

Quality of Life in Alzheimer's Disease: Patient and Caregiver Reports

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This paper describes a new 13-item self- and caregiver-report measure of Quality of Life (QoL) in Alzheimer's Disease (AD), the QoL-AD, and describes the relationship of QoL to demographic characteristics, cognitive and functional status, depression, and pleasant activity level in 77 AD subjects. Each AD subject and a family caregiver completed the assessment. Internal consistency and test-retest reliability, assessed over a 1-week interval, were adequate on both patient- and caregiver-report QoL-AD measures. Validity, as indicated by correlational analysis of QoL-AD scores and other measures that assessed cognitive and functional ability, mood, and pleasant events, was also good. Multivariate modeling indicated that high QoL-AD scores were explained by low levels of depressive symptoms, more independent functioning in Activities of Daily Living, and more years of education. The QoL-AD is a promising measure for future investigations of quality of life in persons with AD.

Alzheimer's Disease (AD) affects afflicted individuals' quality of life in profound ways. As cognitive and functional abilities are lost, individuals with dementia become unable to engage in many of the activities that once gave them a sense of purpose or pleasure (Logsdon & Teri, 1997; Teri & Logsdon, 1991). Behavior and social skills may also deteriorate, precipitating interpersonal conflict that causes the individual with AD to become socially isolated or avoided (Pearson, Teri, Reifler, & Raskind, 1989; Reisberg et al., 1987; Reisberg, Franssen, Sclan, Kluger, & Ferris, 1989; Teri, Borson, Kiyak, & Yamagishi, 1989; Teri, Larson, & Reifler, 1988). This, in turn, impacts the emotional state (Logsdon & Teri, 1997; Teri & Uomoto, 1991; Teri, Logsdon, Wagner, & Uomoto, 1994).

As new treatments to improve cognitive function, delay decline, and treat behavior problems have recently become available for AD, many investigators and clinicians have recognized that, in addition to specific symptom amelioration, it is important to evaluate the extent to which an intervention improves the quality of life (QoL) of the person being treated. Whitehouse and Rabins (1992) go so far as to describe quality of life as "not an isolated concept to be included as one of many measurements of the benefits of our care, but rather . . . it is the central goal of our professional activity,

driving the organization of both our clinical and our research efforts" (p. 136). Yet little has been done to assess QoL of individuals with dementia.

To date, only one published study has empirically investigated QoL in AD. This investigation by Albert and colleagues (1996) indicates that family and institutional caregivers of AD patients in nursing homes show good agreement on ratings of patient QoL, including positive and negative affect and frequency and enjoyment of activities, but this investigation did not include patient ratings of their own QoL.

The purpose of the current investigation was threefold. The first purpose was to develop and provide psychometric data on a new scale that assess perceived QoL in AD patients. The scale was designed to tap the domains identified as important to QoL, including interpersonal, environmental, functional, physical, and psychological status (Birren & Deutchman, 1991; Lawton, 1983, 1991, 1994).

The second purpose was to examine the ability of AD patients and caregivers to provide a reliable and valid report of these subjective states, and to identify the point at which the patient's cognitive impairment would begin to impact measurement reliability. A comparison of patient and caregiver reports of patient QoL is also included to determine the extent to which caregivers and patients agree or disagree in their assessments. It has been found that in reporting depressive symptoms, patients consistently report fewer symptoms in themselves than their caregivers report for them (Moye, Robiner, & Mackenzie, 1993; Teri & Wagner, 1991) and that patients report their functioning on activities of daily living as higher than their caregivers report (Kiyak, Teri, & Borson, 1994). It is important to evaluate differences in responses of caregivers and patients in rating patient QoL, to identify possible biases that impact the accuracy of caregiver and patient reports. It was hypothesized that both mildly and moderately cognitively impaired subjects would be able to reliably report their own QoL, and that individuals with severely impaired cognitive function would be unable to do so. In addition, it is important to consider the primary caregiver's perception of the patient's QoL, because as the disease progresses and the patient's communication skills become more and more limited, the caregiver must report on how the patient is functioning in a variety of areas.

