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ORIGINAL ARTICLE

Quality of life in mild dementia: patterns of change in self and caregiver ratings over time

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Objectives: To determine changes over time in self and caregiver ratings of quality of life (QoL) in people with dementia (PwD) and to identify factors associated with changes in QoL ratings.
Methods: In this longitudinal study, 69 people with mild Alzheimer's disease and their caregivers were assessed at baseline and after 1 year. We examined the association of QoL ratings with the following variables at the two time points: awareness of disease, cognitive status, mood, functionality, neuropsychiatric symptoms, and caregiver burden. Multivariate regression analyses were conducted to examine the contribution of co-factors.
Results: At baseline, PwD self-ratings of QoL were associated with caregiver ratings of PwD QoL ($p = 0.001$). Caregiver ratings were associated with PwD mood ($p = 0.001$) and self-rated QoL ($p = 0.001$). After 1 year, caregiver ratings of PwD QoL changed significantly ($p = 0.049$, $d = -0.27$), whereas PwD self-ratings did not ($p = 0.89$, $d = 0.09$). PwD awareness of disease changed significantly ($p = 0.001$) at 1 year, having declined in 25.4% and improved in 12.3% of participants. PwD QoL self-ratings were associated with caregiver ratings ($p = 0.001$). Caregiver ratings of PwD QoL after 1 year were associated with PwD mood ($p = 0.029$), self-reported QoL ($p = 0.001$), and awareness of disease ($p = 0.033$).
Conclusions: The association between self and caregiver ratings of PwD QoL was maintained over 1 year. The primary factors accounting for the change in caregiver ratings were PwD mood and awareness of disease. QoL and cognitive impairment seem to be relatively independent in mild dementia.

Keywords: Dementia; quality of life; depression; functionality; self-report

Introduction

Quality of life (QoL) is a multidimensional and complex concept, associated with goals, expectations, patterns, and concerns, encompassing the physical and psychological domains, independence, social interaction, environment, and spiritual aspects.[1] In dementia, QoL involves cognitive functioning, activities of daily living, social interaction, and psychological well-being.[2]

There is evidence that people with mild to moderate dementia can reliably rate their own QoL.[3] However, there is substantive literature on the differences between self-reported and caregiver-reported QoL in people with dementia (PwD).[4-6] These differences have been interpreted as indicative of low level of agreement,[7] disagreement,[8] moderately low correlation,[9] and even high correlation.[10] Recognizing the often poor correlations between PwD and caregiver QoL ratings, Huang et al.[11] have suggested as a possible explanation that PwD and caregivers employ different standards to evaluate QoL. Caregivers might be highly distressed by dementia problem behaviors and as a result rate PwD QoL below self-report levels, leading to a marked discrepancy in scores.[11] Furthermore, PwD who have experienced memory loss and decline in other cognitive skills may partially downgrade the importance of these abilities and place more importance on other abilities that are not impaired. Caregivers witnessing the losses experienced by PwD may interpret these losses as a source of distress.[6,11] Other more recent studies have sought to explore predictors for the discrepancies between self-reported and caregiver perceptions of PwD QoL, incorporating associations with PwD characteristics such as mood,[12,13] neuropsychiatric symptoms,[14] and unawareness of impairment and behavioral disturbances[15] as well as caregiver factors such as perceived burden of care. The nature of the PwD-caregiver relationship has also been considered.[16]

Nevertheless, certain aspects of the factors that influence perceived QoL in PwD and caregivers require further clarification, especially regarding how QoL assessment changes as dementia progresses. Studies with care home residents have reported no change in mean PwD QoL scores at 20 weeks,[17] but a significant decline in PwD mean scores at 2 years.[18] Findings from community-dwelling

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samples with mild-to-moderate dementia have been similarly variable. In one study, PwD self-ratings remained stable over the follow-up period, while caregiver ratings declined with increasing impairment.[7] In contrast, it has been suggested that increases or reductions in QoL ratings are not directly attributable to changes in clinical variables.[19]

In this context, the present study aims to determine the patterns of change over time in self and caregiver ratings of PwD QoL and to identify the factors associated with any changes in QoL ratings. Taking into account the disease process, and based on the assumption that QoL is the result of a complex, multidimensional, and essentially subjective appraisal process, we hypothesized that the differences between self and caregiver QoL ratings in people with mild Alzheimer's disease (AD) are not directly related to degree of cognitive impairment.

