

Sousa MFB, Santos RL, Simões P, Conde-Sala JL, Dourado MCN. Discrepancies Between Alzheimer's Disease Patients' and Caregivers' Ratings About Patients' Quality of Life: A 1-year Observation Study in Brazil. *Alzheimer Disease & Associated Disorders*, 2017, Dec. doi: 10.1097/WAD.0000000000000232

Discrepancies Between Alzheimer's Disease Patients' and Caregivers' Ratings About Patients' Quality of Life: A 1-year Observation Study in Brazil.

Authors: Maria Fernanda B. Sousa¹, PhD, Raquel L. Santos¹, PhD, Pedro Simões, PhD, Josep L. Conde-Sala², PhD, Marcia C. N. Dourado¹, PhD

Institutional affiliations:

¹ Center for Alzheimer's Disease, Institute of Psychiatry, Universidade Federal do Rio de Janeiro, Rio de Janeiro, Brazil

² Faculty of Psychology, University of Barcelona, Barcelona, Spain

Running Title: Discrepancies about patients' QoL after one year

Acknowledgements: Spain's Ministry of Economy and Competitiveness (reference PSI2010-19014), Fundação Carlos Chagas Filho de Apoio a Pesquisa do Estado do Rio de Janeiro (FAPERJ, grant number E-26/102.256/2010) and Conselho Nacional de Pesquisa – Brazil (CNPq).

Word count: 3,220. **Word in abstract:** 195; **Tables:** 4

Corresponding Author: Maria Fernanda B. Sousa

Center for Alzheimer's Disease, Institute of Psychiatry, of the Federal University of Rio de Janeiro Avenida Venceslau Brás, 71 – fundos – Botafogo 22290-140 - Rio de Janeiro - Brazil
Phone: +55 21 988490677

E-mail: maria_fernandabs@yahoo.com.br

Abstract

Objectives: We investigated the factors associated with discrepancies between patients' and caregivers' ratings about patients' general QoL and about the domains of Quality of Life in Alzheimer's disease Scale (QoL-AD) at baseline and 12 months.

Methods: Longitudinal study composed by 114 outpatients with Alzheimer's disease and their caregivers. Patients were assessed with the QoL-AD, Mini Mental State Examination, Assessment Scale of Psychosocial Impact of the Diagnosis of Dementia, Cornell Scale for Depression, Functional Activities Questionnaire, Neuropsychiatric Inventory and Clinical Dementia Rating Scale. Caregivers answered the QoL-AD, Zarit Burden Interview and Sociodemographic Questionnaire.

Results: Linear regression analyses indicated that the factors associated with discrepancies of patients' and caregivers' ratings of patients' QoL-AD were impaired awareness and caregiver burden at baseline and impaired awareness at 12 months. Also, the factor associated with discrepancies in domain memory was impaired awareness and in domain ability to do chores, impaired awareness and functional deficit.

Conclusions: The discrepancies between patients and caregivers were related to awareness and caregiver burden at baseline and to awareness at 12 months. These results raise questions regarding the subjective nature of QoL and the validity of patients' evaluation about their own QoL.

Keywords: Alzheimer's disease; quality of life; awareness; activities of daily living; burden; neuropsychiatry symptoms

Introduction

Alzheimer's disease (AD) presents an insidious onset and progressive deterioration. Memory impairment is the main symptom in AD, especially for recent events¹. The recognition of symptoms by caregivers is associated with early diagnosis, treatment and safety of patients affected by dementia². Patients who lack of awareness, i.e. the capacity to recognize changes caused by the deficits related to the disease process³, generally refuse required interventions or place themselves at risk while performing activities of daily living (ADL)². These situations may impact quality of life (QoL) and well-being of the patient-caregiver dyad.

QoL includes four domains: cognitive functioning, ADL, social interaction and well-being⁴. It is also a subjective phenomenon, so the validity of patients' and caregivers' ratings is discussed. The evaluation of QoL should be answered from the perspective of the subject^{4,5}. However, in assessments of AD patients' clinical status, the caregivers' ratings are often used, in particular to measure functionality and neuropsychiatric symptoms. Therefore, one controversial aspect is that patients' QoL is frequently measured by caregivers' ratings⁴. However, studies suggest that patients with mild and moderate AD can reliably evaluate their own QoL^{4,5}. Nevertheless, there are discrepancies between patients and caregivers about AD patients' QoL, and factors have been associated with divergent ratings^{6,7}.

