

Quality of Life of Patients with Alzheimer's Disease: Differential Perceptions between Spouse and Adult Child Caregivers

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Key Words

Quality of life • Caregivers • Alzheimer's disease

Abstract

Background/Aims: Little research has been conducted into differences in the perceived quality of life of patients (QoL-p) when comparing spouse and adult child caregivers of people with Alzheimer's disease (AD). The aim of this study was to identify the differential variables in perceived QoL-p between patients and carers, distinguishing between spouse and adult child caregivers. **Method:** Cross-sectional analytic study of 251 patients and their carers (spouses: 112; adult children: 139) using the QoL-AD scale and sociodemographic and clinical data. **Results:** The more positive perception of spouses was associated with higher educational levels of the caregiver and greater functional autonomy in the patient. The more negative perception of adult children was associated with greater caregiver burden and higher levels of depression in the patient. The perception of daughter caregivers showed the strongest association with mental health and burden. **Conclusions:** Spouse caregivers have a more positive perception of the patient's quality of life than adult child caregivers.

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Introduction

Studies of the quality of life of patients (QoL-p) with Alzheimer's disease (AD), in which the perception of patients is compared with that of family caregivers, have shown differences in the perceived QoL-p (higher scores among patients) and low concordance rates (intraclass correlation coefficients, ICCs, and κ index) [1–14]. Among caregivers, the more negative perception of QoL-p has been related to higher levels of depression, the presence of psychological and behavioral symptoms, and functional deficits in patients. It has also been associated with higher levels of depression and burden alongside poorer physical and mental health in caregivers themselves. In patients, the personal factors reported as having a negative relationship with their perceived QoL are depression, apathy and functional deficits.

Studies that have compared patients and professional caregivers as regards their perception of QoL-p have obtained similar results: patients had a more positive view of their own QoL than professionals [15]. Greater anxiety and depression in patients was related with a more negative perception of QoL-p among patients themselves, while functional deficits and behavioral disorders in the

patient were associated with a more negative perception of QoL-p among professional caregivers.

The relationship between caregiver and patient and its potential effect on perceived QoL-p has been less widely studied. One study reported that spouse caregivers scored higher on perceived QoL-p [16], while another found that the level of agreement between the scores of patients and caregivers as regards QoL-p was higher among spouses than in adult children [17].

A preliminary study of the global perception of patients and caregivers regarding QoL-p found that the variable 'family relationship' produced significant differences [18]. Therefore, using a sample of non-institutionalized patients with mild or moderate AD, the first goal of the present research was to conduct a more specific analysis of the factors that determine the differences in perceived QoL-p, both among and between these different caregiver groups. A second objective was to analyze burden and mental health in the caregiver subgroups according to gender and relationship to the patient (husbands, wives, sons and daughters), and to determine any correlations with perceptions regarding the patient's QoL.

To the best of our knowledge, the literature to date contains no reports of a systematic evaluation, including a large number of sociodemographic and clinical variables, of differences in perceived QoL-p between spouse and adult child caregivers. Identifying differential variables in the perception of QoL-p could be useful in terms of modifying and optimizing not only the educational and emotional support services offered to relatives, but also the pharmacological treatment of patients, especially as regards the behavioral and psychological symptoms of dementia.

Method

Design and Study Population

The research design was a cross-sectional analytic study. The sample comprised 251 patients diagnosed with AD according to DSM-IV criteria [19] or probable AD according to criteria of the National Institute of Neurological and Communicative Disorders and Stroke/Alzheimer's Disease and Related Disorders Associations [20], as well as their respective caregiver relatives (total caregivers, $n = 251$; spouse, $n = 112$; adult child, $n = 139$). Of the initial sample ($n = 279$), 28 cases (10.03%) were excluded as they were cared for by a relative or another person who was not the spouse or an adult child of the patient.

All clinical subjects had been referred on an outpatient 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 AD, 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. All the patients and caregivers were able to complete the Quality of Life in Alzheimer's Disease (QoL-AD) scale. The study data correspond to baseline interviews conducted during the period 2003–2008.

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. The patient and caregiver data were obtained through individual interviews, and the assessment instruments (scales and questionnaires) were administered by a clinical research team based in the hospital.

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.

Measures

Measuring QoL. The Quality of Life in AD (QoL-AD) scale was administered to patients and caregivers in order to assess their perception of the QoL of the AD patient. The scale consists of 13 items that reflect the subject's perception of different aspects related to well-being: physical health, energy, mood, living conditions, memory, family, marriage, friends, self as a whole, ability to do chores around the house, ability to do things for fun, income, and life as a whole. Scores for each item range from 1 to 4, and thus the total score ranges between 13 and 52 [7, 21, 22].

Sociodemographic Analysis. The sociodemographic 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 (CAMDEX-R) [23]. In this case, the Spanish adaptation of this instrument was used [24].

Cognitive Assessment. Cognitive assessment was based on 2 instruments, the first being the Cambridge Cognitive Examination-Revised. This forms part of the CAMDEX-R and assesses various cognitive functions, with scores ranging from 0 to 107. The lower the score the greater the cognitive impairment, with the cutoff point for the Spanish population being 68/69 [24]. The second instrument was the MMSE [25]. This is a brief cognitive assessment tool has scores ranging from 0 to 30, the cutoff point for cognitive impairment being 21/22. Here, it was used to observe the correlation with caregiver burden and to assess the degree of cognitive impairment according to the criteria proposed [26].

Functional Assessment. Functional assessment of the patient was based on the Disability Assessment for Dementia [27]. This scale offers a broad assessment of daily living activities: basic, instrumental and leisure. It comprises 40 items and scores range between 0 and 80 points, which are transformed into percentages. The higher the score, the greater the ability in activities of daily living.