Materials and methods

Design and study population

In this longitudinal study, a consecutive series of 88 PwD and 88 family caregivers was selected from an AD outpatient unit. Of these, 19 PwD were excluded because of low cognitive status (n=10), medical complications (n=5), and mobility difficulties (n=5), for a final sample of 69 PwD-caregiver pairs. Analyses indicated that this sample size had a 95% power to detect effects if they existed, assuming a large effect size, for the major analyses planned.

A psychiatrist made the clinical diagnosis of AD using clinical interviews with the PwD and caregivers, cognitive screening tests, laboratory tests, and imaging exams. The participants were diagnosed with possible or probable AD according to DSM-IV-TR.[20] Only individuals with mild AD according to the Clinical Dementia Rating (CDR = 1)[21] and Mini-Mental State Examination (MMSE score = 18-26)[22] were included in the study. Aphasia, head trauma, alcohol abuse, epilepsy (as defined by DSM-IV-TR criteria), and uncontrolled medical conditions (such as hypertension and diabetes) were exclusion criteria. All PwD were already taking an anticholinesterase inhibitor (galantamine, 8.0 mg, 16.0 mg, or 24.0 mg [day]; donepezil, 10.0 mg [day], or rivastigmine, 6.0 mg, 9.0 mg, or 12.0 mg [day]). Likewise, PwD with depressive symptoms were being treated with fluoxetine (20.0 mg), citalopram (20.0 mg), paroxetine (20.0 mg), or sertraline hydrochloride (50.0 mg).

The primary family caregiver was defined as the person with the most responsibilities relating to the care of the PwD. The caregiver-PwD dyad met face-to-face at least once a week, and the caregivers were able to provide detailed information about the PwD. All of the caregivers had been previously informed of the diagnosis by the psychiatrist.

PwD-caregiver dyads were assessed at baseline and after 1 year. Each PwD-caregiver pair was interviewed individually. PwD completed assessments of awareness of disease, cognition, and QoL. Caregivers provided demographic information about the PwD and assessed PwD's ability to perform activities of daily living (ADLs), QoL, depression, and dementia severity. Caregivers also assessed their own burden of care. The instruments were presented in the same order to all participants.

Instruments

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 PwD and the caregiver. The QoL-AD includes 13 domains: physical health, energy, mood, living situation, memory, family, marriage, friends, chores, fun, money, self, 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. PwD and caregiver ratings of PwD QoL were analyzed separately. We used both versions of the scale.[23,24]

Awareness of disease. The Assessment Scale of Psychosocial Impact of the Diagnosis of Dementia (ASPIDD) is a 30-question scale based on PwD and caregiver reports. This scale was designed to evaluate awareness of disease in PwD through the scoring of discrepant responses across domains that include awareness of cognitive deficits, emotional status, relationships, and ADLs. The caregiver answers the same questions as the PwD. The discordance rate is calculated as the number of discrepant responses between PwD and the caregiver. Awareness is rated as preserved (0 to 4), mildly impaired (5 to 11), moderately impaired (12 to 17), and absent (18 or more).[25,26]

Cognitive function. The Mini-Mental State Examination (MMSE) includes tests of orientation, registration, short-term memory, language use, comprehension, and basic motor skills. The total score ranges from 0 to 30. Lower scores indicate impaired cognition.[22,27]

Dementia severity. The Clinical Dementia Rating (CDR) measures the severity of dementia. Severity stages range from 0 (no dementia) to 3 (severe dementia) according to the degree of cognitive, behavioral, and ADL impairment informed by the caregiver. We used the full protocol.[21,28]

