., Sanders, S., Kelber, S.T., 2007. Grief and personal growth experience of spouses and adult-child caregivers of individuals with Alzheimer's disease and related dementias. Gerontologist 47 (6), 798-809.

Pearlin, L.I., Mullan, J.T., Semple, S.J., Skaff, M.M., 1990. Caregiving and the stress process: an overview of concepts and their measures. Gerontologist 30 (5), 583–594.

Reisberg, B., Ferris, S.H., de Leon, M.J., Crook, T., 1982. The Global Deterioration Scale (GDS). Psychopharmacology Bulletin 24, 629–636.

Reisberg, B., Borenstein, J., Salob, S.P., Ferris, S.H., Franssen, E., Georgotas, A., 1987. Behavioral symptoms in Alzheimer's disease: phenomenology and treatment. Journal of Clinical Psychiatry 48 (suppl. 5), 9-15.

Rinaldi, P., Spazzafumo, L., Mastriforti, R., Mattioli, P., Marvardi, M., Polidori, M.C., Cherubini, A., Abate, G., Bartorelli, L., Bonaiuto, S., Capurso, A., Cucinotta, D., Gallucci, M., Giordano, M., Martorelli, M., Masaraki, G., Nieddu, A., Pettenati, C., Putzu, P., Tammaro, V.A., Tomassini, P.F., Vergani, C., Senin, U., Mecocci, P., 2005. Predictors of high level of burden and distress in caregivers of demented patients: results of an Italian multicenter study. International Journal of Geriatric Psychiatry 20 (2), 168-174.

Robinson, K.M., Buckwalter, K.C., Reed, D., 2005. Predictors of use of services among dementia caregivers. Western Journal of Nursing Research 27 (2), 126-140.

Roig, M.V., Abengózar, M.C., Serra, E., 1998. La sobrecarga en los cuidadores principales de enfermos de Alzheimer. Anales de Psicología 14 (2), 215-227.

Roth, M., Huppert, F.A., Tym, E., Mountjoy, C.Q., 1998. CAMDEX-R: The Cambridge Examination for Mental Disorder of the Elderly (Revised Edition). University Press, Cambridge.

Sanders, S., Ott, C.H., Kelber, S.T., Noonan, P., 2008. The experience of high levels of grief in caregivers of persons with Alzheimer's disease and related dementia. Death Studies 32 (6), 495-523.

Serrano-Aguilar, P.G., López-Bastida, J., Yanes-López, V., 2006. Impact on health-related quality of life and perceived burden of informal caregivers of individuals with Alzheimer's disease. Neuroepidemiology 27 (3), 136-142.

Skaff, M.M., Pearlin, L.I., 1992. Caregiving: role engulfment and the loss of self. Gerontologist 32 (5), 656-664.

Sörensen, S., Pinquart, M., Duberstein, P., 2002. How effective are interventions with caregivers? An updated meta-analysis. Gerontologist 42 (3), 356-372.

Schulz, R., Martire, L. M., 2004. Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. American Journal of Geriatric Psychiatry 12 (3), 240–249.

Teri, L., Mc Curry, S., Logsdon, R., Gibbons, L., 2005. Training community consultants to help family members improve dementia care: a randomized controlled trial. Gerontologist 45 (6), 802-811.

Thompson, C.A., Spilsbury, K., Hall, J., Birks, Y., Barnes, C., Adamson, J., 2007. Systematic review of information and support interventions for caregivers of people with dementia. BioMed Central Geriatrics 7 (18), 1-12.

Turró-Garriga, O., Soler-Cors, O., Garre-Olmo, J., López-Pousa, S., Vilalta-Franch, J., Monserrat-Vila, S., 2008. Distribución factorial de la carga en cuidadores de pacientes con enfermedad de Alzheimer. Revista de Neurología 46 (10), 582-588.

Vilalta-Franch, J., Llinàs-Reglà, J., López-Pousa, S., Amiel, J., Vidal, C., 1990. CAMDEX, validación de la adaptación española. Neurología 5 (4), 117-120.

Vilalta-Franch, J., Lozano-Gallego, M., Hernández-Ferrández, M., Llinàs-Reglà, J., López-Pousa, L., López, O.L., 1999. El inventario neuropsiquiátrico: propiedades psicométricas de su adaptación al castellano. Revista de Neurología 29 (1), 15-19.

Vilagut, G., Valderas, J. M., Ferrer, M., Garin, O., Lopez-Garcia, E., Alonso, J., 2008. Interpretación de los cuestionarios de salud SF-36 y SF-12 en España: componentes físico y mental. Med Clin (Barc) 130 (19), 726-735.