Behavioral and Psychological Symptoms of Dementia. Symptomatology was assessed using the Spanish adaptation [28] of the

Neuropsychiatric Inventory [29]. This tool, which was administered to caregivers, comprises 12 subscales that assess the presence of delusions, hallucinations, agitation/aggression, depression, anxiety, euphoria, apathy, disinhibition, irritability, aberrant motor behavior, sleep/nighttime behavior and appetite/eating disturbances. The overall score ranges between 0 and 144.

Physical and Mental Health of Caregivers. This was assessed using the Spanish adaptation [30] of the Health Survey [31]. 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 12 items, and scores range between 12 and 28. Two global dimensions can be obtained from the direct scores: physical health and mental health. For both dimensions, scores range from 0 to 100, and the higher the score the better the perceived health.

Caregiver Burden. Burden was assessed using the Caregiver Burden Interview (CBI) [32], which has been validated for the Spanish population [33]. This is a self-report instrument that comprises 22 items which are scored on a 5-point Likert scale: never (1), rarely (2), sometimes (3), quite frequently (4), and nearly always (5). Caregivers are asked to indicate how they usually feel with respect to each statement. Scores range from 22 to 110, and the higher the score the greater the perceived burden of the caregiver.

For the internal analysis of the CBI, we used the subscales indicated by a previous factor analysis [34]: factor 1, social burden; factor 2, psychological stress; factor 3, feelings of guilt; factor 4, emotional pressure; and factor 5, relationship of dependency. Factor 1 (social burden) covered the questions about the degree to which the caregiver's social life was affected (items 2, 3, 6, 10, 11, 12, 13 and 17) and it explained 32.9% of the total variance, with an internal consistency coefficient (Cronbach's α) of 0.90. Factor 2 (psychological stress) referred to the degree of stress experienced by the caregiver (items 15, 16, 18 and 19) and it explained 9.1% of the variance, with $\alpha = 0.73$. Factor 3 (feelings of guilt) described the caregiver's feelings (items 20 and 21) and it explained 6.5% of the variance, with $\alpha = 0.90$. Factor 4 (emotional pressure) grouped together the questions about the emotional effect on the caregiver (items 5, 4 and 9) and it explained 5.9% of the variance, with $\alpha = 0.68$. Finally, factor 5 (relationship of dependency) referred to the patient's dependence on the caregiver (items 1, 7, 8 and 14) and it explained 5.3% of the variance, with $\alpha = 0.59$.

Questionnaire about Social Services, Healthcare and Informal Care. This is a questionnaire developed by the Memory and Dementia Assessment Unit to evaluate the resources used by informal caregivers: medical care, day centers and time spent on activities of daily living (both basic and instrumental).

Statistical Analysis

The relationships between the scores of patients and caregivers on the QoL-AD scale and the respective sociodemographic and clinical factors were analyzed by means of the non-parametric Mann-Whitney U and Kruskal-Wallis H tests. When significant differences were observed in the comparison of 2 means, Cohen's *d* was then calculated as a measure of effect size. The correlations between QoL-AD-p scores and the other variables were analyzed 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.

The concordance between total scores on the QoL-AD scale for patients versus caregivers was assessed by calculating the ICCs, while the concordance between items was evaluated by means of the κ index.

The effect of the variables on perceived QoL-p in patients and caregivers was determined by conducting a multivariate regression analysis. Global analyses were performed for caregivers and patients, and also for the 2 subgroups of caregivers (spouses and adult children), including the combined patient and caregiver variables in each of the 6 analyses. The dependent variables were the scores on the QoL-AD scale obtained by patients and caregivers, while the independent variables were those shown to be significant in the bivariate analysis. The multivariate regression analysis was performed using SPSS v.17.0 and the 'stepwise' method, which eliminates non-significant variables and/or those with a high degree of collinearity. The values of the non-significant variables were calculated using the 'enter' method, introducing them together with the significant variables from the regression.

The level of significance was set at $p < 0.05$ for all hypothesis contrasts.

Results

Description of the Sample

The sample comprised 251 patients and their main caregivers. The subgroup of spouse caregivers had 112 patients, while the remaining 139 patients had adult child caregivers. The overall data for caregivers were as follows: gender: male 33.8%, female 66.1%; family relationship: spouses 44.6%, adult children 55.3%.

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 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 sociodemographic data are shown in table 1.

Clinical Factors for Patients and Caregivers in the Spouse and Adult Child Groups

There were no significant differences between the 2 groups of patients (i.e. those cared for by spouses vs. adult children) with respect to functional capacities, behavioral and psychological symptoms (except for delusions), cognitive functioning, time since symptom onset, or the clinical evaluation of dementia. Therefore, any differences in the patient and caregiver perceptions of QoL could not be attributed to differences in the clinical characteristics of the patients in the 2 caregiver groups (table 2).