The third purpose of this investigation was to evaluate the influence of demographic factors (including patient and caregiver age, education, gender, income, relationship, and living situation) on QoL in AD, and whether QoL ratings could be explained by cognitive status, functional ability, mood, or level of participation in pleasant events. It was hypothesized that higher cognitive and functional status, fewer depressive symptoms, and higher levels of participation in pleasant events would be related to better QoL.

METHOD

Subjects

Subjects were recruited from an ongoing patient registry of individuals with AD (Larson et al., 1990). This investigation included 77 AD patients who were community-dwelling, ambulatory, and had an actively involved caregiver who lived with them or spent every day with them. All subjects met National Institute of Neurological and Communicative Disease and Stroke and the Alzheimer's Disease and Related Disorders Association (NINCDS-ADRDA) criteria for "probable" or "possible" AD (McKhann

et al., 1984), based on a comprehensive diagnostic evaluation (Larson et al., 1990).

Patients' mean age was 78.3 years ($SD = 6.1$), educational level was 12.7 years ($SD = 3.4$), and mean MMSE score was 17.1 ($SD = 5.6$). Fifty-three percent were male, 47% were female, 86% were Caucasian and 14% were African American. Caregivers' mean age was 69.8 years ($SD = 13.8$), and educational level was 13.7 years ($SD = 2.7$). Sixty-six percent of caregivers were female, 34% were male; 76% of caregivers were spouses, 10% were children, and 14% were other close relatives or friends who lived with and cared for the patient. Ninety-five percent of patients and caregivers lived together, 5% did not live together but saw each other every day.

Measures

The following measures were collected by an experienced interviewer (BA in psychology and 1 year experience interviewing older adults), who interviewed subjects in their homes.

Mini-Mental State Exam. The Mini-Mental State Exam (MMSE; Folstein, Folstein, & McHugh, 1975), one of the most widely used cognitive screening instruments, provides a total score, ranging from 0-30, with lower scores indicative of greater cognitive impairment.

Physical and Instrumental Self-Maintenance Scale. The Physical and Instrumental Self-Maintenance Scale (Lawton & Brody, 1969) is a 16-item caregiver-report measure that provides an assessment of basic activities of daily living (ADLs), such as bathing and dressing, and more complex instrumental activities (IADLs) such as shopping, transportation, and home management.

Hamilton Depression Rating Scale. The Hamilton Depression Rating Scale (HDRS; Hamilton, 1960; 1967) assesses the frequency and severity of various depression symptoms. It has been used with AD patients to identify individuals who may have major depressive disorder (Logsdon & Teri, 1995). In this investigation, the HDRS was administered to caregivers to assess symptoms of depression both in their patients and in themselves.

Geriatric Depression Scale. The Geriatric Depression Scale (GDS; Yesavage et al., 1983) is a 30-item, self-report measure that is useful and reliable with older adults in residential care settings (Parmelee, Lawton, & Katz, 1989) and as a caregiver-report measure for AD patients (Logsdon & Teri, 1995). For this investigation, caregivers completed the questionnaire about their patients, and AD patients independently completed the GDS. Caregivers completed the measure as a questionnaire; patients were interviewed and asked to respond orally to the statements read to them, with their responses recorded by the interviewer.

Pleasant Events Schedule-AD-Short Form. The Pleasant Events Schedule-AD-Short Form (PES-AD; Logsdon & Teri, 1997; Teri & Logsdon, 1991) asks caregivers to rate whether their patient now enjoys each of 20 activities, whether the patient enjoyed it in the past, and how frequently the patient engaged in each activity during the prior month. In a prior investigation, the PES-AD was demonstrated to have good internal consistency and to correlate with diagnosis and severity of depression in AD patients (Logsdon & Teri, 1997).