Depressive symptoms. The Cornell Scale for Depression in Dementia (CSDD) assesses mood symptoms, physical symptoms, circadian functions, and behavioral symptoms related to depression and informed by the caregiver. Scores above 7 indicate the presence of depression.[29,30]

Functionality. The Pfeffer Functional Activities Questionnaire (PFAQ) is a caregiver-reported inventory that evaluates ADLs. The ratings for each item range from normal (0) to dependent (3), for a total of 30 points. Higher scores indicate worse functional status.[31]

Neuropsychiatric symptoms. The Neuropsychiatric Inventory (NPI) evaluates the presence of delusions, hallucinations, dysphoria, anxiety, agitation/aggression, euphoria, disinhibition, irritability/lability, apathy, aberrant motor activity, night-time behavior disturbances, and appetite and eating abnormalities as informed by the caregiver. Each item is rated in relation to their frequency (1 [absent] to 4 [frequent]) and intensity (1 [mild] to 3 [severe]). The total score can range from zero to 144 points.[32,33]

Burden. The Zarit Burden Interview (ZBI) consists of 22 items. The caregiver assesses the impact of the illness on his/her own life by indicating the frequency of a particular feeling: never (0), rarely (1), sometimes (2), quite frequently (3), or nearly always (4). The total score ranges from zero to 88. Higher scores indicate a higher burden.[34,35]

This study was approved by the Ethics Committee of the Institute of Psychiatry at the Universidade Federal do Rio de Janeiro (UFRJ), Brazil. All PwD were capable of providing signed informed consent. Family caregivers also signed informed consent forms prior to the first interview.

Statistical analysis

All statistical analyses were performed with SPSS version 22.0. Clinical and socio-demographic characteristics of the sample were analyzed using descriptive analysis (absolute number and relative frequencies for qualitative variables and measures of central tendency and dispersion for quantitative variables). The Kolmogorov-Smirnov test was used to verify the normal distribution of variances. We used the *t* independent test, analysis of variance (ANOVA), and the nonparametric Pearson chi-square and Kruskal-Wallis tests to verify the relationship between QoL at baseline and follow-up interviews. The paired Student's *t* test was used to investigate the change in QoL, cognitive function, ADLs, depressive symptoms, neuropsychiatric symptoms, and caregiver burden after 1 year. Cohen's d was used as a measure of effect size when the comparison of two means revealed significant differences. Effect sizes for differences between means (d) were defined as small 276 (0.2-0.4), medium (0.5-0.8), or large (> 0.8).[36]

We used Spearman's correlation to investigate the relationships between QoL and the characteristics of PwD and caregivers (age, gender, educational level, and duration of disease), awareness of disease, cognitive function, ADLs, depressive symptoms, neuropsychiatric symptoms, and caregiver burden at baseline and follow-up. Strong (positive or negative) correlations were defined as 0.71 to 0.9, moderate correlation as 0.31 to 0.70, and weak correlation as 0.1 to 0.30.[37]

Multiple linear regression analyses were performed separately for each of the dependent variables (PwD and caregiver QoL ratings) in order to determine the overall effect of the clinical and demographic factors. Regression models were obtained for each dependent variable, by entering as independent variables those found to be significant in the correlation analyses at baseline and follow-up (mood, neuropsychiatric symptoms, caregiver burden, PwD QoL rating, and awareness of disease). For all analyses, the α-level was set at $p \leqslant 0.05$.

Results

Description of the sample

The initial sample consisted of 69 people with early-stage dementia (50 females) and their 69 family caregivers (58 females). Fifty-five PwD-caregiver dyads completed the study. Fourteen cases assessed at baseline were excluded because of refusal of the family caregiver to be interviewed (n=9), PwD death (n=1), presence of PwD psychotic symptoms (n=1), PwD refusal to continue participating in the research (n=1), PwD medical complications (n=1), and difficulties in communicating to schedule the second interview (n=1). Sociodemographic information of PwD and family caregivers at baseline and of those completing the follow-up assessment is provided in Table 1. Table 2 shows clinical variables at the two time points.