Ware, J.E. Jr., Kosinski, M., Keller, S.D., 1996. A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. Medical Care 34 (3), 220-233.

Winslow, B.W., 1997. Effects of Formal Supports on Stress Outcomes in Family Caregivers of Alzheimer's Patients. Research in Nursing & Health 20 (1), 27–37.

Zabalegui, A., Navarro, M., Cabrera, E., Gallart, A., Bardallo, D., Rodríguez, E., Gual, P., Fernández, M., Argemí, J., 2008. Eficacia de las intervenciones dirigidas a cuidadores principales de personas dependientes mayores de 65 años. Una revisión sistemática. Revista Española de Geriatría y Gerontología 43(3), 157-166.

Zarit, S.H, Todd, P.A., Zarit, J.M., 1986. Subjective burden of husbands and wives as caregivers: a longitudinal study. Gerontologist 26 (3), 260-266.

Zhu, C.W, Torgan, R., Scarmeas, N., Albert, M., Brandt, J., Blacker, D., Sano, M., Stern, Y., 2008. Home health and informal care utilization and costs over time in Alzheimer's disease. Home Health Care Services Quarterly 27 (1), 1-20.

Table 1

Socio-demographic characteristics of the participants

Patients (*N* = 251)	**Sp-CGs (*n* = 112)**	**ADch-CGs (*n* = 139)**
Age (years)		
Mean (*SD*)	75.38 (7.35)	79.56 (5.75)
Range	55-88	59-93
Gender, *n* (%)		
Male	65 (58.0)	20 (14.4)
Female	47 (42.0)	119 (85.6)
Marital status, *n* (%)		
Married	112 (100.0)	52 (37.4)
Widowed	....	86 (61.9)
Level of education, *n* (%)		
Illiterate/no schooling	25 (22.3)	29 (20.9)
< 8 years	71 (63.4)	100 (71.9)
≥ 8 years	16 (14.3)	10 (7.2)

Caregivers (*N* = 251)	**Sp-CGs (*n* = 112)**	**ADch-CGs (*n* = 139)**
Age (years)		
Mean (*SD*)	73.66 (7.48)	49.39 (7.29)
Range	56-87	28-65
Gender, *n* (%)		
Male	47 (42.0)	38 (27.3)
Female	65 (58.0)	101 (72.7)
Marital status, *n* (%)		
Married	112 (100.0)	106 (76.3)
Widowed	....	6 (4.3)
Single	....	15 (10.8)
Divorced	....	12 (8.6)
Level of education, *n* (%)		
Illiterate/no schooling	28 (25.0)	2 (1.4)
< 8 years	59 (52.7)	34 (24.5)
≥ 8 years	25 (22.3)	100 (71.9)
Living with the patient, *n* (%)		
Yes	112 (100.0)	55 (39.6)
Sole caregiver, *n* (%)		
Yes	94 (83.9)	57 (41.0)
Other family burdens, *n* (%)		
Yes	10 (8.9)	70 (50.4)
Employment status, *n* (%)		
Working	6 (5.4)	113 (81.3)

Sp-CGs = Spouse caregivers, ADch-CGs = Adult child caregivers

Table 2 *Clinical factors for patients and spouse/adult child caregivers*

Patient factors	**Sp-CGs(*n* = 112)**		**ADch-CGs(*n* = 139)**		**Differences**		**Cohen's d**
	M	*SD*	*M*	*SD*	*U*	*p*	*d*
DAD	81.54	10.43	80.62	11.02	-0.69	.489	
NPI							
A Delusions	0.12	0.91	0.46	1.64	-2.61	.009 **	0.25
B Hallucinations	0.09	0.80	0.18	1.10	-0.85	.391	
C Agit./Aggress.	0.83	1.85	1.08	2.32	-0.92	.358	
D Depression	1.15	2.04	1.77	3.05	-0.94	.343	
E Anxiety	0.69	1.67	0.82	1.85	-0.63	.525	
F Euphoria	0.05	0.39	0.02	0.23	-0.23	.815	
G Apathy	2.11	2.75	2.58	3.20	-1.06	.288	
H Disinhibition	0.21	1.04	0.32	1.11	-1.18	.236	
I Irritability	1.33	2.05	1.48	2.69	-0.30	.764	
J Aber. mot. beh.	0.22	1.16	0.39	1.39	-1.47	.142	
K Sleep/night beh.	0.89	2.03	0.77	2.15	-0.69	.489	
L App./eat. disturb.	1.02	2.53	1.16	2.35	-1.20	.228	
Total	8.75	9.05	11.10	13.24	-1.38	.228	
CAMCOG-R	56.82	12.34	54.79	10.99	-1.45	.145	
MMSE	18.26	4.33	17.97	4.08	-0.64	.521	
Time since onset (months)	34.69	26.85	29.38	22.09	-1.81	.069	
	n	*%*	*n*	*%*	x^2	*p*	
Severity of dementia							
Minimal	56	50.0	65	46.8	0.61	.433	
Mild	47	42.0	50	36.0			
Moderate	8	7.1	19	13.7			