The differences between the 2 groups were mainly observed in caregiver factors. Adult child caregivers scored

Table 1. Sociodemographic characteristics of participants

| | Spouse caregivers (n = 112) | Adult child caregivers (n = 139) |
|-----------------------------|--------------------------------|-------------------------------------|
| <i>Patients (n = 251)</i> | | |
| Age, years | | |
| Mean \pm SD | 75.3 \pm 7.3 | 79.5 \pm 5.7 |
| Range | 55–88 | 59–93 |
| Gender | | |
| Women | 47 (42.0) | 119 (85.6) |
| Marital status | | |
| Married | 112 (100.0) | 52 (37.4) |
| Widowed | – | 86 (61.9) |
| Divorced | – | 1 (0.7) |
| Living situation | | |
| With spouse only | 112 (100.0) | 36 (25.9) |
| With adult children | – | 55 (39.6) |
| Alone | – | 36 (25.9) |
| With other family | – | 12 (8.6) |
| Level of education | | |
| Illiterate/no schooling | 25 (22.3) | 29 (20.9) |
| <8 years | 71 (63.4) | 100 (71.9) |
| \geq 8 years | 16 (14.3) | 10 (7.2) |
| <i>Caregivers (n = 251)</i> | | |
| Age, years | | |
| Mean \pm SD | 73.6 \pm 7.4 | 49.3 \pm 7.2 |
| Range | 56–87 | 28–65 |
| Gender | | |
| Women | 65 (58.0) | 101 (72.7) |
| Marital status | | |
| Married | 112 (100.0) | 106 (76.3) |
| Widowed | – | 6 (4.3) |
| Single | – | 15 (10.8) |
| Divorced | – | 12 (8.6) |
| Level of education | | |
| Illiterate/no schooling | 28 (25.0) | 2 (1.4) |
| <8 years | 59 (52.7) | 34 (24.5) |
| \geq 8 years | 25 (22.3) | 100 (71.9) |
| Living with the patient | | |
| Yes | 112 (100.0) | 55 (39.6) |
| Sole caregiver | | |
| Yes | 94 (83.9) | 57 (41.0) |
| Other family burdens | | |
| Yes | 10 (8.9) | 70 (50.4) |
| Employment status | | |
| Working | 6 (5.4) | 113 (81.3) |

Figures in parentheses are percentages.

higher on physical health (with a medium/high effect size), while spouse caregivers had better scores on mental health. Global burden (CBI) was greater among adult children, and they scored higher on the following subscales: F1, social burden; F2, psychological stress; F3, feel-

ings of guilt. The most significant differences were observed in this latter factor. No differences between spouses and adult children were observed as regards the time spent on helping with activities of daily living (table 2).

Global Perception of QoL for Patients and Caregivers

The global perception of QoL-AD-p for caregivers as a whole (mean \pm SD: 31.84 \pm 5.0) was worse than that for patients as a whole (34.75 \pm 4.5), this difference being significant ($z = -7.83$, $p < 0.001$, $d = 0.66$).

Table 3 presents the findings regarding the perception of caregivers and patients and the differences between the groups of spouse and adult child caregivers. Spouse caregivers had a more positive perception of QoL-p than adult children, both globally (33.0 vs. 30.8, $U = -3.37$, $p = 0.001$, $d = 0.46$) and on the items 'marriage', 'self as a whole', 'friends', 'life as a whole' and 'income'. The patients' own perceptions of QoL-p were also more positive in the group cared for by spouses, both globally (35.7 vs. 33.9, $U = -2.98$, $p = 0.003$, $d = 0.39$) and on the items 'marriage', 'life as a whole', 'ability to do things for fun', 'living conditions' and 'mood'.

As regards the differences in perceived QoL-p between caregivers and patients, and considering the 2 subgroups of spouse and adult child caregivers, the level of agreement (as measured by the κ index and the ICCs) between the scores of caregivers and patients was low, although slightly higher in the subgroup of spouse caregivers. The correlation between the scores of caregivers and patients was also slightly higher among spouse compared to adult child caregivers. In the group of spouse caregivers, the greatest differences between caregivers and patients were found in the global score (33.0 vs. 35.7, $T = -5.52$, $p < 0.001$, $d = 0.61$) and on the items 'memory', 'mood' and 'ability to do things for fun'. In the group of adult child caregivers, the differences between caregivers and patients were also greater on the global score (30.8 vs. 33.9, $T = -5.75$, $p < 0.001$, $d = 0.62$) and on a larger number of items, with highly significant differences on 'memory', 'ability to do chores', 'self as a whole', 'friends', 'family' and 'marriage'.

Gender and Family Relationship of Caregivers with Respect to Perceived QoL-p, Burden and Mental Health

We then analyzed the scores of the caregiver subgroups (husbands, wives, sons and daughters) as regards perceived QoL, burden and mental health. Overall results were analyzed and correlations between these variables were calculated (table 4).