Table 1 Sociodemographic information of people with dementia and family caregivers

	Baseline (n=69)	Follow-up (n=55)
People with dementia		
Age, years	76.8±7.3	76.9±7.2
Educational level, years	8.2±4.0	8.3±3.8
Disease duration, years	4.6±2.6	4.7±2.6
Gender (male:female), %	28:72	19:81
Caregiver		
Age, years	57.5±13.5	58.4±13.2
Educational level, years	11.3±3.3	11.5±3.1
Gender (male:female), %	16:84	15:85

Data presented as mean ± standard deviation unless otherwise specified.

Baseline

At baseline, 45.5% (n=31) of PwD showed preserved awareness, 41.8% (n=29) had mildly impaired awareness, 10.9% (n=8) had moderately impaired awareness, and 1.8% (n=1) did not have any awareness of the disease.

Univariate analyses

PwD QoL ratings were weakly correlated with mood ($r = -0.285$, $p = 0.018$) and neuropsychiatric symptoms ($r = 0.081$, $p = 0.019$), and moderately correlated with caregiver ratings of PwD QoL ($r = 0.483$, $p < 0.001$). There was no correlation between PwD QoL ratings and sociodemographic characteristics of PwD or caregivers, cognitive function, functionality, awareness of disease, and caregiver burden.

Caregiver ratings of PwD QoL were moderately correlated with PwD mood ($r = -0.516$, $p < 0.001$), neuropsychiatric symptoms ($r = -0.516$, $p < 0.001$), and QoL ($r = 0.483$, $p < 0.001$), as well as weakly correlated with caregiver burden ($r = 0.279$, $p = 0.020$). There was no correlation between caregiver ratings of PwD QoL and sociodemographic characteristics of PwD or caregivers, PwD cognitive function, functionality, and awareness of disease.

The correlations between QoL ratings and sociodemographic and clinical variables are depicted in Tables 3 and 4.

Multivariate analysis

The results of the linear regression model examined the association between QoL and significantly correlated variables in the univariate analyses. PwD self-rated QoL was

Table 2 Baseline and endpoint scores of clinical variables

	Baseline (n=69)	Follow-up (n=55)	p-value	Cohen's d
MMSE	21.4±3.5	19.4±4.6	0.001*	0.41
CSDD	6.4±5.7	7.2±4.5	0.264	-0.12
PFAQ	12.2±8.2	16.0±9.2	0.001*	-0.36
NPI	10.8±10.9	14.2±10.9	0.020†	-0.25
ZBI	30.2±16.1	30.4±18.6	0.083	-0.00
QoL-AD PwD	32.4±3.6	31.9±5.5	0.894	0.09
QoL-AD caregivers	29.8±6.1	31.8±5.6	0.049†	-0.27
ASPIDD	5.0±4.0	6.6±4.2	0.001*	-0.32

Data presented as mean ± standard deviation unless otherwise specified.
ASPIDD = Assessment Scale of Psychosocial Impact of the Diagnosis of Dementia; CSDD = Cornell Scale for Depression in Dementia; MMSE = Mini-Mental State Examination; NPI = Neuropsychiatric Inventory; PFAQ = Pfeffer Functional Activities Questionnaire; PwD = people with dementia; QoL-AD = Quality of Life in Alzheimer's Disease; ZBI = Zarit Burden Interview.
*$p \leqslant 0.001$, †$p \leqslant 0.05$.

associated with caregiver ratings (p = 0.001). The final model explained 27% of the variance ($p < 0.001$). Table 5 shows the adjusted R2 and standardized regression weights.

Caregiver ratings of PwD QoL were associated with PwD mood (p = 0.001) and QoL (p = 0.001). The final model explained 40% of the variance ($p < 0.001$). The adjusted R2 and standardized regression weights are shown in Table 6.