Caregiver factors	**Sp-CGs(*n* = 112)**		**ADch-CGs(*n* = 139)**		**Differences**		**Cohen's d**
	M	*SD*	*M*	*SD*	*U*	*p*	*d*
Time spent caring (min/day)							
Basic ADLs	15.58	41.98	18.83	40.63	-0.96	.333	
Instrumental ADLs	62.14	71.53	63.21	66.36	-0.45	.649	
SF-12. Health							
Physical	46.20	9.78	52.83	7.48	-5.58	.000 ***	0.76
Mental	48.66	8.79	44.30	12.25	-2.50	.012 *	0.40
CBI. Total	37.82	10.39	41.97	13.04	-2.55	.011 *	0.35
F1. Social burden	11.59	4.60	13.36	6.05	-2.23	.025 *	0.32
F2. Psychol. stress	5.82	2.31	6.77	2.77	-2.95	.003 **	0.37
F3. Guilt	2.56	1.32	3.52	2.03	-4.45	.000 ***	0.56
F4. Pressure	4.31	1.87	4.76	2.27	-1-32	.185	
F5. Rel. Dependence	11.75	3.81	11.43	3.51	-0.64	.518	

* $p < .05$, ** $p < .01$, *** $p < .001$.

Sp-CGs = Spouse caregivers, ADch-CGs = Adult child caregivers, DAD = Disability Assessment for Dementia, NPI = Neuropsychiatric Inventory, CAMCOG-R = Cambridge Cognitive Examination–Revised, MMSE = Mini Mental State Examination, ADL = Activities of Daily Living, SF-12 = Short Form of Health Survey, CBI = Caregiver Burden Interview.

U = Mann Whitney, x^2 = Kruskal-Wallis, *d* = Cohen's effect size.

Table 3

Relationships between the CBI scores of spouse and adult child caregivers and the patient and caregiver factors

Patient factors	**Sp-CGs (*n* = 112)**			**ADch-CGs (*n* = 139)**			**Inter-group dif.**		
	n	*M*	*SD*	n	*M*	*SD*	U/x^2	*p*	*d*
Gender									
Male	65	39.80	11.14	20	41.15	14.26	-0.08	.930	
Female	47	35.08	8.64	119	42.10	12.88	-3.26	.001**	-0.64
Intra-group dif.	U = -2.05, p = .039* d = 0.473			U = -0.67, p = .530					
Time since onset of symptoms									
< 12 months	27	34.29	6.85	36	43.16	11.60	-3.38	.001**	-0.93
13-24 months	29	34.93	9.10	48	39.85	11.80	-1.59	.111	
25-36 months	24	39.62	11.20	27	40.37	12.73	-0.37	.706	
> 36 months	32	42.06	11.81	27	45.55	16.75	-0.53	.594	
Intra-group dif.	x^2 = 9.70, p = .021* d = -0.80			x^2 = 2.92, p = .40					
Clinical evaluation of severity									
Minimal	56	36.57	10.18	65	38.26	10.19	-0.97	.328	
Mild	47	38.93	10.42	50	44.54	15.26	-1.87	.060	
Moderate	8	41.50	11.25	19	48.31	13.31	-1.35	.175	
Intra-group dif.	x^2 = 2.86, p = .238			x^2 = 10.74, p = .005** d = -0.84					
	n	r_s	*p*	*n*	r_s	*p*			
DAD	112	-.41	.000***	139	-.36	.000***			
NPI	112			139					
A Delusions		.10	.275		.25	.002**			
C Agit./Aggress.		.22	.019*		.35	.000***			
F Euphoria		.02	.810		.17	.041*			
G Apathy		.44	.000***		.40	.000***			
H Disinhibition		.14	.134		.23	.006**			
I Irritability		.26	.004**	.31	.000***				
L Appetite		.36	.000***		.27	.001**			
Total		.50	.000***		.47	.000***			

Table 3 (cont.)