Table 2. Clinical factors of patients and caregivers

| | n | Spouse caregivers (n = 112) | n | Adult child caregivers (n = 139) | Intergroup differences | | |
|---|----|--------------------------------|----|-------------------------------------|------------------------|-----------|------|
| | | | | | U | p | d |
| <i>Patient factors</i> | | | | | | | |
| Disability Assessment for Dementia Neuropsychiatric Inventory | | 81.5 ± 10.4 | | 80.6 ± 11.0 | -0.69 | 0.489 | |
| A Delusions | | 0.1 ± 0.9 | | 0.4 ± 1.6 | -2.61 | 0.009** | 0.25 |
| B Hallucinations | | 0.0 ± 0.8 | | 0.1 ± 1.1 | -0.85 | 0.391 | |
| C Agitation/aggression | | 0.8 ± 1.8 | | 1.0 ± 2.3 | -0.92 | 0.358 | |
| D Depression | | 1.1 ± 2.0 | | 1.7 ± 3.0 | -0.94 | 0.343 | |
| E Anxiety | | 0.6 ± 1.6 | | 0.8 ± 1.8 | -0.63 | 0.525 | |
| F Euphoria | | 0.0 ± 0.3 | | 0.0 ± 0.2 | -0.23 | 0.815 | |
| G Apathy | | 2.1 ± 2.7 | | 2.5 ± 3.2 | -1.06 | 0.288 | |
| H Disinhibition | | 0.2 ± 1.0 | | 0.3 ± 1.1 | -1.18 | 0.236 | |
| I Irritability | | 1.3 ± 2.0 | | 1.4 ± 2.6 | -0.30 | 0.764 | |
| J Aberrant motor behavior | | 0.2 ± 1.1 | | 0.3 ± 1.3 | -1.47 | 0.142 | |
| K Sleep/night behavior | | 0.8 ± 2.0 | | 0.7 ± 2.1 | -0.69 | 0.489 | |
| L Appetite/eating disturbances | | 1.0 ± 2.5 | | 1.1 ± 2.3 | -1.20 | 0.228 | |
| Total | | 8.7 ± 9.0 | | 11.1 ± 13.2 | -1.38 | 0.228 | |
| Cambridge Cognitive Examination-Revised MMSE | | 56.8 ± 12.3 | | 54.7 ± 10.9 | -1.45 | 0.145 | |
| Time since onset of dementia (months) | | 34.6 ± 26.8 | | 29.3 ± 22.0 | -1.81 | 0.060 | |
| MMSE/Levels | | | | | | | |
| >24, GDS 3 | 12 | 25.4 ± 1.6 | 14 | 25.0 ± 0.9 | -0.16 | 0.871 | |
| 15-23, GDS 4 | 80 | 18.8 ± 2.4 | 93 | 18.7 ± 2.3 | -0.02 | 0.978 | |
| 10-14, GDS 5 | 20 | 11.8 ± 2.3 | 32 | 12.5 ± 1.5 | -0.90 | 0.368 | |
| <i>Caregiver factors</i> | | | | | | | |
| SF-12 physical | | 46.2 ± 9.7 | | 52.8 ± 7.4 | -5.58 | <0.001*** | 0.76 |
| SF-12 mental | | 48.6 ± 8.7 | | 44.3 ± 12.2 | -2.50 | 0.012* | 0.40 |
| Time spent caring, min/day | | | | | | | |
| Basic ADL | | 15.5 ± 41.9 | | 18.8 ± 40.6 | -1.02 | 0.334 | |
| Instrumental ADL | | 62.1 ± 71.5 | | 63.2 ± 66.3 | -0.38 | 0.703 | |
| CBI total | | 37.8 ± 10.3 | | 41.9 ± 13.0 | -2.55 | 0.011* | 0.35 |
| F1 Social burden | | 11.5 ± 4.6 | | 13.3 ± 6.0 | -2.23 | 0.025* | 0.32 |
| F2 Psychological stress | | 5.8 ± 2.3 | | 6.7 ± 2.7 | -2.95 | 0.003** | 0.37 |
| F3 Guilt | | 2.5 ± 1.3 | | 3.5 ± 2.0 | -4.45 | <0.001*** | 0.56 |
| F4 Emotional pressure | | 4.3 ± 1.8 | | 4.7 ± 2.2 | -1.32 | 0.185 | |
| F5 Relationship of dependence | | 11.7 ± 3.8 | | 11.4 ± 3.5 | -0.64 | 0.518 | |

Data presented as means ± SD. GDS = Global Deterioration Scale; ADL = activities of daily living. * p < 0.05, ** p < 0.01, *** p < 0.001.

Perceived QoL. Wife caregivers had the most positive perception of QoL-p, while daughter caregivers had the most negative. Patients in the subgroup of wife caregivers also had a more positive perception of their own QoL, whereas the most negative perception was that of patients who were cared for by their son. The greatest differences between caregivers and patients were observed among wife ($T = 5.20$, $p < 0.001$, $d = 0.90$) and daughter caregivers ($T = 5.17$, $p < 0.001$, $d = 0.67$).

Burden, Mental Health and Perceived QoL-p. Husbands, wives, daughters and sons, in this order, reported progressively greater burden ($\chi^2 = 11.15$, $p = 0.011$, $d = 0.74$) and progressively worse mental health ($\chi^2 = 12.56$, $p = 0.006$, $d = 0.77$). The 2 variables, burden and mental health, therefore, showed a completely inverse relationship.

However, when analyzing the correlations between perceived QoL-p and both burden and mental health, the

Table 3. QoL-p as perceived by caregivers and patients and differences between spouse and adult child caregivers**a** QoL-p assessed by caregivers and patients