Quality of Life-AD. The Quality of Life-AD (QoL-AD) was developed for this investigation. This measure obtains a rating of the patient's QoL from both the patient

and the caregiver. Items for the QoL-AD were selected based on a review of relevant literature on QoL in older adults and on the assessment of QoL in other chronically ill populations. (For more information about relevant literature and domains of QoL, please refer to the Introduction to this special issue.) To optimize the measure's usefulness with mildly to moderately impaired AD patients, it uses simple and straightforward language and responses, with detailed instructions for the interviewer. During its development, the QoL-AD was reviewed by AD patients and caregivers, cognitively intact older adults, and experts in the field of geriatrics and gerontology, in order to maximize construct validity and to ensure that it addresses aspects of QoL that are particularly important to individuals with AD. Based on their feedback, an item on "energy level" was added and an item about "ability to perform tasks" was broken into two items: "ability to do chores around the house" and "ability to do things for fun." After administering the measure to 20 pilot subjects (patients and caregivers from the University of Washington Geriatric and Family Services Clinic), interviewer instructions were expanded and clarified based on recommendations of interviewers and caregivers. Response options were simplified to a 4-choice multiple choice format that is consistent across all questions, because this type of response was easier for patients to consistently follow than a Likert-type scale or more open-ended response. Patients were best able to complete the measure in interview format. Interviewers use a set of explicit instructions to avoid influencing the patient's responses; patients follow along on their own copy of the measure, and may respond verbally while the interviewer circles the response on the form, or may circle their own response. Caregivers were able to complete the measure as a questionnaire, with assistance from the interviewer if there was a question they didn't understand or if they were not sure how to respond. Caregivers in the pilot group required very little assistance.

In summary, the QoL-AD includes the patient's and caregiver's appraisal of the patient's physical condition, mood, interpersonal relationships, ability to participate in meaningful activities, financial situation, and an overall assessment of self as a whole and life quality as a whole. The measure has 13 items, rated on a 4-point scale, with "1" being poor and "4" being excellent. Total scores range from 13 to 52. Separate scores are calculated for patient and caregiver reports. These reports can also be combined into a single composite QoL score that incorporates both patient and caregiver ratings of the patient's QoL. Since the patient's QoL is the focus of the evaluation, a weighted composite QoL-AD score is calculated by multiplying the patient score by 2, adding the caregiver score, and dividing the sum by 3, to produce a composite score that weights the patient rating more heavily than the caregiver rating. The composite score consists of the same range of possible scores as the patient and caregiver report forms alone. (A copy of the measure, along with instructions for administration and a more detailed description of the instrument development process is available from the first author.)

RESULTS

Reliability of the QoL-AD

Table 1 shows the internal consistency of the QoL-AD. The correlation of each item with the total QoL-AD score, the correlation of each item with the single item on which subjects rated "life as a whole," and coefficient alpha are shown for both patient and caregiver report versions of the QoL-AD. Overall coefficient alpha levels for both

TABLE 1. Item–Total Correlation and Coefficient Alpha of the Quality of Life–AD Scale

Item	Patient Correlations		Caregiver Correlations	
	(Total)	“Life as a Whole”	(Total)	“Life as a Whole”
1. Physical health	.58	.53	.47	.29
2. Energy	.67	.39	.47	.38
3. Mood	.61	.52	.59	.40
4. Living situation	.65	.59	.45	.22
5. Memory	.42	.24	.34	.13
6. Family	.41	.29	.47	.27
7. Marriage	.58	.41	.63	.36
8. Friends	.46	.43	.60	.40
9. Self.	.60	.35	.58	.55
10. Ability to do chores	.56	.56	.49	.37
11. Ability to do things for fun	.54	.54	.53	.40
12. Money	.53	.43	.39	.44
13. Life as a whole	.67	—	.54	—
Coefficient Alpha	.88		.87	

patient and caregiver reports were well within the acceptable range (.88 and .87, respectively), indicating that the items did indeed measure a cohesive construct. In addition, correlations of each item with the single item where subjects rated “life as a whole” were good.