Relationships between the CBI scores of spouse and adult child caregivers and the patient and caregiver factors

Caregiver factors	**Sp-CGs (*n* = 112)**			**ADch-CGs (*n* = 139)**			**Inter-group dif.**		
	n	*M*	*SD*	n	*M*	*SD*	*U*/ x^2	*p*	*d*
Gender									
Male	47	35.08	8.64	38	43.84	14.15	-2.99	.003**	-0.74
Female	65	39.80	11.14	101	41.26	12.60	-0.76	.446	
Intra-group dif.	*U* = -2.05, *p* = .039* *d* = 0.473			*U* = -0.77, *p* = .437					
Living with patient									
Yes	112	37.82	10.39	55	46.94	11.70	-4.82	.000***	-0.82
No	....			84	38.71	12.90	....		
Intra-group dif.				*U* = -4.13, *p* = .000*** *d* = 0.688					
Sole caregiver									
Yes	90	38.03	10.78	56	42.01	11.74	-2.11	.034*	-0.35
No	22	36.95	8.78	82	41.87	13.99	-1.42	.155	
Intra-group dif.	*U* = -0.23, *p* = .812			*U* = -0.26, *p* = .790					
	n	*r*	*p*	*n*	*r*	*p*			
Time spent caring (min/day)									
BADLs	112	.17	.067	139	.23	.000***			
IADLs	112	.47	.000***	139	.37	.000***			
	n	r_s	*p*	*n*	r_s	*p*			
SF-12. Phys. health	112	-.11	.245	139	-.06	.460			
SF-12 Mental health	112	-.18	.054	139	-.50	.000***			
Anxiety symptoms		-.19	.041*		-.50	.000***			
Depressive symptoms		-.15	.102		-.48	.000***			
Dif. in social relat.		-.16	.092		-.35	.000***			

* $p < .05$, ** $p < .01$, *** $p < .001$.

Sp-CGs = Spouse caregivers, ADch-CGs = Adult child caregivers, CBI = Caregiver Burden Interview, CAMCOG-R = Cambridge Cognitive Examination–Revised, MMSE = Mini Mental State Examination, DAD = Disability Assessment for Dementia, NPI = Neuropsychiatric Inventory, BADLs = Basic Activities of Daily Living, IADLs = Instrumental Activities of Daily Living, SF-12 = Short Form of Health Survey.

U = Mann Whitney, x^2 = Kruskal-Wallis, *d* = Cohen's effect size, *r* = Pearson's coefficient, r_s = Spearman's coefficient.

Table 4

Gender and family relationship of caregivers. Burden and mental health

Caregivers		**Burden Total (CBI)**		**Mental health Total (SF-12)**	
	n	*M*	*SD*	*M*	*SD*
Husbands	47	35.08	8.64	50.31	8.59
Wives	65	39.80	11.14	47.47	8.80
Daughters	101	41.26	12.60	44.87	12.79
Sons	38	43.84	14.15	42.79	10.70
		x^2 = 11.15, *p* = .011* *d* = 0.74		x^2 = 12.56, *p* = .006** *d* = 0.77	

Caregivers	**Correlations CBI / SF-12**							
	Total mental health		Anxiety symptoms		Depressive symptoms		Difficulties in social relationship	
	r_s	*p*	r_s	*p*	r_s	*p*	r_s	*p*
Husbands	.04	.752	.11	.444	.13	.382	.15	.314
Wives	-.28	.022*	.17	.168	.27	.025*	.16	.178
Sons	-.35	.028*	.51	.001**	.33	.039*	.25	.128
Daughters	-.54	.000***	.50	.000***	.53	.000***	.38	.000***

* *p* < .05, ** *p* < .01, ****p* < .001.

CBI = Caregiver Burden Interview, SF-12 = Short Form of Health Survey.

x^2 = Kruskal-Wallis, *d* = Cohen's effect size, r_s = Spearman's coefficient.

