

Factors related to perceived quality of life in patients with Alzheimer's disease: the patient's perception compared with that of caregivers

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SUMMARY

Aims To compare care recipient and caregiver perceptions of quality of life in patients (QoL-p) with Alzheimer's disease (AD). To identify associated factors, and the concordances-discrepancies.

Method Cross-sectional analytic study of 236 patients and their carers using the Quality of Life in Alzheimer's Disease (QoL-AD) scale, socio-demographic data and clinical examination.

Results Patients scored the QoL-AD more favourably than did caregivers (34.4 vs 31.3, $p < 0.001$). Cognitive deterioration did not affect the perception of QoL-AD ($\rho = -0.05$, $p = 0.394$). The neuropsychiatric symptoms was associated with a negative perception of the QoL-AD in both patients ($\rho = -0.22$, $p < 0.01$) and caregivers ($\rho = -0.47$, $p < 0.001$). Greater functional autonomy was associated with a better perception of the QoL-AD in patients ($\rho = 0.17$, $p < 0.01$) and even more so in caregivers ($\rho = 0.56$, $p < 0.001$). In carers, burden ($\rho = -0.56$, $p < 0.001$) and mental health ($\rho = 0.31$, $p < 0.001$) were inversely associated with the QoL-AD. QoL-AD scores of both patients and caregivers were higher for men, married subjects, those who lived with their spouse and those living in their own home. When the carer was a spouse both patients and caregivers scored the QoL-AD higher than when the carer was a son or daughter (35.5 vs 33.4 and 33.7; 32.9 vs 30.5 and 27.7, $p < 0.001$).

Conclusions Patients have a better perception of QoL-p. Caregivers give a more negative evaluation of neuropsychiatric symptoms, but have a more positive view of functional autonomy. Carers who are spouses have a better perception of QoL-p than do carers who are sons or daughters. Copyright © 2008 John Wiley & Sons, Ltd.

KEY WORDS — Quality of life; Alzheimer's disease; caregivers

INTRODUCTION

Alzheimer's disease (AD) is a significant public health concern due to its high prevalence, the serious consequences for patients, and the burden it places on families (Garre-Olmo *et al.*, 2000). Given the enormous costs to the individual and the family that derive from the chronicity and severity of the disease one of the key objectives of the services offered to patients and their relatives is therefore to maintain quality of life.

The concept of and emphasis placed on the quality of life of patients (QoL-p) with dementia has emerged particularly over the last decade (Whitehouse *et al.*, 2003; Lucas-Carrasco, 2007), and evaluation of this aspect has been progressively included as part of clinical guidelines for treating dementia patients. Since 2001 the Group for Harmonization of Dementia Drug Guidelines and the Alzheimer's Society (Mack and Whitehouse, 2001) have recommended the evaluation of quality of life to verify the efficacy and appropriateness of therapeutic interventions, not only from the patient's perspective but also from that of family caregivers or professionals. However, research is still needed to clarify a number of key questions: which measures are the most valid and

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reliable for assessing QoL-p, what is the best type of administration (auto or rater-administrated questionnaire) according to the degree of cognitive impairment, who are the best informants, and which factors influence the perception of QoL-p in patients and other informants (Naglie, 2007).

The aims of the present study were, firstly, to compare the perceptions of patients and family caregivers of QoL-p in AD; secondly, to identify the socio-demographic and clinical factors associated with the care recipient and caregiver perception of QoL-p; and thirdly, to identify the points of agreement and disagreement between patients and carers as regards QoL-p.

METHODS

Study population

The sample comprised 236 patients diagnosed with AD according to DSM-IV (APA, 2001) criteria and probable AD according to NINCDS-ADRDA (McKhann *et al.*, 1984) criteria, along with their corresponding family caregivers. The main carer was defined as the person who was responsible for helping the patient with daily living activities, both basic (self-care such as bathing, dressing and undressing, etc.) and instrumental (personal autonomy such as using the telephone or managing money), as well as for supervising him or her at home.

All the AD subjects were seen as out-patients in the Memory and Dementia Assessment Unit of the Santa Caterina Hospital in Girona (Spain) and formed part of the SIDEA research project (Seguimiento Integral de la Enfermedad de Alzheimer—Comprehensive Follow-Up of Alzheimer's Disease). This is a four-year observational, longitudinal and pragmatic cohort study. Using a standardized protocol it aims to describe and follow-up a large cohort of patients diagnosed with AD, as well as their family caregivers, who receive outpatient medical and social care at secondary-level centres in our area. The study was approved by the Ethics Committee for Clinical Research of the local health authority. All the patients and their carers gave their written consent to participate in the study. The data analysed corresponded to the baseline assessment session of the SIDEA study.