| | Spouse caregivers (n = 112) | Adult child caregivers (n = 139) | Intergroup differences | | |
|---------------------------------|--------------------------------|-------------------------------------|------------------------|----------------|-------------|
| | | | U | p | d |
| Perception of caregivers | | | | | |
| Physical health | 2.6 ± 0.6 | 2.4 ± 0.7 | -1.54 | 0.123 | |
| Energy | 2.4 ± 0.6 | 2.3 ± 0.7 | -0.83 | 0.402 | |
| Mood | 2.2 ± 0.6 | 2.1 ± 0.7 | -0.59 | 0.553 | |
| Living conditions | 2.7 ± 0.4 | 2.7 ± 0.6 | -0.79 | 0.424 | |
| Memory | 1.5 ± 0.5 | 1.6 ± 0.5 | -0.66 | 0.504 | |
| Family | 2.9 ± 0.5 | 2.8 ± 0.6 | -1.54 | 0.123 | |
| Marriage (children, n = 52) | 3.0 ± 0.5 | 2.5 ± 0.7 | -4.06 | <0.001*** | 0.68 |
| Friends | 2.8 ± 0.6 | 2.5 ± 0.8 | -3.31 | 0.001** | 0.43 |
| Self as a whole | 2.7 ± 0.4 | 2.3 ± 0.6 | -4.06 | <0.001*** | 0.55 |
| Ability to do chores | 2.3 ± 0.7 | 2.2 ± 0.6 | -1.40 | 0.160 | |
| Ability to do things for fun | 2.1 ± 0.8 | 1.9 ± 0.8 | -1.32 | 0.186 | |
| Income | 2.7 ± 0.6 | 2.6 ± 0.6 | -2.36 | 0.018* | 0.26 |
| Life as a whole | 2.7 ± 0.5 | 2.4 ± 0.6 | -3.08 | 0.002** | 0.43 |
| Total | 33.0 ± 4.4 | 30.8 ± 5.2 | -3.37 | 0.001** | 0.46 |
| Perception of patients | | | | | |
| Physical health | 2.7 ± 0.6 | 2.5 ± 0.6 | -1.75 | 0.080 | |
| Energy | 2.5 ± 0.6 | 2.4 ± 0.6 | -1.78 | 0.075 | |
| Mood | 2.5 ± 0.6 | 2.3 ± 0.7 | -2.09 | 0.036* | 0.28 |
| Living conditions | 2.8 ± 0.5 | 2.7 ± 0.5 | -2.60 | 0.009** | 0.33 |
| Memory | 1.9 ± 0.6 | 2.0 ± 0.6 | -0.52 | 0.600 | |
| Family | 3.1 ± 0.4 | 3.1 ± 0.5 | -0.45 | 0.652 | |
| Marriage (children, n = 52) | 3.2 ± 0.5 | 2.8 ± 0.6 | -5.21 | <0.001** | 0.71 |
| Friends | 3.0 ± 0.4 | 2.9 ± 0.6 | -1.21 | 0.226 | |
| Self as a whole | 2.8 ± 0.4 | 2.7 ± 0.5 | -1.94 | 0.052 | |
| Ability to do chores | 2.6 ± 0.6 | 2.6 ± 0.6 | -0.04 | 0.967 | |
| Ability to do things for fun | 2.4 ± 0.6 | 2.2 ± 0.7 | -2.60 | 0.009** | 0.32 |
| Income | 2.7 ± 0.4 | 2.7 ± 0.5 | -0.75 | 0.453 | |
| Life as a whole | 2.8 ± 0.4 | 2.6 ± 0.5 | -2.84 | 0.004** | 0.38 |
| Total | 35.7 ± 4.1 | 33.9 ± 4.6 | -2.98 | 0.003** | 0.39 |

order of the subgroups changed. Although, in absolute terms, the greatest burden and the worst mental health corresponded to son caregivers, it was daughter caregivers who showed the highest correlations between perceived QoL-p and burden ($r_s = -0.59$, $p < 0.001$), global mental health ($r_s = 0.42$, $p < 0.001$) and the 'downhearted and blue' item ($r_s = 0.48$, $p < 0.001$). Burden also showed a high correlation with QoL-p among husbands ($r_s = -0.54$, $p < 0.001$) and wives ($r_s = -0.55$, $p < 0.001$).

Multivariate Linear Regression Analysis of QoL-AD for Patients and Caregivers

In the bivariate analysis of patients and caregivers considered as a whole, a number of variables were shown

to be significant. In patients, these were marital status and living situation, while for caregivers the significant variables were living with the patient, other family burdens and being the sole caregiver. However, these variables were not significant in the bivariate analysis of the spouse and adult child caregiver subgroups. Neither were they significant in the multivariate linear regression analysis for patients and caregivers as a whole, nor when considering the spouse and adult child caregiver groups separately. In contrast, the variable 'relationship between the caregiver and the patient' (i.e. spouse vs. adult child) was retained in the regression analysis when considering perceived QoL-p for both the caregiver ($\beta = -0.19$, $p = 0.001$) and the patient ($\beta = -0.27$, $p < 0.001$).

Table 3 (continued)

b Differences between patient and caregiver perceptions in the spouse and adult child groups

| | Spouse caregivers (n = 112) | | | | Adult child caregivers (n = 139) | | | |
|-----------------------------|-----------------------------|----------|-----------|------------------|----------------------------------|----------|-----------|------------------|
| | κ | Wilcoxon | | Cohen's <i>d</i> | κ | Wilcoxon | | Cohen's <i>d</i> |
| | | <i>T</i> | <i>p</i> | | | <i>T</i> | <i>p</i> | |
| Physical health | 0.32 | -1.97 | 0.048* | 0.19 | 0.14 | -0.83 | 0.404 | |
| Energy | 0.20 | -2.42 | 0.015* | 0.26 | 0.19 | -1.77 | 0.075 | |
| Mood | 0.35 | -4.89 | <0.001*** | 0.56 | 0.22 | -3.25 | 0.001** | 0.31 |
| Living conditions | 0.18 | -1.59 | 0.124 | | 0.02 | -0.46 | 0.644 | |
| Memory | 0.14 | -4.71 | <0.001*** | 0.69 | 0.00 | -5.70 | <0.001*** | 0.72 |
| Family | 0.19 | -2.89 | 0.004** | 0.37 | 0.02 | -3.91 | <0.001*** | 0.46 |
| Marriage (children, n = 52) | 0.21 | -2.89 | 0.004** | 0.31 | 0.22 | -5.50 | <0.001*** | 0.33 |
| Friends | 0.25 | -2.73 | 0.006** | 0.31 | 0.15 | -4.84 | <0.001*** | 0.53 |
| Self as a whole | 0.25 | -2.40 | 0.016* | 0.27 | 0.13 | -4.92 | <0.001*** | 0.58 |
| Ability to do chores | 0.24 | -3.20 | 0.001** | 0.38 | 0.16 | -5.41 | <0.001*** | 0.59 |
| Ability do things for fun | 0.20 | -4.00 | <0.001*** | 0.46 | 0.18 | -3.07 | 0.002** | 0.33 |
| Income | 0.13 | -0.38 | 0.700 | | 0.04 | -2.11 | 0.034* | 0.23 |
| Life as a whole | 0.15 | -2.12 | 0.034* | 0.27 | 0.17 | -2.79 | 0.005** | 0.32 |
| Total | | -5.52 | <0.001*** | 0.61 | | -5.75 | <0.001*** | 0.62 |