Table 5

Multivariate linear regression model. CBI scores of spouse and adult child caregivers with patient and caregiver factors

	Sp-CGs (n = 112)			ADch-CGs (n = 139)		
	β	p	95% CI	β	p	95% CI
	r^2 = .49			r^2 = .54		
Patient factors						
NPI-G Apathy	.24	.006**	0.27 / 1.58	.11	.090	-0.07 / 1.04
NPI-H Disinhibition	.04	.548	-0.99 / 1.86	.16	.013*	0.42 / 3.44
NPI-I Irritability	.23	.002**	0.43 / 1.94	.17	.013*	0.18 / 1.49
NPI-L Appetite disturb.	.15	.048*	0.00 / 1.27	.10	.109	-0.13 / 1.33
Caregiver factors						
Living with patient	....			.20	.001**	2.17 / 8.83
Time spent on BADLs	.01	.878	-0.03 / 0.04	.14	.029*	0.00 / 0.09
Time spent on IADLs	.33	.000***	0.02 / 0.07	.10	.137	-0.00 / 0.04
SF-12 Physical health	-.10	.146	-0.27 / 0.04	-.14	.023*	-0.47/ -0.03
SF-12 Mental health	-.18	.011*	-0.39 /-0.05	-.36	.000***	-0.53 /-0.24

* $p < .05$, ** $p < .01$, *** $p < .001$.

Sp-CGs = Spouse caregivers, ADch-CGs = Adult child caregivers, CBI = Caregiver Burden Interview, NPI = Neuropsychiatric Inventory, BADLs = Basic Activities of Daily Living, IADLs = Instrumental Activities of Daily Living, SF-12 = Short Form of Health Survey.

r^2 = Determination coefficient of the multivariate model, β = Standardised beta coefficient, CI = Confidence interval.

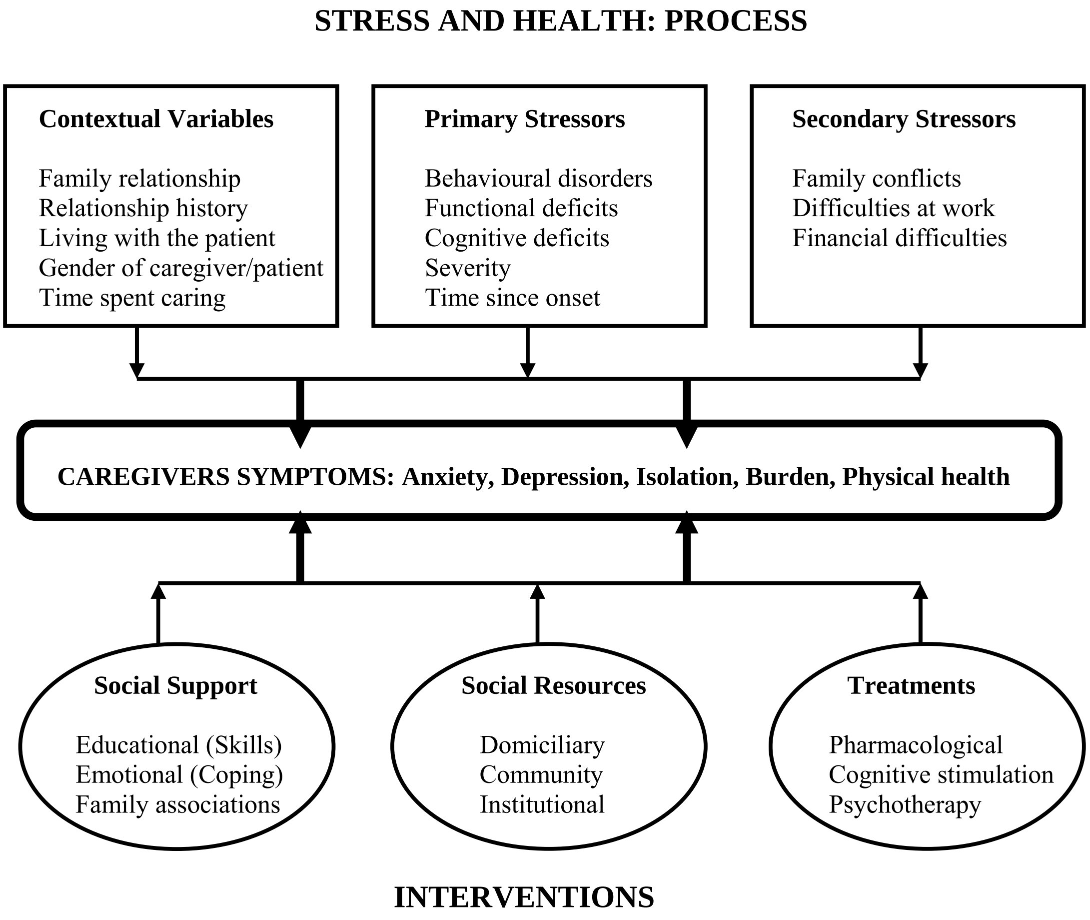

Figure 1. Theoretical Framework and Interventions