In longitudinal studies, Missotten *et al.*, 2007⁸ show that the functional and cognitive impairments are related to a negative evaluation of QoL by the patient. In contrast, another study indicated that depression and anxiety⁹ - but not cognitive decline – may be associated with patients' negative assessment of their own QoL. When the relationship between awareness and QoL was evaluated, Conde-Sala *et al.*, 2014⁶ and Hurt *et al.*, 2010¹⁰, observed that patients with impaired awareness overestimate their own QoL. In contrast, the factors that negatively impact caregivers' ratings seem to be the impairment in functionality and presence of neuropsychiatric symptoms^{5,6,11}. Few studies indicate that the caregiver's ratings about the

patients' QoL are negatively influenced by caregiver burden^{6,12} and impaired patients' awareness^{6,13}. Therefore, it is observed that the influence of clinical factors on longitudinal evaluation of patients and caregivers require further clarification.

It is also essential to understand, longitudinally, the increase of discrepancies between patients' and caregivers' ratings about patients' general QoL and about domains of patients' QoL to observe the maintenance or not of variables (clinical aspects and / or sociodemographic data). Nevertheless, longitudinal studies about the increase of discrepancies between patients' and caregivers' ratings about patients' QoL are rare. Two studies evaluated and found that there were discrepancies in total score and in domains of QoL-AD scale^{6,7}.

In our previous cross-sectional study¹⁴, we found discrepancies between patients' and caregivers' ratings about patients' QoL in total score and in domains of QoL-AD scale – ability to do chores, memory and energy. This study aims to investigate the factors associated with the discrepancies between patients' and caregivers' ratings about patients' QoL in total and domains of the QoL-AD scale at baseline and 12 months.

Methods

Design. The study had a longitudinal design.

Participants

The data came from a consecutive sample of 114 outpatients seen at Center for Alzheimer's Disease of the Federal University of Rio de Janeiro (UFRJ). They were all diagnosed as possible or probable AD according to the criteria of the Diagnostic and Statistical Manual of Mental Disorders¹. Only individuals with mild AD according to the Clinical Dementia Rating (CDR) (CDR = 1)^{15,16} and Mini-Mental State Examination^{17,18} scores of 13–26 were included in the study. Patients were excluded if they presented aphasia, head trauma, alcohol abuse, or epilepsy, and uncontrolled medical problems, such as hypertension and diabetes. All the

caregivers were relatives, who routinely cared patients ADL, continuously supervising patient situation.

Measures

The sociodemographic characteristics of the patient and caregiver (age, gender, marital status, schooling and family relationship) were recorded.

Patient measurements

Quality of life. The Quality of Life in Alzheimer's disease (QoL-AD) scale is a 13-item measure of QoL that is completed by both the patients and the caregivers. This questionnaire was developed specifically for the assessment of QoL in patient with AD. The QoL-AD includes 13 domains: physical health, energy, mood, living situation, memory, family, marriage, friends, self, ability to do chores, ability to do things for fun, money and life as a whole. The 13 domains are rated as poor (1), fair (2), good (3), or excellent (4), and the total score ranges from 13 to 52^{19,20}. Cronbach's alpha for both patients' and caregivers' ratings were high range (0.88 and 0.87, respectively)¹⁹.

Cognitive status. The MMSE includes tests of orientation, registration, short-term memory, language use, comprehension, and basic motor skills. The total score ranges from 0 to 30^{17,18}.

Dementia severity: The CDR measures the severity of dementia. The stages range from 0 (no dementia) to 3 (severe dementia) according to the degree of cognitive, behavioral, and ADL impairment^{15,16}.

Awareness: The Assessment Scale of Psychosocial Impact of the Diagnosis of Dementia (ASPIDD) is a 30-question scale based on patients' and caregivers' ratings. This scale was designed to evaluate awareness in patient through the scoring of discrepant

responses between patients and their caregivers across domains that include awareness of cognitive functioning and health condition, ADL, emotional state and social functioning and relationships. The ratings of awareness are preserved (0 to 4) to absent (18 or more)³.

Depressive symptoms: The Cornell Scale for Depression in Dementia (CSDD) assesses mood symptoms, physical symptoms, circadian functions, and behavioral symptoms related to depression. Scores above seven indicate the presence of depression^{21,22}.

Functionality: The Pfeffer Functional Activities Questionnaire (PFAQ) is a caregiver-reported inventory that evaluates the ADL. The ratings for each item ranges from normal (0) to dependent (3), with a total of 30 points^{23,24}.

Neuropsychiatric symptoms: The Neuropsychiatric Inventory (NPI) evaluates 12 domains: delusions, hallucinations, dysphoria, anxiety, agitation/aggression, euphoria, disinhibition, irritability/lability, apathy, aberrant motor activity, night-time behavior disturbances, and appetite and eating abnormalities. Each item is rated in relation to their frequency [one (absent) to four (frequently) and intensity one (mild) to three (severe)]. The total score can range from zero to 144 points^{25,26}. Cronbach's alpha for overall reliability was 0.88²⁵.