| | ICC | CI | ICC | CI |
|------------------------|------|-----------|------|-----------|
| ICC absolute agreement | 0.34 | 0.11-0.52 | 0.31 | 0.10-0.48 |
| ICC consistency | 0.41 | 0.24-0.55 | 0.37 | 0.21-0.50 |
| Spearman's correlation | 0.38 | <0.001*** | 0.33 | <0.001*** |

Where indicated, data presented as means ± SD. *T* = Wilcoxon test. * *p* < 0.05, ** *p* < 0.01, *** *p* < 0.001.

Table 5 shows the global results for patients and caregivers, as well as those for the spouse and adult child subgroups.

Perception of Caregivers. For caregivers as a whole, the most positive perception of QoL-p was associated with a higher educational level in the caregiver ($\beta = 0.19, p < 0.001$) and greater functional autonomy in the patient ($\beta = 0.35, p < 0.001$). The most negative perception was associated with greater burden in the caregiver (factor 2, psychological stress, $\beta = 0.23, p < 0.001$) and being an adult child caregiver ($\beta = -0.19, p = 0.015$), as well as with depression ($\beta = -0.24, p < 0.001$) and apathy ($\beta = -0.21, p < 0.001$) in the patient.

With respect to the caregiver subgroups, the above-mentioned positive perception associated with a higher educational level ($\beta = 0.20, p = 0.002$) in the caregiver and greater functional autonomy in the patient was more marked in the group of spouse caregivers ($\beta = 0.51, p < 0.001$). In contrast to the above, greater psychological stress ($\beta = -0.28, p < 0.001$) in the caregiver and higher levels of depression ($\beta = -0.31, p < 0.001$) in the

patient were associated with a worse perception of QoL-p, this effect being more marked among adult child caregivers.

Among the factors specific to the group of adult child caregivers, mention should be made of greater caregiver burden (factor 2: psychological stress; factor 3: feelings of guilt), which had a negative effect on perceived QoL-p. The specific factors related to the group of spouse caregivers were a lower cognitive level and greater eating disturbances in the patient ($\beta = -0.15, p = 0.023$).

Perception of Patients. Having an adult child caregiver was associated with more negative perceptions of QoL-p ($\beta = -0.27, p < 0.001$). The patient factor that was correlated with the most negative perception of QoL-p was depression ($\beta = -0.32, p < 0.001$).

A factor specific to the group of spouse caregivers was that patients' wives had a worse perception of QoL ($\beta = -0.23, p = 0.008$). A greater number of factors were found to be specific to the group of adult child caregivers. Here, higher educational level in the caregiver and older age in the patient were associated with a more positive percep-

Table 4. Perceived QoL, gender, family relationship, burden and mental health of caregivers

a Perceived QoL

| | n | Caregivers | Patients | | Intergroup differences | | |
|------------------------|-----|---|----------|---|------------------------|-----------|------|
| | | mean ± SD | FR | mean ± SD | T | p | d |
| Wives | 65 | 33.2 ± 4.2 | (H) | 36.6 ± 3.2 | -5.20 | <0.001*** | 0.90 |
| Husbands | 47 | 32.8 ± 4.6 | (W) | 34.4 ± 4.8 | -2.35 | 0.019* | 0.32 |
| Sons | 38 | 31.0 ± 5.6 | (P) | 33.7 ± 4.8 | -2.71 | 0.007** | 0.51 |
| Daughters | 101 | 30.7 ± 5.1 | (P) | 34.0 ± 4.6 | -5.17 | <0.001*** | 0.67 |
| Intragroup differences | | $\chi^2 = 12.09$ p = 0.007** d = 0.52 | | $\chi^2 = 14.15$ p = 0.003** d = 0.70 | | | |
| Bonferroni post hoc | | B = 2.45, p = 0.011 | | B = 2.59, p = 0.002 | | | |

b Burden and mental health of caregivers

| | n | Burden (CBI) mean ± SD | Mental health (SF-12) mean ± SD |
|------------------------|-----|--|---|
| Husbands | 47 | 35.0 ± 8.6 | 50.3 ± 8.5 |
| Wives | 65 | 39.8 ± 11.1 | 47.4 ± 8.8 |
| Daughters | 101 | 41.2 ± 12.6 | 44.8 ± 12.7 |
| Sons | 38 | 43.8 ± 14.1 | 42.7 ± 10.7 |
| Intragroup differences | | $\chi^2 = 11.15$ p = 0.011* d = 0.74 | $\chi^2 = 12.56$ p = 0.006** d = 0.77 |
| Bonferroni post hoc | | B = -8.75, p = 0.005 | B = 7.52, p = 0.010 |

c Correlations between caregiver perceptions of QoL

| | n | SF-12 | | | | Burden (CBI) | |
|-----------|-----|---------------|-----------|----------------------|-----------|--------------|-----------|
| | | Mental health | | Downhearted and blue | | r_s | p |
| | | r_s | p | r_s | p | | |
| Sons | 38 | 0.16 | 0.338 | -0.15 | 0.350 | -0.39 | 0.014* |
| Husbands | 47 | 0.23 | 0.106 | -0.17 | 0.230 | -0.54 | <0.001*** |
| Wives | 65 | 0.23 | 0.064 | -0.22 | 0.079 | -0.55 | <0.001*** |
| Daughters | 101 | 0.42 | <0.001*** | -0.48 | <0.001*** | -0.59 | <0.001*** |

FR = Family relationship; W = wives; H = husbands; P = parents. T = Wilcoxon, χ^2 = Kruskal-Wallis.
* p < 0.05, ** p < 0.01, *** p < 0.001.

tion. In contrast, more time dedicated to instrumental activities of daily living, feelings of guilt in the caregiver ($\beta = -0.19$, p = 0.006), and apathy ($\beta = -0.25$, p = 0.001) in the patient were all associated with a more negative perception in the adult child group.