Follow-up

Caregiver rating of PwD QoL (p = 0.049, d = -0.27) changed significantly between baseline and follow-up. PwD self-rated QoL did not vary significantly between the two moments of evaluation (p = 0.89, d = 0.09). Awareness of disease was significantly different (p = 0.001) at baseline and follow-up. There was no change in the level of awareness of disease in 61.8% (n=34). In 25.4% (n=14), the level of awareness declined. However, the level of awareness of disease improved in 12.3% (n=7).

Univariate analysis

PwD self-rated QoL was moderately correlated with mood (r = -0.408, p = 0.002) and caregiver ratings (r = 0.520, p = 0.001). There was no correlation between PwD self-rated QoL and sociodemographic characteristics of PwD and caregivers, cognitive function, functionality, neuropsychiatric symptoms, awareness of disease, and burden.

Caregiver ratings of PwD QoL were moderately correlated with PwD mood (r = -0.472, p = 0.001) and self-rated QoL (r = 0.520, p = 0.001), and weakly correlated with PwD neuropsychiatric symptoms (r = -0.292, p = 0.031) and awareness of disease (r = -0.266, p = 0.050). There was no correlation between caregiver ratings of PwD QoL and sociodemographic characteristics of PwD and caregivers, PwD cognitive function and functionality, and burden. The correlations between QoL and sociodemographic and clinical variables are depicted in Tables 3 and 4.

Multivariate analyses

PwD self-rated QoL was associated with caregiver ratings of PwD QoL (p = 0.001). The final model explained 28% of the variance ($p < 0.001$). Table 5 shows the adjusted R2 and standardized regression weights. Caregiver ratings

Table 3 Spearman's correlation between people with dementia self-rated QoL and study variables

	Baseline (n=69)		Follow-up (n=55)	
	ρ	p-value	ρ	p-value
PwD				
Age	0.090	0.461	0.193	0.158
Educational level	-0.083	0.500	-0.015	0.916
Disease duration	0.235	0.051	0.175	0.201
Gender	0.006	0.964	0.116	0.399
Caregiver				
Age	- 0.292	0.114	0.067	0.626
Educational level	-0.042	0.732	0.137	0.319
Gender	0.017	0.890	-0.133	0.331
MMSE	0.127	0.298	-0.115	0.403
CSDD	**-0.285**	**0.018***	**-0.408**	**0.002†**
PFAQ	-0.029	0.812	- 0.074	0.593
ZBI	0.008	0.949	0.047	0.731
NPI	**-0.081**	**0.019***	-0.068	0.623
QoL-AD caregivers	**0.483**	**0.001‡**	**0.520**	**0.001‡**
ASPIDD	0.102	0.404	0.160	0.243

Significant correlations appear in bold.
ASPIDD = Assessment Scale of Psychosocial Impact of the Diagnosis of Dementia; CSDD = Cornell Scale for Depression in Dementia; MMSE = Mini-Mental State Examination; PFAQ = Pfeffer Functional Activities Questionnaire; PwD = people with dementia; QoL-AD = Quality of Life in Alzheimer's Disease; ZBI = Zarit Burden Interview.
*$p \leqslant 0.05$, †$p \leqslant 0.01$, ‡$p \leqslant 0.001$.

Table 4 Spearman's correlation between caregiver ratings of people with dementia QoL and study variables

	Baseline (n=69)		Follow-up (n=55)	
	ρ	p-value	ρ	p-value
PwD				
Age	-0.001	0.925	0.105	0.444
Educational level	-0.005	0.868	-0.070	0.610
Disease duration	0.172	0.158	0.015	0.912
Gender	0.006	0.964	0.119	0.389
Caregiver				
Age	0.011	0.926	-0.068	0.620
Educational level	0.002	0.990	0.048	0.725
Gender	-0.085	0.489	-0.137	0.318
MMSE	0.116	0.343	-0.115	0.403
CSDD	**-0.516**	**0.001***	**-0.472**	**0.001***
PFAQ	-0.229	0.059	-0.242	0.076
ZBI	**0.279**	**0.020†**	0.254	0.062
NPI	**-0.516**	**0.001***	**-0.292**	**0.031†**
PWD QoL-AD	**0.483**	**0.001***	**0.520**	**0.001***
ASPIDD	-0.209	0.084	**-0.266**	**0.050†**