Caregiver measurements

Burden: The Zarit Burden Interview (ZBI) consists of 22 items. The caregivers assess the impact of the illness on their own lives by indicating how often they experience a particular feeling: never (0) to nearly always (4). The total score ranges from zero to 88^{27,28}.

Procedure

The interviews and questionnaires were administered to patients and caregivers separately and independently at baseline and 12 months (2012-2016). The patients had their quality of life,

cognition and awareness assessed. The caregivers provided information about the patients (including sociodemographic, QoL, ADL, neuropsychiatric symptoms, depressive symptoms and dementia severity) and had caregiver burden assessed. The caregivers were blinded to the statements of the patients.

The psychiatrists from the Dementia Unit identified eligible people according to the inclusion criteria. All of the caregivers had previously been informed of the diagnosis by the psychiatrists. Informed consent was obtained for patients and caregivers. The study was approved by Ethics Committee of the Institute of Psychiatry at the UFRJ.

Data analysis

All variables were inspected for normality before analysis. Mann-Whitney U for continuous variables and Pearson χ^2 test for categorical variables were performed as an initial comparison of caregivers and patients' sociodemographic and clinical characteristics at baseline, 12 months and lost cases.

The Wilcoxon test was used to assess the discrepancies between patients' and caregivers' ratings of patients' QoL and to identify the discrepancies between ratings in total and various domains of the QoL-AD scale (physical health, energy, mood, living situation, memory, family, marriage, friends, self, ability to do chores, ability to do things for fun, money and life as a whole) at baseline and 12 months. We used Cohen's *d* to measure effect size in relation to discrepancies between patients' and caregivers' QoL-AD scores. The values indicated weak (< 0.5), moderate (0.5-0.8), or high (> 0.8) effects.

Multivariate linear regression analyses were completed to identify the variables that were associated with the discrepancies between patients' and caregivers' ratings in total and various domains of the QoL-AD scale at baseline and 12 months. We used the total scores of the discrepancies at baseline and 12 months such as dependent variables. Also, we used the

domains of QoL-AD scale that presented discrepancies with high effect size at 12 months such as dependent variables. The independent variables were the scores of MMSE, CDR, CSDD, PFAQ, ASPIDD, NPI, ZBI and sociodemographic data. Linear regressions were conducted using the Enter method. All variables were introduced in a single step, adjusting the model with significant variables. In the linear regressions analyses, the coefficients of contribution for each variable were calculated by: beta coefficient \times the coefficient of correlation with the dependent variable.

The statistical analysis was performed using the Statistical Package for Social Sciences (IBM Corporation, Armonk, NY) for Windows v. 22.0, with a significance level that was equal to or less than 0.05 and confidence intervals (CI) at 95%.

Results

Clinical and sociodemographic data of the lost cases

A total of 39 of the 114 baseline cases were lost during the follow-up, because of refusal of the caregiver to be interviewed 21 (53.9%), medical complications 10 (25.7%), mobility difficulties 4 (10.3%), patients' death 3 (7.6%) and patient's refusal to participate in the interview 1 (2.5%). The characteristics related to loss of patients were less schooling and greater dementia severity. For caregivers, the related factors were high schooling and family relationship. The differences between the follow-up and lost cases are shown in Table 1.

Table 1

Discrepancies of patients' and caregivers' ratings of patients' QoL-AD

Scores and significant discrepancies of patients' and caregivers' ratings of patients' general QoL-AD and of each domain of QoL-AD at baseline and 12 months are provided in table 2.

At baseline. The highest discrepancies between patients' and caregivers' ratings of patients' QoL-AD domains were ability to do chores ($d = 0.92$); and memory ($d = 0.80$).

At 12 months. The highest discrepancies between patients' and caregivers' ratings of patients' QoL-AD domains were memory ($d = 1.07$); and ability to do chores ($d = 0.90$).

Table 2

Multivariate linear regression analyses

At baseline. Linear regression indicated that the factors associated with discrepancies of patients' and caregivers' ratings of patients' QoL-AD were impaired awareness ($p = 0.001$) and caregiver burden ($p = 0.029$). The highest contribution effect was impaired awareness (14.6%).

At 12 months. Impaired awareness ($p < 0.001$) was related to discrepancies of patients' and caregivers' ratings of patients' QoL-AD. The contribution effect was impaired awareness (24.5%).

Sociodemographic data, CSDD and PFAQ were not statistically significant at baseline and 12 months.

The linear regression analyses are shown in Table 3.

Table 3

When the effect of patients' total QoL-AD score was analysed as an independent variable, it explained 15.1% of discrepancy between patients and caregivers at baseline ($r^2 = 0.151$, $\beta = 0.38$, $t = 3.60$, $p = 0.001$) and 30.4% of discrepancy at 12 months ($r^2 = 0.304$, $\beta = 0.55$, $t = 5.64$, $p < 0.001$).