Procedure

In the initial interview the aims of the study were explained to patients and caregivers, who were then

interviewed separately. The assessment instruments were administered by a clinical neuropsychology research team from the hospital.

Study protocol

Measuring quality of life. The Quality of Life in Alzheimer's Disease (QoL-AD) scale was administered to patients and caregivers in order to assess their perception of QoL-p. The scale consists of thirteen items that reflect the subject's perception of different aspects related to wellbeing: physical health, energy, mood, living situation, memory, family, marriage, friends, self as a whole, ability to do chores around the house, ability to do things for fun, money, and life as a whole. Possible scores range from 13–52 (Logsdon *et al.*, 1999, 2002).

Instruments for examining socio-demographic and clinical variables. The socio-demographic characteristics of the patient and caregiver (age, gender, marital status, level of education, place of residence, family relationship, whether they lived together, employment situation, other family burdens such as children or disabled people care) were recorded by means of a structured interview, the Cambridge Mental Disorders of the Elderly Examination (CAMDEX-R, Sections A and H) (Roth *et al.*, 1986).

The clinical examination of the patient was conducted using the following instruments:

- Cambridge Cognitive Examination-Revised (CAMCOG-R). This forms part of the CAMDEX and assesses various cognitive functions, with possible scores ranging from 0–107, with the cut-off point for the Spanish population being 68/69 (Vilalta-Franch *et al.*, 1990).
- Mini Mental State Examination (MMSE). A brief cognitive examination whose scores range from 0 to 30, the cut-off point for cognitive impairment being 21/22 (Folstein *et al.*, 1975). This was used to evaluate the severity of cognitive impairment (Kraemer *et al.*, 1998).
- Disability Assessment for Dementia (DAD). This scale assesses a wide range of daily living activities (ADL): basic, instrumental and leisure. It comprises 40 items and scores range from 0–100 (Gélinas *et al.*, 1999; Feldman *et al.*, 2001).
- Neuropsychiatric Inventory (NPI). This instrument for evaluating psychiatric symptomatology in AD is administered to the carer. It comprises twelve subscales and score ranges from 0–144. (Cummings *et al.*, 1994; Vilalta-Franch *et al.*, 1999).

The clinical examination of the carer was conducted using the following instruments:

- SF-12 Health Survey (SF-12v1) Short form of the SF-36 Health Survey. It comprises 12 items and scores range from 12–47. Two global dimensions can be obtained from the direct scores: physical health and mental health, and in both dimensions the score ranges from 0–100 (Ware *et al.*, 1996; Alonso *et al.*, 1998).
- Caregiver Burden Interview (CBI). A questionnaire designed to assess the burden experienced by carers. It comprises 22 items and scores range from 0–88 (Zarit *et al.*, 1986; Martín *et al.*, 1996).

Statistical analysis

A descriptive analysis of the data was conducted and differences in means for the QoL-AD scale were calculated using the non-parametric Wilcoxon signed-rank test. The degree of correlation and concordance between the scores of patients and caregivers on the QoL-AD were also analysed by means of Spearman's rank correlation coefficient and the Kappa index, respectively.

The analysis of relationships between the scores of patients and caregivers on the QoL-AD and the socio-demographic and clinical factors of patients and caregivers was conducted using the non-parametric Mann-Whitney U and Kruskal-Wallis tests. The correlations used were Pearson's for continuous variables and Spearman's for discontinuous variables.

When the comparison of two means revealed significant differences Cohen's *d* was used as a measure of effect size.

In order to determine the overall effect of the clinical and socio-demographic variables on the perception of QoL-p in patients and caregivers, two multivariate linear regression analyses were carried out. The dependent variables were scores on the QoL-AD of the patient and caregiver, while the independent variables were those found to be significant in the bivariate analysis.

Statistical significance was set at 0.05 in order to compare hypotheses.

RESULTS

Description of the sample

The mean age of patients was 77.8 (SD = 6.9) and that of caregivers 59.9 (SD = 14.6). Of the patient group 79 were men (33.5%) and 157 women (66.5%), while

caregivers were 70 men (29.7%) and 166 women (70.3%). As regards the family relationship, 103 (43.6%) caregivers were the patient's spouse and 109 (46.2%) were the son or daughter. The number of caregivers who lived with the patient was 153 (64.8%), while 83 (35.2%) supervised the care of but did not live with the patient (Table 1).