Significant correlations appear in bold.
ASPIDD = Assessment Scale of Psychosocial Impact of the Diagnosis of Dementia; CSDD = Cornell Scale for Depression in Dementia; MMSE = Mini-Mental State Examination; PFAQ = Pfeffer Functional Activities Questionnaire; PwD = people with dementia; QoL-AD = Quality of Life in Alzheimer's Disease; ZBI = Zarit Burden Interview.
*$p \leqslant 0.001$, †$p \leqslant 0.05$.

Table 5 Regression model of factors predicting PwD QoL

	B	β	R^2	Adjusted R^2	Significance
Caregiver QoL at baseline	0.400	0.528	0.279	0.268	⩽0.001
Caregiver QoL during follow-up	0.524	0.534	0.285	0.271	⩽0.001

QoL = quality of life.

of PwD QoL were associated with PwD mood (p = 0.029), QoL (p = 0.001), and awareness of disease (p = 0.033). The final model explained 45% of the variance ($p < 0.001$). The adjusted R2 and standardized regression weights are shown in Table 6.

Discussion

In the present study, we investigated the changes over time in self and caregiver ratings of PwD QoL. Our findings indicate that the association between self and caregiver ratings of PwD QoL was maintained over time. This association highlights the subjective nature of the concept of QoL and raises questions regarding the differences in the way PwD and caregivers perceive PwD QoL.[23] Vogel et al.[14] emphasized that some people adapt to their situation with time, modifying their interpretation of subjective well-being and health accordingly, in a way that may not reflect the clinical progression of disease. Despite the presence of association between self and caregiver PwD QoL ratings, the decrease in caregiver ratings of PwD QoL was more significant than the changes in PwD self-rated QoL. Our results are in line with those of other studies in which PwD self-ratings of QoL did not change substantially during follow-up, although caregiver ratings were more likely to decline.[1,7,14,19]

Our second objective was to identify the factors associated with any changes in QoL ratings. Measures of cognitive and functional impairment (MMSE and PFAQ) declined over 1 year, indicating typical dementia progression in this PwD group. However, as reported in a previous study,[5] we found that cognitive impairment and functionality were not the primary factors that accounted for self and caregiver ratings of PwD QoL. PwD perception analyses yielded no evidence of significant differences over time, showing caregiver ratings of PwD QoL as the main predictor of PwD self-ratings of QoL. The finding that PwD self-ratings of QoL do not inevitably decline as dementia progresses concurs with the results of several other studies using both PwD self-reports and caregiver measures of PwD QoL.[5,8,10]

There are some reasons for the stability in self-rated PwD QoL. First, it could be explained to some extent by the lower self-rated rates of depressive and neuropsychiatric symptoms (compared to caregiver ratings) detected at the two time points.[14] A certain clinical stability may provide accuracy to PwD perceptions of caregivers' well-being, suggesting that the perceptions held by PwD influence their self-ratings of QoL.[19] This finding also confirms the importance of seeking the PwD perspective whenever possible, rather than relying strictly on proxy ratings.

Another hypothesis that can be put forward to explain the stability in PwD ratings of QoL, regardless of actual cognitive impairment, is related to awareness of disease. Awareness of disease can be expressed at different levels, including ability to monitor immediate performance, to make evaluative judgments about functioning in a given domain, and to reflect on the nature and impact of a diagnosis or health condition.[25] ASPIDD is a multidimensional scale designed to evaluate awareness of disease in PwD through the scoring of discrepant responses across domains that include awareness of cognitive deficits, family and social relationships, and instrumental and basic ADLs. Studies suggest a relative independence between awareness levels for different objects.[38,39] In our study, the level of awareness of disease was significantly different at baseline and follow-up. PwD with impaired awareness tend to underestimate the presence of their cognitive and functional deficits, and overestimate QoL, a behavior that may be attributed to the failure in updating the mental representations of the functional activity.[40] The reduced awareness might suppress the impact of worsening symptoms and functioning on the QoL reported by PwD. However, we did not analyze the association between QoL and ASPIDD domains. Further studies should investigate the relationship between the patterns of change in QoL and specific domains of awareness.