Memory domain: Linear regression indicated that the factor associated with discrepancies of patients' and caregivers' ratings of patients' QoL-AD in domain memory was impaired awareness ($p = 0.002$).

Ability to do chores domain: Impaired awareness ($p = 0.003$), and functional deficit ($p = 0.022$) were related to discrepancies of patients and caregivers' ratings of patients' QoL-AD in the domain ability to do chores.

The linear regression analyses are shown in Table 4.

Table 4

Discussion

In this study, there were discrepancies between patients' and the caregivers' ratings of patients' QoL at baseline and also at follow-up, one year after the first evaluation. This result is corroborated by other studies that demonstrate the presence of discrepancies in patients' and caregivers' ratings^{6,7}. At baseline, the factors associated with the discrepancy between patients and caregivers were impaired awareness and burden. At 12 months, the discrepancy between patients and caregivers was related to impaired awareness.

Effect of caregiver burden on patients QoL assessment

For caregivers, burden is determined by multiple factors: aspects that are related to patients such as level of functional impairment, neuropsychiatric symptoms and clinical comorbidities; physical, emotional and social characteristics of caregiver; caregiver coping capacity, ability to manage daily patients care, social and health resources²⁹. The cross-sectional finding about the influence of burden in discrepancy between patients and caregivers, is consistent with recent findings that demonstrate an association between

caregiver's psychosocial well-being (particularly level of burden and depression) and these discrepancies in ratings of patients' QoL^{6,30}. In a study of factors that influence caregiver evaluations about patient aspects, caregiver burden was the most important factor to explain the variability in assessments, especially in relation to early-stage patients due to greater initial impact of the diagnosis of disease²⁹. Caregiver burden can lead to negative assessments of patients' status, particularly in neuropsychiatric symptoms and QoL^{6,30}. Caregivers with moderate levels of burden experience difficulties in managing patients care and in their daily situations, which negatively affects their ratings about the patients' QoL^{4,31}. Thus, burden is a multidimensional response to impact caused by the disease. Understanding the elements of patients' disease and the care experience associated with caregiver burden can be useful in predicting a positive or negative evaluation of caregivers about patients' QoL, assisting in daily management with patients.

Effect of awareness on patients QoL assessment

Another factor that influenced the level of discrepancy was impaired awareness at both baseline and 12 months^{6,32}. The impairment of awareness has been related to more positive patients' ratings about their own QoL and to more negative assessment by caregivers^{7,14}. This lack of awareness suggests that patients' ratings may correspond to mental image before their disease⁶.

Moreover, patients may be only partially aware of some deficits and changes in some domains, but not in others¹⁰. The individual variability in awareness and its relation to different dimensions may be observed in patients with mild to moderate AD, in studies focusing mainly the recognition of cognitive deficits². Different domains of awareness have been studied, such as the ability to monitor their own performance, evaluate the functioning of a particular domain and reflect on the nature and impact of diagnostic^{3,33}. Clare *et al.*, 2012²

suggest that two domains of awareness - memory and functionality – show weak correlation with the patients’ ratings about their own QoL. Another study indicated significant relationship between patients’ ratings of their own QoL and the level of awareness in three areas of social-emotional functioning (emotional recognition and empathy, social relations and prosocial behavior)³³. These aspects illustrate the complexity and heterogeneity of the phenomenon. Future studies may investigate the relationship between patterns of change in QoL and the perception of specific domains of awareness.

Evaluation of QoL in follow-up

At 12 months, despite the disease progression, the patients’ ratings about their own QoL did not change, while the caregivers’ ratings were slightly worse, even if not statistically significant. Studies indicate that patients scores do not change substantially at follow-up⁸, while caregivers scores significantly decrease¹¹. Thus, the stability of patients’ ratings about their own QoL over time is in agreement with several studies that did not find a relation between patients’ ratings and cognitive decline^{5,13}. Patients may develop mechanisms to cope with new difficulties that they are facing, and may not perceive any decline in their QoL⁷. Another explanation might be that the study of Andrieu *et al.* (2016)⁷ did not evaluate the level of impaired awareness. Thus, it may be assumed that, although the discrepancy is not related to cognitive deficit, the participants demonstrate higher lack of awareness and presence of neuropsychiatric symptoms, which may have contributed to stability of patients’ assessment. This context leads some authors to question the reliability of patients’ ratings about their own QoL when they present greater impairment of awareness. The impairment of ability to judge and evaluate, may interfere in patients’ perception of their difficulties and lead to underestimation of their importance³². Other authors argue that the two perspectives

(patients and caregivers) may be considered as equally valid and may highlight different aspects related to QoL^{4,5}.