Clinical data

The mean score of patients on the CAMCOG was 56.0 (SD = 11.6). Seventy-six patients (32.2%) patients had mild cognitive impairment (MMSE > 20), 154 (65.3%) showed moderate cognitive impairment (MMSE = 11–20), and 6 (2.5%) had severe cognitive impairment (MMSE < 11). The mean DAD score was 85.4 (SD = 8.0) and the mean total score on the NPI was 10.6 (SD = 12.2).

The clinical questionnaires administered to caregivers revealed a mean score on the SF-12 of 46.7 (SD = 10.9) and 49.4 (SD = 9.3) for the mental and physical health dimensions, respectively. The mean score on the CBI was 40.7 (SD = 12.3) (Table 2).

Perception of QoL-p in patients and caregivers

The item 'marriage' from the QoL-AD scale was only applied to patients and caregivers when the patients had a spouse (*n* = 148) at the time of the interview; for each of the remaining subjects (*n* = 88) the scores for this item were weighted according to the total scale score.

The total mean score of the QoL-AD scale showed that patients (mean = 34.4; SD = 4.6) and caregivers (mean = 31.3; SD = 5.2) had a different subjective perception of QoL-p, this difference being significant ($z = -7.462$; $p < 0.001$; $d = 0.628$) with a medium/high effect size. Patients also scored significantly higher on all items except living situation. Particularly noteworthy among these differences was that for memory ($z = -6.479$; $p < 0.001$; $d = 0.642$) (Table 3).

Patient factors associated with the perception of QoL-p in patients and caregivers

The analysis of associations between the socio-demographic data of patients and QoL-AD scores (Table 4) revealed, for patients, higher perceived QoL-p for men ($p < 0.001$; $d = 0.612$), those who were married, who lived with their spouse and those who lived in their own home. The data for caregivers showed agreement on all these aspects: men, those who were married, who lived with their spouse

Table 1. Socio-demographic factors of participants

Patients (<i>n</i> = 236)		Caregivers (<i>n</i> = 236)	
Age, years		Age, years	
Mean (s.d.)	77.8 (6.9)	Mean (s.d.)	59.9 (14.6)
Range	55–93	Range	27–87
Gender		Gender	
Female, <i>n</i> (%)	157 (66.5)	Female, <i>n</i> (%)	166 (70.3)
Marital status, <i>n</i> (%)		Marital status, <i>n</i> (%)	
Married	148 (62.7)	Married	204 (86.5)
Widowed	80 (33.9)	Widowed	8 (3.4)
Single	8 (3.4)	Single	15 (6.4)
Divorced	—	Divorced	9 (3.8)
Level of education, <i>n</i> (%)		Level of education, <i>n</i> (%)	
Illiterate, no schooling	53 (22.5)	Illiterate, no schooling	30 (12.7)
<8 years	159 (67.4)	<8 years	83 (35.2)
>8 years	24 (10.2)	>8 years	120 (50.8)
Living situation, <i>n</i> (%)		Family relationship of caregiver, <i>n</i> (%)	
With spouse	120 (50.8)	Spouse	103 (43.6)
With relative	39 (16.5)	Son/daughter	109 (46.2)
Alone	34 (14.4)	Other relative	23 (9.7)
Residence, <i>n</i> (%)		Living with patient, <i>n</i> (%)	
Own home	193 (81.8)	Yes	153 (64.8)
Relative's home	42 (17.8)	Sole carer, <i>n</i> (%)	
		Yes	137 (58.1)
		Other family burdens, <i>n</i> (%)	
		Yes	87 (36.9)
		Employment situation, <i>n</i> (%)	
		In work	101 (43.3)
		Retired	98 (42.1)
		Housewife	26 (11.2)
		Unemployed	8 (3.4)

($p < 0.001$; $d = 0.812$) and those who lived in their own home; an additional factor here was younger age.

There were no significant differences in the QoL-AD score according the educational groups, neither among patients nor caregivers.

The most relevant clinical factor was depression, as lower scores for QoL-p were given by patients who scored high on NPI-depression ($p < 0.001$). Smaller but still significant correlations were also observed for NPI-apathy, NPI-total score and greater autonomy on the DAD ($p < 0.01$).

In caregivers the significant correlations with clinical data were more diverse. The DAD, NPI-apathy, NPI-total, NPI-depression and NPI-appetite all showed greater significant correlations ($p < 0.001$), as did, with a smaller effect, NPI-agitation, NPI-anxiety and NPI-elation ($p < 0.01$).

No significant correlations were observed, for either patients or caregivers, between QoL-AD scores and cognitive tests.

As regards gender, patients and caregivers agreed in perceiving that men had better QoL-p. Examination of the clinical data of patients showed that the only

significant differences related to gender concerned depression and anxiety, with higher scores for women: NPI-depression ($z = -2.572$; $p < 0.01$) and NPI-anxiety ($z = -3.696$; $p < 0.001$; $d = -0.512$).