Functional deficits[7,14] and neuropsychiatric symptoms[5] are the factors most often cited in previous research as having a negative impact on caregiver ratings of PwD QoL. Conversely, our findings show that changes in caregiver ratings of PwD QoL are associated with different factors. Self-rated PwD QoL, awareness of disease, and mood

Table 6 Regression model of factors predicting caregiver ratings of people with dementia QoL

	β	R^2	Adjusted R^2	Significance
Baseline				
CSDD -0.412 (p = 0.001)	-0.383	0.401	0.383	⩽0.001
PwD QoL 0.490 (p = 0.001)	0.371			
Follow-up				
CSDD -0.342 (p = 0.029)	-0.279	0.454	0.422	⩽0.001
PwD QoL 0.458 (p = 0.001)	0.449			
ASPIDD -1.882 (p = 0.033)	-0.248			

ASPIDD = Assessment Scale of Psychosocial Impact of the Diagnosis of Dementia; CSDD = Cornell Scale for Depression in Dementia, PwD = people with dementia, QoL = quality of life.
$p \leqslant 0.001$.

played an important role in caregivers' ratings of PwD QoL over time. Caregivers reported low levels of PwD QoL when the PwD exhibited impaired awareness of disease. This finding is in line with those of other studies that have indicated that lack of awareness contributed to the discrepancy between proxy- and self-ratings of QoL.[13,41,42]

Mood was relatively stable in our sample over time. Although depressive symptoms did not increase significantly, there is an indication that PwD mood has an impact on caregivers' ratings of PwD QoL regardless of cognitive status or functional impairment.[14] This mood stability may have led to more positive QoL evaluations by the caregiver. The impact of depression in this regard has been widely reported[7,41] and suggests the existence of differences between perceptions of psychological well-being that could be due to caregiver-related variables (personal beliefs or expectations).[43] Thus, it is acceptable to assume that there is an association between caregivers' perceptions of PwD QoL and PwD well-being in mild dementia. It seems that changes in caregiver scores are relatively dependent on the effect of change in other clinical parameters. Apparently, when caregivers provide their ratings of PwD QoL, they may take into account a variety of factors, and their observation of PwD well-being is a critical component. This finding highlights the subjective nature of the concept of QoL.[43] Thus, other longitudinal studies including the pattern of PwD and caregiver individual differences would be interesting.

Some limitations of the present study must be acknowledged. One important limitation associated with longitudinal studies of people with AD is the loss to follow-up. It may be that PwD who experience significant declines in QoL are also more likely to be lost to follow-up.[5] Also, the present findings are only applicable to people with mild AD and may not be generalized to other stages of AD. It is important that future studies compare these results with those obtained with more advanced stages of AD. Moreover, this study enrolled a small sample, and the fact that many variables were included in the regression analysis may have produced some chance associations. We would argue, however, that our observations are consistent with those of other studies, suggesting that this explanation is unlikely for our findings. Finally, cognitive impairment was evaluated by the MMSE. Further studies should use a more comprehensive cognitive assessment.

In conclusion, we found that PwD self-ratings of QoL remained stable over 1 year, while caregiver ratings of PwD QoL declined significantly over time. There was an association between PwD and caregiver perceptions of QoL, although caregiver ratings were influenced by PwD mood and awareness of disease. The results of our study clearly demonstrate that in people with mild dementia, QoL measures tap different functions than those reflected by typical clinical variables (e.g., cognitive dysfunction and psychiatric symptoms).

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Disclosure

The authors report no conflicts of interest.

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