Evaluation of QoL domains in follow-up

In evaluation of QoL, we can also analyze multidimensional perception of patients and caregivers, because QoL-AD scale measures aspects regarding cognitive functioning, ADL, social interaction and well-being in its 13 domains⁴. Multidimensional perception is useful to explain the importance of various domains of QoL, which can approach aspects of clinical practice⁴. At both moments, patients and caregivers' evaluation in each domain was compared to verify if there was discrepancy. At baseline, we found discrepancies in domains energy, mood, memory, friends, ability to do chores and ability to do things for fun. At follow-up, domains with significant difference were energy, mood, memory, family, friends, ability to do chores, ability to do things for fun and life as a whole. As expected, more domains showed discrepancy at follow-up. This finding may be related to differences between what is relevant for the assessment of patients and caregivers regarding QoL. Thus, interpretation may be ambiguous when patients and caregivers are asked to answer the same questions about QoL³⁴. Furthermore, we analyzed which variables were related to domains memory and ability to do chores that presented discrepancies with high effect size at 12 months. In domain memory, impaired awareness was associated with discrepancies of patients' and caregivers' ratings of patients' QoL-AD, while in domain ability to do chores, impaired awareness and functional deficit were related to discrepancies. It should be emphasized that most patients presented impaired awareness at baseline and this impairment was increased at follow-up; maybe patients with memory deficits and decline in other cognitive abilities care less about these abilities¹⁴. For caregivers, they may perceive the loss of patients' abilities, especially functional deficits^{4,6}, and understand them as a source of suffering for themselves and

patients³⁴. Therefore, patients' and caregivers' perception are related to individual aspects and should be both considered in evaluation of QoL.

Some limitations of this study must be acknowledged. One limitation is the loss of patients to follow-up of assessment, patients who may have had significant variations in QoL may not have been reevaluated. Also, the findings are specific to patients with mild AD and may not be generalizable to other stages of AD. Furthermore, the cognitive status was evaluated only with MMSE. Finally, clinical aspects of caregivers such as the level of depression, and anxiety were not evaluated.

Conclusions

We identified that discrepancies between patients and caregivers were related to awareness and caregiver burden at baseline and awareness at 12 months. Therefore, the concept of QoL in AD and the discrepancies between patients and caregivers bring questions regarding the subjective nature of construct and the validity of patients' evaluation about their own QoL.

The relevance of assessing the discrepancy is the possibility to assist the validity of patients' ratings about their own QoL and understanding dimensional aspects of QoL. Furthermore, monitoring of QoL changes in patients with AD may suggest new areas of intervention to maintain or improve QoL of patients and caregivers. Moreover, future studies should identify strategies to improve accuracy and reliability of QoL and other subjective status of patients with AD in order to preserve decision-making and autonomy.

Conflict of interest

None.

Acknowledgments

This research in Brazil was supported by the Conselho Nacional de Pesquisa (CNPq) and Fundação Carlos Chagas Filho de Apoio a Pesquisa do Estado do Rio de Janeiro (FAPERJ, grant number E-26/102.256/2010). The research of Spain was conducted in the Memory and Dementia Assessment Unit of the Santa Caterina Hospital (Salt, Spain) and formed part of the SIDEA research project (Seguimiento Integral de la Enfermedad de Alzheimer / Comprehensive Follow-Up of Alzheimer's Disease, 2003–12).

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TABLE 1. Comparison (at baseline) of two groups