Caregiver factors associated with the perception of QoL-p in patients and caregivers

Comparison of the socio-demographic data for caregivers with QoL-AD scores (Table 5) revealed that both patients ($p < 0.001$) and caregivers ($p < 0.01$) perceived better QoL-p when the caregiver was older.

Patients and caregivers agreed in scoring higher QoL-p when the caregiver was a spouse without other family burdens, who was the sole carer and who lived with the patient.

No significant differences were found as regards gender, years of education, marital status or the employment situation of caregivers.

In terms of clinical factors, caregivers with a higher correlation on the mental health dimension ($\rho = 0.311$; $p < 0.001$) perceived better QoL-p, while those

Table 2. Clinical factors of participants

Patients	n	Mean	SD	Range
DAD	236	85.4	8.0	52.50–100
NPI	236			
A Delusions		0.3	1.3	0–12
B Hallucinations		0.1	1.0	0–08
C Agitation		1.0	2.2	0–12
D Depression		1.6	2.7	0–12
E Anxiety		0.8	1.8	0–12
F Elation		0.05	0.4	0–03
G Apathy		2.5	3.0	0–12
H Disinhibition		0.3	1.0	0–06
I Irritability		1.3	2.2	0–12
J Aberrant motor behaviour		0.4	1.4	0–08
K Sleep disorders		0.9	2.2	0–12
L Appetite		1.0	2.3	0–12
TOTAL		10.6	12.2	0–96
CAMCOG-R	236	56.0	11.6	29–86
MMSE levels, n (%)	236			
Mild	>20	76 (32.2)		
Moderate	11–20	154 (65.3)		
Severe	<11	6 (2.5)		
Caregivers		Mean	SD	Range
SF-12				
Mental component	234	46.7	10.9	15.30–65.70
Physical component	234	49.4	9.3	21.01–67.01
CBI Zarit	236	40.6	12.3	22–82

CAMCOG-R = Cambridge Cognitive Examination-Revised; CBI = Caregiver Burden Interview; DAD = Disability Assessment for Dementia; MMSE = Mini Mental State Examination; NPI = Neuropsychiatric Inventory; SF-12 = Short Form of Health Survey.

with high levels of burden perceived worse QoL-p ($\rho = 0.562$; $p < 0.001$).

Spouse caregivers and son/daughter caregivers in relation to QoL-p

Son/daughter caregiver scores (mean = 30.5; SD = 5.3) on the QoL-AD were significantly lower than those of spouse caregivers (mean = 32.9; SD = 4.4); ($z = -3.272$; $p < 0.01$; $d = 0.477$). A similarly significant difference was also observed in the QoL-AD of patients with son/daughter caregivers (mean = 33.4; SD = 4.6) compared to those who were cared for by a spouse (mean = 35.5, SD = 4.2); ($z = -3.366$; $p < 0.01$; $d = 0.418$).

The level of burden of son/daughter caregivers (CBI = 42.4; SD = 12.7) was greater than that of spouse caregivers (CBI = 37.7; SD = 10.2), this difference being significant ($z = -2.723$; $p < 0.01$; $d = 0.414$). The correlation between caregiver burden and the QoL-AD was significant for the two groups ($p < 0.001$), although the value was higher in the case of sons/daughters (son/daughter caregivers, $\rho = -0.636$; spouse caregivers, $\rho = -0.508$).

As regards physical health, spouse caregivers (SF-12 = 45.9; SD = 9.7) suffered the effects more than did son/daughter caregivers (SF-12 = 52.5; SD = 8.1), this difference being highly significant ($z = -5.177$; $p < 0.001$; $d = 0.715$); however, there was no significant correlation with the QoL-AD score of patients and caregivers.

Table 3. Patient's quality of life according to the QoL-AD score of patients and caregivers