Perception of Husband, Wife, Son and Daughter Caregivers. A specific multivariate linear regression analysis was also performed for each of the caregiver subgroups

in order to identify the most relevant factors affecting perceived QoL-p.

In the subgroup of husband caregivers, the positive factors were greater functional autonomy in the patient ($\beta = 0.60$, p < 0.001) and higher educational level in the caregiver ($\beta = 0.26$, p = 0.006). A negative factor was social burden, i.e. factor 1 of the CBI ($\beta = -0.26$, p = 0.013).

Table 5. Multivariate linear regression: perceived QoL-p in caregivers and patients and in the spouse and adult child groups

a Perception of caregivers

| | Caregivers (n = 251; r ² = 0.550) | | Spouse caregivers (n = 112; r ² = 0.626) | | Adult child caregivers (n = 139; r ² = 0.492) | |
|-------------------------------|---|-----------|--|-----------|---|-----------|
| | β | p | β | p | β | p |
| Caregiver factors | | | | | | |
| Level of education | 0.19 | <0.001*** | 0.20 | 0.002** | 0.13 | 0.036* |
| CBI factor 2: psychol. stress | -0.23 | <0.001*** | -0.15 | 0.024* | -0.28 | <0.001*** |
| CBI factor 3: guilty feelings | -0.13 | 0.003** | 0.03 | 0.529 | -0.20 | 0.002** |
| Relationship to patient | -0.19 | 0.001** | | | | |
| Patient factor | | | | | | |
| DAD | 0.35 | <0.001*** | 0.51 | <0.001*** | 0.23 | 0.002** |
| NPI-D depression | -0.24 | <0.001*** | -0.14 | 0.025* | -0.31 | <0.001*** |
| NPI-G apathy | -0.21 | <0.001*** | -0.18 | 0.019* | -0.21 | 0.005** |
| CAMCOG-R | -0.10 | 0.042* | -0.16 | 0.047* | -0.12 | 0.077 |
| NPI-L appet./eating disturb. | -0.03 | 0.429 | -0.15 | 0.023* | 0.02 | 0.707 |
| Collinearity | | | | | | |
| Tolerance | 0.639–0.912 | | 0.610–0.901 | | 0.693–0.978 | |
| Variance inflation factor | 1.09–1.56 | | 1.11–1.53 | | 1.02–1.44 | |

b Perception of patients

| | Patients (n = 251; r ² = 0.310) | | Spouse caregivers (n = 112; r ² = 0.167) | | Adult child caregivers (n = 139; r ² = 0.391) | |
|-------------------------------|---|-----------|--|---------|---|-----------|
| | β | p | β | p | β | p |
| Caregiver factors | | | | | | |
| Relationship to patient | -0.27 | <0.001*** | | | | |
| Hours spent on instr. ADL | -0.15 | 0.007** | -0.17 | 0.075 | -0.15 | 0.043* |
| Level of education | 0.15 | 0.020* | 0.10 | 0.253 | 0.22 | 0.002** |
| CBI factor 3: guilty feelings | -0.13 | 0.019* | -0.06 | 0.485 | -0.19 | 0.006** |
| Gender | 0.11 | 0.036* | 0.20 | 0.032* | 0.03 | 0.617 |
| Patient factors | | | | | | |
| NPI-D depression | -0.32 | <0.001*** | -0.30 | 0.001** | -0.34 | <0.001*** |
| Age | 0.13 | 0.026* | 0.08 | 0.398 | 0.17 | 0.019* |
| NPI-G apathy | -0.13 | 0.027* | 0.04 | 0.626 | -0.25 | 0.001** |
| Gender | -0.06 | 0.361 | -0.23 | 0.008** | 0.00 | 0.907 |
| Collinearity | | | | | | |
| Tolerance | 0.604–0.977 | | 0.989–0.989 | | 0.784–0.978 | |
| Variance inflation factor | 1.02–1.65 | | 1.01–1.01 | | 1.02–1.27 | |

ADL = Activities of daily living. CAMCOG-R = Cambridge Cognitive Examination-Revised; DAD = Disability Assessment for Dementia; NPI = Neuropsychiatric Inventory; r² = determination coefficient of the multivariate model; β = standardized β-coefficient.

* p < 0.05, ** p < 0.01, *** p < 0.001.

In the subgroup of wife caregivers, the positive factors were greater functional autonomy in the patient (β = 0.36, p < 0.001), higher educational level in the caregiver (β = 0.28, p = 0.003) and being the sole caregiver (β = 0.19, p = 0.028). The negative factors were greater apathy in the

patient (β = -0.34, p = 0.001) and psychological stress, i.e. factor 2 of the CBI (β = -0.24, p = 0.013).

In the subgroup of son caregivers, the only significant positive factor was greater functional autonomy in the patient (β = 0.23, p = 0.034). The negative factors were

factor 4 of the CBI (emotional pressure; $\beta = -0.41$, $p < 0.001$) and apathy in the patient ($\beta = -0.51$, $p < 0.001$).