| | Baseline | | Lost to follow-up | | Differences | |
|----------------------------|----------|---------|-------------------|---------|-------------|-------------------------------|
| | n = 75 | | n = 39 | | Test | P |
| Patients | | | | | | |
| Age, mean (SD) | 76.5 | (6.9) | 77.0 | (6.8) | 0.2 | 0.827 ^a |
| Women, n (%) | 52 | (69.3) | 23 | (59.0) | 1.2 | 0.269 ^b |
| Schooling, n (%) | | | | | 15.4 | 0.002^b |
| 1 - 4 years | 19 | (25.3) | 21 | (53.8) | | |
| 5 - 8 years | 27 | (36.0) | 14 | (35.9) | | |
| 9 - 11 years | 22 | (29.3) | 1 | (2.6) | | |
| ≥ 12 years | 7 | (9.3) | 3 | (7.7) | | |
| Marital Status, n (%) | | | | | 1.7 | 0.422 ^b |
| Married | 34 | (45.3) | 22 | (56.4) | | |
| Widowed | 33 | (44.0) | 15 | (38.5) | | |
| Other | 8 | (10.7) | 2 | (5.1) | | |
| QoL-AD, mean (SD) | 33.1 | (4.5) | 33.3 | (4.5) | 0.1 | 0.907 ^a |
| MMSE, mean (SD) | 21.2 | (3.5) | 21.1 | (3.2) | 0.2 | 0.782 ^a |
| PFAQ, mean (SD) | 12.8 | (8.0) | 13.2 | (9.1) | 0.0 | 0.988 ^a |
| ASPIDD, mean (SD) | 5.8 | (4.2) | 7.3 | (5.3) | 1.3 | 0.189 ^a |
| CSDD, mean (SD) | 6.5 | (5.3) | 7.3 | (5.4) | 0.7 | 0.440 ^a |
| NPI, mean (SD) | 11.0 | (10.1) | 12.6 | (12.9) | 0.1 | 0.902 ^a |
| CDR, n (%) | | | | | | |
| 1 | 75 | (100.0) | 39 | (100.0) | | |
| Caregivers | | | | | | |
| Age, mean (SD) | 59.6 | (13.4) | 54.8 | (14.7) | 1.5 | 0.117 ^a |
| Women, n (%) | 65 | (86.7) | 30 | (76.9) | 1.7 | 0.185 ^b |
| Schooling, n (%) | | | | | 20.6 | < 0.000^b |
| 1 - 4 years | 5 | (6.7) | 5 | (12.8) | | |
| 5 - 8 years | 18 | (24.0) | 24 | (61.5) | | |
| 9 - 11 years | 32 | (42.7) | 5 | (12.8) | | |
| ≥ 12 years | 20 | (26.7) | 5 | (12.8) | | |
| Family Relationship, n (%) | | | | | 10.4 | 0.015^b |
| Spouse | 27 | (36.0) | 18 | (46.2) | | |
| Sons | 7 | (9.3) | 4 | (10.3) | | |
| Daughters | 24 | (32.0) | 17 | (43.6) | | |
| Other (sisters or nieces) | 17 | (22.7) | --- | ----- | | |
| Living together, n (%) | | | | | 0.0 | 0.785 ^b |
| Yes | 52 | (69.3) | 28 | (71.8) | | |
| No | 23 | (30.7) | 11 | (28.2) | | |
| QoL-AD, mean (SD) | 29.8 | (5.7) | 29.5 | (5.5) | 0.4 | 0.632 ^a |
| ZBI, mean (SD) | 28.3 | (15.4) | 28.6 | (17.2) | 0.0 | 0.929 ^a |

^a Mann-Whitney U test; ^b Pearson χ^2 test

QoL-AD, Quality of Life - Alzheimer's disease scale; MMSE, Mini Mental State Examination; PFAQ, Functional Activities Questionnaire; ASPIDD, Assessment Scale of Psychosocial Impact of the Diagnosis of Dementia; CSDD, Cornell Scale for Depression in Dementia; NPI, Neuropsychiatric Inventory; CDR, Clinical Rating Dementia; ZBI, Zarit Burden Interview

Table 2. Baseline and follow-up scores of clinical variables

| | Baseline | Follow-up | Differences | | |
|-------------------|---------------|---------------|-------------|---------------------|------------|
| | <i>n</i> = 75 | <i>n</i> = 75 | Test | <i>p</i> | <i>d/V</i> |
| Patients | | | | | |
| QoL–AD, mean (SD) | 33.1 (4.5) | 33.1 (5.3) | 0.0 | 0.945 ^a | 0.01 |
| MMSE, mean (SD) | 21.2 (3.5) | 19.5 (4.3) | 3.7 | <0.001 ^a | 0.43 |
| PFAQ, mean (SD) | 12.8 (8.0) | 16.4 (8.5) | 5.0 | <0.001 ^a | 0.43 |
| ASPIDD, mean (SD) | 5.8 (4.2) | 7.5 (4.9) | 3.0 | 0.002 ^a | 0.38 |
| CSDD, mean (SD) | 6.5 (5.3) | 6.8 (4.3) | 0.4 | 0.632 ^a | 0.05 |
| NPI, mean (SD) | 11.0 (10.1) | 13.9 (10.4) | 2.1 | 0.028 ^a | 0.28 |
| CDR, <i>n</i> (%) | | | 34.4 | <0.001 ^b | 0.47 |
| 1 | 75 (100.0) | 47 (62.7) | | | |
| 2 | | 28 (37.3) | | | |
| Caregivers | | | | | |
| QoL–AD, mean (SD) | 29.8 (5.7) | 28.8 (5.3) | 1.6 | 0.093 ^a | 0.18 |
| ZBI, mean (SD) | 28.3 (15.4) | 29.3 (17.6) | 0.4 | 0.665 ^a | 0.06 |