QoL-AD	N = 236	Patients		Caregivers		Wilcoxon		Cohen's d	Spearman coeff.		Kappa k
		Mean	SD	Mean	SD	z	p		rho	p	
Physical health		2.6	0.6	2.5	0.7	-2.127	0.033	0.169	0.297	0.000	0.229
Energy		2.5	0.7	2.3	0.7	-3.646	0.000	0.300	0.287	0.000	0.191
Mood		2.4	0.7	2.1	0.7	-5.925	0.000	0.420	0.316	0.000	0.175
Living situation		2.8	0.5	2.7	0.6	-0.229	0.819	0.018	0.093	0.153	0.066
Memory		2.0	0.6	1.6	0.5	-6.479	0.000	0.642	0.055	0.401	0.080
Family		3.2	0.5	3.0	0.6	-5.109	0.000	0.467	0.134	0.040	0.059
Marriage	(n = 148)	3.2	0.6	2.9	0.6	-4.740	0.000	0.496	0.225	0.006	0.171
Friends		3.0	0.6	2.6	0.8	-5.348	0.000	0.447	0.265	0.000	0.169
Self as a whole		2.7	0.5	2.5	0.6	-5.685	0.000	0.491	0.264	0.000	0.223
Ability to do chores		2.6	0.6	2.2	0.7	-5.385	0.000	0.451	0.301	0.000	0.214
Ability to do things for fun		2.3	0.7	2.0	0.8	-4.737	0.000	0.398	0.293	0.000	0.180
Money		2.8	0.5	2.6	0.6	-2.990	0.003	0.247	0.142	0.030	0.100
Life as a whole		2.7	0.5	2.6	0.6	-3.510	0.000	0.298	0.255	0.000	0.194
Total score		34.4	4.6	31.3	5.2	-7.462	0.000	0.628	0.360	0.000

QoL-AD = Quality of Life in Alzheimer's Disease.

Table 4. Patient factors and relationships with the QoL-AD scale for patients and caregivers

Patient factors	N	QoL-AD patients				QoL-AD caregivers			
		Mean	SD	p	Cohen's d	Mean	SD	p	Cohen's d
Age ¹	236	77.8	6.9	$r = 0.125$ $p = 0.054$		77.8	6.9	$r = -0.176$ $p = 0.007^{**}$	
Gender ²									
Male	79	36.1	3.7	$z = -4.042$	0.612	32.6	5.1	$z = -2.912$	0.363
Female	157	33.5	4.7	$p = 0.000^{***}$		30.7	5.2	$p = 0.004^{**}$	
Education ³									
Illiterate, no sch.	53	33.5	4.9	$\chi^2 = 3.636$		31.6	4.9	$\chi^2 = 1.261$	
<8 years	159	34.5	4.4	$p = 0.162$		31.1	5.3	$p = 0.532$	
>9 years	24	35.5	4.7			32.4	5.2		
Marital status ³									
Married	148	35.1	4.4	$\chi^2 = 12.973$	0.422	32.3	4.9	$\chi^2 = 15.053$	0.526
Widowed	80	33.2	4.4	$p = 0.002^{**}$		29.7	5.3	$p = 0.001^{**}$	
Single	8	32.6	6.1			28.8	6.8		
Living situation ³									
With spouse	120	35.0	4.4	$\chi^2 = 8.395$	0.447	32.9	4.9	$\chi^2 = 20.472$	0.862
With relative	39	33.0	4.8	$p = 0.015^*$		28.5	5.3	$p = 0.000^{***}$	
Alone	34	34.0	4.2			30.7	5.6		
Residence ²									
Own home	193	34.8	4.4	$z = 2.838$	0.475	31.8	5.1	$z = 2.697$	0.489
Relative's home	42	32.6	4.8	$p = 0.005^{**}$		29.2	5.4	$p = 0.007^{**}$	
MMSE levels ³									
Mild >20	76	34.1	4.5	$\chi^2 = 1.777$		30.1	5.3	$\chi^2 = 0.821$	
Moderate 11–20	154	34.7	5.6	$p = 0.411$		30.6	5.5	$p = 0.663$	
Severe <11	6	33.0	6.8			30.1	2.9		
DAD ⁴	236	rho	p			rho	p		
NPI	236	0.179	0.006 ^{**}			0.565	0.000 ^{***}		
A Delusions		-0.017	0.793			-0.076	0.247		
B Hallucinations		-0.001	0.982			-0.046	0.482		
C Agitation		0.085	0.193			-0.195	0.003 ^{**}		
D Depression		-0.289	0.000 ^{***}			-0.318	0.000 ^{***}		
E Anxiety		-0.145	0.026 [*]			-0.188	0.004 ^{**}		
F Elation		-0.058	0.373			-0.170	0.009 ^{**}		
G Apathy		-0.204	0.002 ^{**}			-0.504	0.000 ^{***}		
H Disinhibition		-0.026	0.687			-0.123	0.059		
I Irritability		0.082	0.212			-0.122	0.062		
J Aber. motor beh.		-0.065	0.321			-0.133	0.041 [*]		
K Sleep disorders		-0.064	0.330			-0.082	0.209		
L Appetite		-0.144	0.027 [*]			-0.250	0.000 ^{***}		
Total		-0.223	0.001 ^{**}			-0.472	0.000 ^{***}		
CAMGOC-R	236	-0.056	0.394			0.097	0.139		

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

¹Pearson's coefficient. ²Mann-Whitney U test. ³Kruskal-Wallis. ⁴Spearman's coefficient.