Table 2 shows the mean scores reported by patients and caregivers on each QoL-AD item, along with the Spearman correlation between patient and caregiver reports on each item and the Pearson correlation for the total measure. As can be seen, patients and caregivers achieved fairly good agreement on items related to mood, energy, physical health, and self, while agreement on items most affected by the patient’s dementia, including memory and ability to do chores, was lower. This is consistent with prior findings that subjects with dementia rated their functional abilities higher than their caregivers rated them (Kiyak, Teri, & Borson, 1994; Magaziner, Simonsick, Kashner, & Hebel, 1988). Agreement on the total score was adequate ($r = .40, p > .001$), particularly for a subjective scale with no behavioral anchors. It may be that the different methods of administration lowered the correlation between patient and caregiver reports.

Finally, test-retest reliability was evaluated on a subset of 30 patient-caregiver pairs, at a one week interval. Intra-class correlation coefficients were within the acceptable range (ICC = .76 for patients and .92 for caregivers).

Validity of the QoL-AD

Table 3 shows the correlation of QoL-AD scores with other constructs, including cognitive status, activities of daily living and instrumental activities of daily living, depression, and pleasant events. Patient QoL-AD scores were modestly correlated with MMSE scores ($r = .24, p < .05$), with higher scores on the MMSE related to higher QoL ratings. Interestingly, caregiver ratings on the QoL-AD were not correlated with patient

TABLE 2. Mean Scores, Standard Deviations, and Correlations for Patient and Caregiver Reports on QoL-AD Items

Item	Patient Report		Caregiver Report		Correlation ^a
1. Physical health	2.84	(.78)	2.80	(.77)	.35**
2. Energy	2.70	(.71)	2.12	(.82)	.45***
3. Mood	2.82	(.77)	2.39	(.80)	.40***
4. Living situation	3.31	(.61)	3.19	(.61)	.21
5. Memory	2.26	(.71)	1.43	(.60)	.13
6. Family	3.39	(.61)	3.12	(.68)	.24*
7. Marriage	3.42	(.61)	3.16	(.70)	.21
8. Friends	3.00	(.67)	2.61	(.88)	.26*
9. Self	2.81	(.69)	2.63	(.63)	.31**
10. Ability to do chores	2.69	(.78)	2.05	(.73)	.04
11. Ability to do things for fun	3.06	(.68)	2.68	(.76)	.20
12. Money	2.66	(.74)	2.44	(.81)	.29**
13. Life as a whole	3.06	(.69)	2.73	(.58)	.22*
Total Score	38.03	(5.81)	33.35	(5.91)	.40***

^aSpearman correlations are given for items; Pearson correlation is given for the total score. * $p < .05$. ** $p < .01$. *** $p < .001$.

TABLE 3. Validity of the QoL-AD: Correlation With Related Measures

	Patient Report QoL-AD	Caregiver Report QoL-AD	Composite QoL-AD
Mini-Mental State Exam	0.24*	0.02	0.19
Activities of Daily Living ^a	-0.33**	-0.32**	-0.37***
Instrumental Activities of Daily Living ^a	-0.12	-0.08	-0.13
Hamilton Depression Rating Scale-Patient Depression	-0.43***	-0.25*	-0.43***
Geriatric Depression Scale (Patient report about self)	-0.56***	-0.14	-0.49***
Geriatric Depression Scale (Caregiver report about patient)	-0.40***	-0.57***	-0.53***
Pleasant Event Scale-AD	0.30**	0.41***	0.40***
Hamilton Depression Rating Scale-Caregiver Depression	0.00	-0.23*	-0.07

^aPhysical and Instrumental Self-Maintenance Scale.

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

MMSE scores. On the Physical and Instrumental-Self Maintenance Scales, the Activities of Daily Living score was significantly correlated with both the patient and caregiver ratings on the QoL-AD (r 's = -.33 and -.32, respectively, $p < .01$), indicating that patients with the greatest impairment had lower QoL ratings. However, the Instrumental Activities of Daily Living score, which assesses less severe levels of functional impairment was not significantly correlated with the QoL-AD.