^a Wilcoxon test; ^b Pearson χ^2 test; Effect size: Cohens *d* / Cramer's *V*

QoL–AD, Quality of Life – Alzheimer's disease scale; MMSE, Mini Mental State Examination; PFAQ, Functional Activities Questionnaire; ASPIDD, Assessment Scale of Psychosocial Impact of the Diagnosis of Dementia; CSDD, Cornell Scale for Depression in Dementia; NPI, Neuropsychiatric Inventory; CDR, Clinical Rating Dementia; ZBI, Zarit Burden Interview

Table 3. Discrepancies of patients' and caregivers' ratings of patients' QoL-AD

| QoL-AD | Baseline | | | | | | 12 months | | | | | |
|------------------------------|--------------|--------------|--------------|------|------------------|----------|--------------|--------------|--------------|------|------------------|----------|
| | Patients | | Caregivers | | Discrepancies | | Patients | | Caregivers | | Discrepancies | |
| | n = 75 | n = 75 | n = 75 | | n = 75 | n = 75 | n = 75 | n = 75 | n = 75 | | n = 75 | n = 75 |
| | Mean (SD) | Mean (SD) | Mean (SD) | Test | <i>p</i> | <i>d</i> | Mean (SD) | Mean (SD) | Mean (SD) | Test | <i>p</i> | <i>d</i> |
| Physical health | 2.57 (0.66) | 2.58 (0.75) | 0.01 (0.83) | 0.12 | 0.905 | 0.01 | 2.54 (0.87) | 2.49 (0.68) | -0.05 (0.98) | 0.49 | 0.619 | 0.06 |
| Energy | 2.57 (0.79) | 2.14 (0.86) | -0.42 (0.93) | 3.67 | <0.001 | 0.52 | 2.58 (0.80) | 2.13 (0.81) | -0.45 (0.85) | 3.98 | <0.001 | 0.55 |
| Mood | 2.60 (0.75) | 2.36 (0.78) | -0.24 (0.89) | 2.23 | 0.025 | 0.31 | 2.62 (0.83) | 2.40 (0.78) | -0.22 (0.87) | 2.18 | 0.029 | 0.27 |
| Living situation | 3.18 (0.56) | 3.05 (0.73) | -0.13 (0.74) | 1.55 | 0.119 | 0.19 | 3.24 (0.69) | 3.04 (0.90) | -0.20 (1.05) | 1.48 | 0.139 | 0.24 |
| Memory | 2.09 (0.64) | 1.58 (0.63) | -0.50 (0.97) | 3.93 | <0.001 | 0.80 | 2.09 (0.71) | 1.41 (0.54) | -0.68 (0.98) | 4.86 | <0.001 | 1.07 |
| Family | 2.98 (0.62) | 2.84 (0.71) | -0.14 (0.72) | 1.71 | 0.087 | 0.21 | 3.17 (0.68) | 2.82 (0.82) | -0.34 (0.92) | 3.13 | 0.002 | 0.46 |
| Marriage | 1.48 (1.63) | 1.42 (1.56) | -0.05 (1.01) | 0.79 | 0.425 | 0.03 | 1.57 (1.62) | 1.46 (1.55) | -0.10 (1.18) | 0.79 | 0.428 | 0.06 |
| Friends | 2.85 (0.71) | 2.44 (0.90) | -0.41 (0.93) | 3.44 | 0.001 | 0.50 | 2.84 (0.78) | 2.45 (0.96) | -0.38 (0.91) | 3.38 | 0.001 | 0.44 |
| Self | 2.66 (0.72) | 2.53 (0.74) | -0.13 (1.05) | 1.08 | 0.278 | 0.17 | 2.70 (0.76) | 2.33 (0.64) | -0.37 (0.88) | 3.44 | 0.001 | 0.52 |
| Ability to do chores | 2.73 (0.62) | 2.08 (0.78) | -0.65 (0.83) | 5.27 | <0.001 | 0.92 | 2.61 (0.73) | 1.93 (0.77) | -0.68 (0.96) | 4.92 | <0.001 | 0.90 |
| Ability to do things for fun | 2.44 (0.91) | 2.08 (0.92) | -0.36 (1.04) | 2.87 | 0.004 | 0.39 | 2.37 (0.85) | 2.00 (0.83) | -0.37 (0.96) | 3.09 | 0.002 | 0.44 |
| Money | 2.16 (0.77) | 2.22 (0.78) | 0.06 (0.93) | 0.63 | 0.523 | 0.07 | 2.17 (0.81) | 2.06 (0.89) | -0.10 (1.04) | 0.94 | 0.366 | 0.12 |
| Life as a whole | 2.74 (0.69) | 2.53 (0.70) | -0.21 (0.82) | 2.14 | 0.032 | 0.30 | 2.65 (0.70) | 2.36 (0.74) | -0.29 (0.83) | 2.89 | 0.004 | 0.40 |
| Total score | 33.10 (4.51) | 29.89 (5.76) | -3.21 (5.74) | 4.48 | <0.001 | 0.62 | 33.17 (5.39) | 28.89 (5.33) | -4.28 (5.84) | 5.23 | <0.001 | 0.79 |