CAMCOG-R = Cambridge Cognitive Examination-Revised; DAD = Disability Assessment for Dementia; MMSE = Mini Mental State Examination; NPI = Neuropsychiatric Inventory; QoL-AD = Quality of Life in Alzheimer's Disease.

With respect to the mental health dimension, spouse caregivers had better health (SF-12 = 48.4; SD = 9.1) than son/daughter caregivers (SF-12 = 44.3; SD = 12.6), this difference being less significant ($z = -2.005$; $p < 0.05$); however, the correlation between mental health and the QoL-AD was only significant and in a positive direction (the better the mental health, the higher the QoL-p score) for son/daughter caregivers $\rho = 0.428$; $p < 0.001$).

Multivariate linear regression analysis

The linear regression analysis (Table 6) revealed that the QoL-AD patient score predictors were, in patients, depression ($p < 0.001$), gender ($p < 0.01$) and the DAD score ($p < 0.05$); in caregivers the predictors were the DAD score ($p < 0.001$), apathy ($p < 0.001$) and depression ($p < 0.01$). The coefficient of determination of the multivariate model was 0,298. The

FACTORS RELATED TO PERCEIVED QOL IN PATIENTS WITH AD

Table 5. Caregiver factors and relationships with the QoL-AD scale for patients and caregivers

Caregiver factors	n	QoL-AD patients				QoL-AD caregivers			
		Mean	SD	p	Cohen's d	Mean	SD	p	Cohen's d
Age ¹	236	59.9	14.6	$r = 0.230$ $p = 0.000***$		59.9	14.6	$r = 0.174$ $p = 0.009**$	
Gender ²									
Male	70	33.7	4.8	$z = -1.246$		31.1	5.4	$z = -0.470$	
Female	166	34.7	4.4	$p = 0.213$		31.4	5.2	$p = 0.638$	
Education ³									
Illiterate, no sch.	30	34.6	3.6	$\chi^2 = 0.094$		30.3	4.8	$\chi^2 = 4.162$	
<8 years	83	34.4	4.7	$p = 0.954$		32.1	4.9	$p = 0.125$	
>9 years	120	34.8	4.7			31.0	5.5		
Marital status ³									
Single	15	33.3	5.3	$\chi^2 = 2.137$		29.4	4.1	$\chi^2 = 4.896$	
Married	204	34.6	4.4	$p = 0.544$		31.6	5.3	$p = 0.180$	
Widowed	8	32.0	6.2			29.9	6.0		
Divorced	9	34.7	4.9			29.5	5.1		
Family relationship ³									
Spouse	103	35.5	4.2	$\chi^2 = 11.870$		32.9	4.4	$\chi^2 = 21.143$	
Son/daughter	109	33.5	4.6	$p = 0.003**$	0.463	30.5	5.4	$p = 0.000**$	0.477
Other relative	23	33.7	4.8			27.7	5.5		
Living with patient ²									
Yes	153	34.8	4.5	$z = 2.060$		31.9	5.1	$z = 2.424$	
No	83	33.6	4.6	$p = 0.039*$	0.275	30.3	5.3	$p = 0.015*$	0.308
Sole caregiver ²									
Yes	137	35.1	4.4	$z = 2.977$		32.3	4.9	$z = 3.416$	
No	98	33.3	4.5	$p = 0.003**$	0.398	29.9	5.4	$p = 0.001**$	0.470
Other family burdens ²									
Yes	87	33.4	4.9	$z = -2.372$		30.4	5.5	$z = -2.206$	
No	149	35.0	4.3	$p = 0.018*$	-0.340	31.9	5.0	$p = 0.027*$	-0.286
Employment situation ³									
Retired	98	35.2	4.5	$\chi^2 = 6.919$		32.2	4.8	$\chi^2 = 4.804$	
In work	101	33.7	4.5	$p = 0.075$		31.0	5.3	$p = 0.187$	
Domestic work	26	34.7	4.4			29.7	5.8		
Unemployed	8	33.0	5.6			30.1	6.4		
SF-12 ⁴	234								
SF-12 Physical		-0.092	0.162			-0.059	0.371		
SF-12 Mental		0.110	0.094			0.311	0.000***		
CBI. Zarit	236	-0.149	0.022*			-0.562	0.000***		

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

¹Pearson's coefficient. ²Mann-Whitney U test. ³Kruskal-Wallis. ⁴Spearman's coefficient.