Depression correlated most highly with the QoL-AD. Patient report QoL-AD was significantly correlated with patient HDRS score ($r = -.43, p < .001$) and patient and caregiver reports on the GDS ($r = -.56$ and $-.40$, respectively, $p < .001$). Caregiver report QoL-AD was also correlated with patient HDRS ($r = -.25, p < .05$) and with caregiver-report GDS ($r = -.57, p < .001$). Both patient and caregiver reports on the QoL-AD were significantly correlated with caregiver reports of pleasant events ($r = .30, p < .01$ and $r = .41, p < .001$, respectively). Interestingly, caregiver depression (rated on the HDRS) was correlated with caregiver report QoL-AD ($r = -.23, p < .05$), but not with patient report QoL-AD scores.

For the composite QoL-AD score, a similar pattern of results was seen, with QoL most highly correlated with depression ($r = -.43$ to $-.53$) and pleasant events ($r = .40$), followed by ADL scores ($r = -.37$). The composite QoL-AD score was not significantly correlated with MMSE scores, IADLs, or caregiver depression.

Impact of Cognitive Impairment on Reliability and Validity of the QoL-AD

In order to evaluate the impact of patient cognitive status on ability to complete the QoL-AD, reliability and validity analyses were repeated with subjects divided into two groups according to their MMSE scores. Subjects with scores of less than 18 on the MMSE were placed in the "lower cognitive" group ($n = 41$), while those with scores of 18 or higher were placed in the "higher cognitive" group ($n = 36$). Table 4 shows the results of this analysis. For the "lower cognitive" (moderately impaired) group, the mean MMSE score was 13 ($SD = 3$; range 4-17), the mean patient report QoL-AD score was 36 ($SD = 6$; range 25-50), and coefficient alpha for the patient report QoL-AD was .90. For the "higher cognitive" (mildly impaired) group, the mean MMSE score was 22 ($SD = 3$; range 18-28), the patient QoL-AD was 40 ($SD = 5$; range 28-50), and coefficient alpha was .81. The correlation of patient QoL-AD with caregiver QoL-AD was .42 for the more impaired group, and .31 for the less impaired group. Thus, moderate levels of cognitive impairment did not have a negative impact on reliability or validity.

TABLE 4. Correlation of Patient Report QoL-AD With Related Measures

	Moderate Impairment MMSE < 18	Mild Impairment MMSE ≥ 18
Activities of Daily Living ^a	-0.30*	-0.07
Instrumental Activities of Daily Living ^a	-0.11	0.23
Hamilton Depression Rating Scale- Patient Depression	-0.51**	-0.22
Geriatric Depression Scale (Patient report about self)	-0.54***	-0.54***
Geriatric Depression Scale (Caregiver report about patient)	-0.44**	-0.21
Pleasant Event Scale-AD	0.44**	0.07
Hamilton Depression Rating Scale- Caregiver Depression	0.01	0.01
Caregiver QoL-AD	0.42**	0.31

^aPhysical and Instrumental Self-Maintenance Scale.

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

Characteristics of Quality of Life in Alzheimer's Disease

It was expected that QoL would be related to a variety of patient and caregiver characteristics. To determine which, if any, variables were related to QoL-AD scores, a series of correlations and regression analyses was conducted. To reduce the number of potential variables in the regression analyses, correlations were calculated for all demographic, cognitive, functional, and depression variables. Of the demographic variables, only patient educational level and caregiver educational level were significantly correlated with patient or caregiver reports on the QoL-AD. Correlations with other measures are shown in Table 3.