Wilcoxon test; *d*, Cohen's *d*; QoL-AD, Quality of Life – Alzheimer's disease scale

Table 4. Factors associated with discrepancies between patients and caregivers in QoL-AD**A. Baseline**

| $r^2 = 0.231$ | β | t | p | r | CC (%) |
|--|-------------|------|------------------|-------|--------|
| Awareness (ASPIDD) | 0.331 | 3.11 | 0.003 | 0.389 | 12.9 |
| Burden (ZBI) | 0.248 | 2.28 | 0.025 | 0.335 | 8.3 |
| Behaviour (NPI) | 0.102 | 0.96 | 0.341 | 0.185 | 1.9 |
| F (df), p | 7.1 (3, 71) | | <0.001 | | |
| Collinearity. TOL / VIF: 0.92-0.95 / 1.04-1.08. Condition Index: 5.3 | | | | | |

B. Follow-up

| $r^2 = 0.317$ | β | t | p | r | CC (%) |
|--|--------------|------|------------------|-------|--------|
| Awareness (ASPIDD) | 0.465 | 4.62 | <0.001 | 0.516 | 24.0 |
| Burden (ZBI) | 0.087 | 0.83 | 0.408 | 0.216 | 1.9 |
| Behaviour (NPI) | 0.188 | 1.78 | 0.079 | 0.312 | 5.8 |
| F (df), p | 10.9 (3, 71) | | <0.001 | | |
| Collinearity. TOL / VIF: 0.86-0.95 / 1.05-1.15. Condition Index: 5.3 | | | | | |

Multiple linear regression. F = ANOVA; r^2 = coefficient of determination; β = standardized beta coefficient; r = Pearson correlation (zero-order); CC = coefficient of contribution (%), [$(\beta \cdot r) \times 100$].

TOL = Tolerance; VIF = Variance Inflation Factor

QoL-AD, Quality of Life – Alzheimer's disease scale; ASPIDD, Assessment Scale of Psychosocial Impact of the Diagnosis of Dementia; ZBI, Zarit Burden Interview; NPI, Neuropsychiatric inventory.

Table 5. Factors associated with discrepancies between patients and caregivers in domains of QoL-AD at 12 months**A. Memory**

| $r^2 = 0.225$ | β | t | p | r | CC (%) |
|---|-------------|------|--------------|-------|--------|
| Awareness (ASPIDD) | 0.383 | 3.18 | 0.002 | 0.437 | 16.7 |
| Functional activities (PFAQ) | 0.113 | 0.95 | 0.341 | 0.283 | 3.2 |
| Burden (ZBI) | 0.129 | 1.14 | 0.256 | 0.169 | 2.2 |
| Behaviour (NPI) | 0.074 | 0.65 | 0.515 | 0.061 | 0.4 |
| F (df), p | 4.8 (4, 70) | | 0.002 | | |
| Collinearity. TOL / VIF: 0.77-0.88 / 1.12-1.29. Condition index: 6.79 | | | | | |

B. Ability to do chores

| $r^2 = 0.333$ | β | t | p | r | CC (%) |
|---|-------------|------|------------------|-------|--------|
| Awareness (ASPIDD) | 0.346 | 3.10 | 0.003 | 0.489 | 16.9 |
| Functional activities (PFAQ) | 0.282 | 2.57 | 0.012 | 0.449 | 12.7 |
| Burden (ZBI) | 0.083 | 0.80 | 0.426 | 0.036 | 0.3 |
| Behaviour (NPI) | 0.148 | 1.40 | 0.166 | 0.229 | 3.4 |
| F (df), p | 8.4 (4, 70) | | <0.001 | | |
| Collinearity. TOL / VIF: 0.77-0.88 / 1.12-1.29. Condition index: 6.79 | | | | | |

Multiple linear regression. $F =$ ANOVA; $r^2 =$ coefficient of determination; $\beta =$ standardized beta coefficient; $r =$ Pearson correlation (zero-order); CC = coefficient of contribution (%), [$(\beta \cdot r) \times 100$].

TOL = Tolerance; VIF = Variance Inflation Factor

QoL-AD, Quality of Life – Alzheimer's disease scale; ASPIDD, Assessment Scale of Psychosocial Impact of the Diagnosis of Dementia; FAQ, Functional Activities Questionnaire; ZBI, Zarit Burden Interview; NPI, Neuropsychiatric inventory.