CBI = Caregiver Burden Interview; QoL-AD = Quality of Life in Alzheimer's Disease; SF-12 = Short Form of Health Survey.

QoL-AD caregiver score predictors were, in patients, age and caregiver burden ($p < 0.05$); in caregivers the predictors were burden ($p < 0.001$), mental health and family relationship ($p < 0.05$). The coefficient of determination of the multivariate model was 0,522.

DISCUSSION

Differences in the perception of QoL-p

Concordance between the two QoL-AD scores, measured by means of the Kappa index, was low

for all items, as only correlations above 0.4 can be considered clinically significant. This differing perception of patients and caregivers, with better scores among patients, is similar to that reported by other studies (Thorgrimsen *et al.*, 2003; Sands *et al.*, 2004; Ready *et al.*, 2006). In addition, and in line with previous research (Hoe *et al.*, 2005; Vogel *et al.*, 2006), the perception of QoL-p was not correlated in either patients or caregivers with levels of cognitive impairment; indeed, the better scores among patients were preserved, with a similar difference between patients and caregivers for all levels of impairment.

Table 6. Multivariate linear regression analysis

Patient factors ^a	QoL-AD patients		QoL-AD caregivers	
	Beta	<i>p</i>	Beta	<i>p</i>
Gender	-0.232	0.001**	-0.098	0.077
DAD	0.164	0.023*	0.393	0.000***
NPI D Depression	-0.278	0.000***	-0.170	0.003**
NPI G Apathy	-0.049	0.502	-0.227	0.000***
Caregiver factors ^b	QoL-AD patients		QoL-AD caregivers	
	Beta	<i>p</i>	Beta	<i>p</i>
Age	0.198	0.039*	-0.149	0.074
Relationship	0.019	0.841	-0.204	0.013*
SF-12 Mental	0.143	0.024*
CBI Zarit	-0.135	0.049*	-0.452	0.000***

^a $r^2 = 0,298$. ^b $r^2 = 0,522$.

* $p < 0,05$; ** $p < 0,01$; *** $p < 0,001$.

Adjusted for: non-significant patient factors: age, marital status, living situation, residence, NPI-Agitation, NPI-Anxiety, NPI-Elation, NPI-Aber. motor behaviour., NPI-Appetite and non-significant caregiver factors: living with patient, sole carer, other family burden. CBI = Caregiver Burden Interview; DAD = Disability Assessment for Dementia; NPI = Neuropsychiatric Inventory; QoL-AD = Quality of Life in Alzheimer's Disease; SF-12 = Short Form of Health Survey.

Studies that compared the perception of patients with that of the professionals caring for them also report better QoL-p scores among patients (Cheon *et al.*, 2005; Hoe *et al.*, 2006).

In global terms there appear to be two independent and distinct points of view (Ready *et al.*, 2006), in which the disease situation seems to affect caregivers more than patients themselves. In this regard, it should be noted that studies of subjective wellbeing in dementia (Livingston *et al.*, 2008) and in normal ageing (Mroczek and Kolarz, 1998) also report this paradox, namely the presence of high levels of wellbeing in the face of objective difficulties or contextual or socio-demographic risk factors that intuitively would be expected to cause unhappiness.

Clinical factors

Neuropsychiatric symptoms in the patient (depression and apathy) were associated with lower perceived QoL-p in both the patient and caregiver groups. Among the neuropsychiatric symptoms associated with lower QoL-p, relatives included those that imply heightened motor activity (agitation, anxiety, elation and aberrant motor behaviour) and which placed an increased burden on the caregiver.

The correlation between the degree of autonomy for ADL and the QoL-AD was significant for both

patients and caregivers, although it was of greater relevance for the latter. From the caregivers' perspective, reduced autonomy implied a greater global impairment in the patient, and therefore greater burden for the caregiver.

Among caregivers the degree of burden and mental health were inversely associated with perceived QoL-p: a greater burden was linked to lower perceived QoL-p while a higher score on the mental health dimension was associated with a higher score for perceived QoL-p.

The linear regression analysis revealed that the most important predictors were depression, for patients, and autonomy in ADL, apathy and caregiver burden for carers. In line with several previous studies depression in the patient was the main clinical factor associated with lower perceived QoL-p in patients themselves (Sands *et al.*, 2004; Cheon *et al.*, 2005; Selwood *et al.*, 2005; Snow *et al.*, 2005; Vogel *et al.*, 2006; Hoe *et al.*, 2006; Fuh and Wang, 2006; Hoe *et al.*, 2007). In caregivers the main clinical factors associated with lower perceived QoL-p were caregiver burden (Thorgrimsen *et al.*, 2003; Sands *et al.*, 2004), autonomy for ADL (Cheon *et al.*, 2005; Snow *et al.*, 2005; Hoe *et al.*, 2006, 2007) and apathy (Hoe *et al.*, 2007). In fact, these three aspects could be considered to be related: depressive symptoms increase functional disability (ADL), are associated with an increased presence of non-cognitive symptoms and, overall, increase caregiver burden (Garre-Olmo *et al.*, 2002).