In the subgroup of daughter caregivers, the significant positive factors were greater functional autonomy in the patient ($\beta = 0.21$, $p = 0.009$) and a higher educational level in the caregiver ($\beta = 0.25$, $p = 0.001$). The negative factors were factor 1 of the CBI (social burden; $\beta = -0.24$, $p = 0.012$), factor 2 of the CBI (psychological stress; $\beta = -0.29$, $p = 0.001$), factor 3 of the CBI (feelings of guilt; $\beta = -0.27$, $p < 0.001$) and depression in the patient ($\beta = -0.26$, $p = 0.001$).

Discussion

Differences in Perceived QoL-p between Patients and Caregivers

The fact that AD patients themselves have a more positive perception of QoL-p than caregivers has been repeatedly reported [2, 10, 13, 18]. This finding could be interpreted in terms of what has been called the 'disability paradox', i.e. the presence of high levels of subjective well-being alongside objective difficulties in physical, mental or relational functioning that, from the observer's perspective, should theoretically produce dissatisfaction and distress. This paradox has been reported by overall reviews of well-being in disability [35], as well as by those focused on subjective well-being in normal ageing [36] and dementia [37]. One way of understanding the paradox would be as an adaptive coping strategy used by human beings in the face of insuperable difficulties, although it remains unclear why it occurs in the case of dementia.

At all events it could be argued that the concept of QoL is based more on a personal and subjective viewpoint, whereas caregiver burden can be analyzed in more objective terms (degree of deterioration and disorders in the patient, number of hours spent on caring, other family burdens and the caregiver's own occupation). The present results suggest that the perception of QoL becomes more negative as the relationship to the patient becomes further removed. Thus, patients themselves, their spouse, their adult children and then other family caregivers would, in this order, report a progressively more negative view of QoL-p.

Differences in Perceived QoL-p between Spouse and Adult Child Caregivers

Spouse caregivers had a more positive perception of QoL-p than adult child caregivers, and patients who were

cared for by spouses also had a more positive perception of their own QoL than patients with adult child caregivers. The higher score for patients being cared for by a spouse is consistent with previous findings [16], as is the greater agreement between patient and caregiver perceptions in the subgroup of spouse caregivers [17].

In other words, being cared for by a spouse rather than an adult child was more favorable to both parties involved. These findings cannot be explained in terms of differences in the objective clinical status of patients. However, as suggested by other authors [38], the different nature of spouse and adult child relationships with the patient could be a key factor in terms of understanding the differences in perceived QoL-p. Thus, spouse caregivers would consider the tasks of caring as part of their marital commitment and would be closer, both physically and emotionally, to the patient. At the same time, the task of caring would provide them with a role in their old age that, despite the associated difficulties, would give meaning and purpose to their lives. As noted by other authors [39], this task would thus be associated with less burden.

In contrast, adult child caregivers would experience notable generational differences with respect to the patient and might also feel more distant emotionally. Furthermore, they would have to combine the care tasks with other obligations (such as family and work) and this could more easily lead to a clash of responsibilities and greater burden. As stated by other authors [40–42] the feelings of guilt reported by adult child caregivers, which also have negative repercussions for patients, could be associated with the difficulties that caregivers face in providing the best possible care for their parents or the emotional distance they feel with respect to them.

An interesting finding of the present study, not previously reported in the literature, is that a higher educational level among caregivers was associated with a more positive perception of QoL-p in both patients and caregivers. Such education may help caregivers to understand the illness better, and perhaps enables them to make greater use of appropriate resources.

Gender and Family Relationship of Caregivers

The differences between spouses and adult children were also found when analyzing the subgroups of caregivers and patients. Both wife and husband caregivers had a more positive perception of QoL-p than son and daughter caregivers, the same was true for the respective patients. Sons and daughters not only had a more negative perception of QoL-p, but also reported greater bur-

den and worse mental health. Mental health and burden were especially related to a more negative perception of QoL-p among daughter caregivers, and this could influence the more negative perception of QoL-p held by the corresponding subgroup of patients. Daughter caregivers, who may find it more difficult to combine their family responsibilities with caring for their parent, would tend to internalize their psychological distress more. The greater burden experienced by daughter caregivers has been previously reported [43].

These findings could be generalizable as the overall caregiver data in terms of the percentages for gender and family relationship were very similar to the results of the studies conducted by Alzheimer Europe [44].

Clinical Implications

Focusing therapeutic interventions and service provision on adult child caregivers would help to minimize the difficulties they face in terms of combining the tasks of caring with other obligations, thereby reducing the burden they experience and improving their mental health. These 2 variables, greater burden and worse mental health, are the key factors that need to be addressed in order to improve perceived QoL. Indeed, improving the caregiver's QoL would enable him or her to take a more

positive view of the patient's QoL, which in turn may indirectly improve the patient's own perception in this regard. As such, therapeutic interventions, whether individual or group based, should take into account the different nature of these spouse and adult child relationships with the patient in order to address more specifically the main factors associated with each.

To conclude, the high correlation between caregiver and patient perceptions of the latter's QoL suggests that improving the perceptions of caregivers could lead to a concomitant improvement in the perceptions of patients themselves.

Limitations

The present study was conducted with a relatively large sample and numerous sociodemographic and clinical variables were analyzed and compared; thus, providing a robust set of results. However, it would be useful to carry out a longitudinal study of AD patients with a higher level of deterioration. Research of this kind would enable caregiver perceptions to be monitored over time, particularly at the point when greater outside resources become more necessary. One would expect the perceptions of spouse and adult child caregivers to evolve differently over time, as is the case with caregiver burden.

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