Despite the differences indicated between patients and caregivers, however, it should be noted that some studies which compared the perceptions of patients and professionals reported even greater discrepancies, both qualitatively and quantitatively, among the factors associated with QoL-p. Whereas the predominant factors among patients were depression and anxiety, professionals cited the increasing problems of dependency and behaviour (Hoe *et al.*, 2006).

Socio-demographic factors

The analysis of the socio-demographic factors that affect patient and caregiver perceptions of QoL-p according to the QoL-AD scale proved to be a more complex and novel task. Two aspects need to be highlighted here.

Gender of the patient. Patients and caregivers agreed in perceiving better QoL-p in patients who were men. The results indicate that women had higher levels of depression and anxiety, as occurs in the general

population (Regier *et al.*, 1993; Copeland *et al.*, 1999). This finding is consistent with what is observed in clinical practice when offering support to relatives of patients with Alzheimer's disease, and could also be related to the greater difficulties women face in terms of continuing to perform the tasks associated with their role in the family and generational context (Conde-Sala, 2006).

Relationship of the caregiver to the patient. The data show that caregivers had a more positive perception of QoL-p when patients were married, lived with their spouse or lived in their own home. At the same time, older caregivers, those who were the patient's spouse, who lived with him/her, were the sole carer and who had no other family burdens scored higher for QoL-p. These results suggest that two clearly distinct subgroups could be defined within the group of family caregivers: spouse caregivers and son/daughter caregivers. In this regard, son/daughter caregivers scored lower for perceived QoL-p than did spouse caregivers. This difference was also observed among patients: those who were cared for by a son or daughter scored lower for perceived QoL-p than did those who were looked after by a spouse.

Given the results obtained it would not seem that this difference can be explained by any especially relevant or differential clinical factor linked to patients. Furthermore, the only clinical factor for caregivers of relevance here would be burden, which was high in both sub-groups, although more so in the group of son/daughter caregivers.

One explanation for these differences could be the nature of the family relationship between patient and caregiver and the factors associated with this. Spouse caregivers would be closer to the patient in many aspects of life such as age, the fact of living together, and family and generational factors, and in this context the task of caring for the patient would occupy a sizeable proportion of their life together, thus generating greater empathy between them. In contrast, for son/daughter caregivers the abovementioned aspects of life would not only be more distant but may clash with other obligations: work, their own children, etc.

The analysis of socio-demographic data thus suggests that when it comes to perceived QoL-p, caregivers should not be treated as a uniform group; rather, the family relationship variable (spouse *vs* son/daughter) should be introduced in order to observe the behaviour of the two sub-groups with respect to clinical and socio-demographic data.

Clinical implications

The results of the present study, especially those obtained in the multivariate linear regression analysis, support the importance of treating depression in patients with Alzheimer's disease; depression is not only associated with other neuropsychiatric (NPI) and functional (ADL) symptoms (Garre-Olmo *et al.*, 2003), but also has repercussions for the quality of life of both patients and their relatives (López-Pousa *et al.*, 2007).

As regards caregivers, it is important to address aspects related to burden and mental health. Information about the disease, the provision of healthcare resources, and social and emotional support are clearly necessary to reduce caregiver burden, which not only affects carers but also, in an indirect way, patients (Conde-Sala, 2006). Thus, the mental health needs of caregivers must be taken into account and evaluated, as this aspect affects the perception of QoL-p, especially when the carer is a son or daughter.

The distinction between spouse and son/daughter caregivers has implications for the approach of professionals in alleviating the symptoms of caregiver burden; indeed, the different position in the relationship and social/family situation generates different behaviours and perceptions as regards QoL-p depending on whether the caregiver is the spouse or son/daughter of the patient.

Limitations

As already indicated, analysing caregivers as a uniform group may undermine some of the results, and it would be advisable to distinguish between spouse and son/daughter caregivers and the relationship between these two sub-groups and perceived QoL-p for all the data; further studies are thus required in order to consider these differences in greater detail.

The data from participants correspond to the baseline interview of the study. It would therefore be useful to observe the evolution in perceived QoL-p in both patients and caregivers in a subsequent longitudinal study.

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