Stepwise linear regression analyses were conducted for the patient, caregiver, and composite ratings of QoL-AD, entering all theoretically relevant predictor variables (listed in Table 3), and two significantly correlated demographic variables (patient and caregiver education) as candidates for the models. Standardized regression coefficients for the models are shown in Table 5. The presence of depressive symptoms was the best predictor of QoL-AD scores. As hypothesized, individuals with fewer depressive symptoms reported higher QoL. More independent ADL functioning was also hypothesized to be related to higher QoL; this was confirmed. Educational level of the patient was the only demographic variable that was related to QoL, with more years of education related to higher QoL. Other variables hypothesized to relate to QoL, including IADL and MMSE scores, did not add significant predictive value to the model.

DISCUSSION

The proposed QoL-AD is a brief, easily administered assessment of QoL in AD. This investigation provides psychometric data for both a patient-interview version and a caregiver-questionnaire version of the measure, and it provides a method for calculat-

TABLE 5. Stepwise Multiple Regression to Identify Factors Associated With Quality of Life in AD

Variables in the Equation	Patient Report QoL-AD	Caregiver Report QoL-AD	Composite QoL-AD
	β^a	β^a	β^a
Patient Education	0.320***	0.275**	0.356****
Geriatric Depression Scale (Patient report)	-0.566****	—	-0.360****
Geriatric Depression Scale (Caregiver report)	—	-0.548****	-0.326***
Activities of Daily Living	-0.260**	-0.201*	-0.281***
Adjusted R ²	0.485	0.429	0.567

^a β = Standardized Regression Coefficient.

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

ing a composite score that combines both the patient and caregiver reports and is scaled in the same way as the individual reports. Each version of the measure appears to be reliable and valid. Further, patients appear able to provide a subjective assessment of their own QoL, and although patient and caregiver reports are related, they are not identical. It also appeared that caregiver depression may have influenced caregiver ratings of the patient's QoL, with depressed caregivers rating patient QoL lower than nondepressed caregivers. As QoL receives increasing attention in descriptive and treatment outcome research, the QoL-AD provides a useful tool for obtaining an assessment of the patient's QoL from both the patient and the caregiver.

The current investigation also provides data about factors related to QoL in AD. The factor most strongly associated with QoL-AD scores was depressive symptoms. Individuals with fewer depressive symptoms reported higher QoL. This is consistent with a recent investigation of social support, functional status, and QoL in nondemented older adults (Newsom & Schulz, 1996) which found that depression and life satisfaction ratings were highly correlated ($r = -.44$). More independent functioning in activities of daily living was also predictive of higher QoL in the present sample. Of the demographic variables examined, education was the only one that was related to QoL-AD scores, with more years of education related to higher QoL. Since education may be related to a number of other factors, including income, range of interests, and reading level, additional research is needed to clarify how educational achievement impacts QoL.

Although MMSE scores were modestly correlated with patient QoL-AD scores, cognitive status was not a significant predictor of QoL in the regression analysis. This is not to say that cognitive impairment does not affect QoL, but it does suggest that certain ADL losses are more significant to QoL than are purely cognitive changes, and that once the ADL scores were entered into the regression equation, MMSE did not add predictive value. The ability to perform more complex IADLs was not correlated with QoL. More investigation is needed to clarify the relationship between the ability to perform activities and QoL, and to determine whether the inability to independently perform IADLs (such as shopping, doing laundry, housework) is less disturbing to most individuals than is the inability to dress and bathe without assistance.

In the current investigation of QoL in community-residing AD patients, only 5 patients were unable to complete the QoL-AD interview. All 5 had MMSE scores of less than 10. In no case was a subject in the current sample with an MMSE score greater than 10 unable to complete the measure.

Finally, the frequency of pleasant events was related to QoL, with patients who engage in more pleasant events obtaining higher QoL-AD scores. Although the PES-AD score was not significant in the regression equation, once the impact of depression was explained, the correlation suggests that pleasant events may be important to QoL in AD.

In conclusion, the QoL-AD is a promising measure for investigations of QoL in AD. It is brief, readily accepted by individuals with AD and their caregivers, can be reliably used by individuals with MMSE scores between 10-28, and provides both the patient's and caregiver's assessments of QoL. Investigations currently under way will provide additional data regarding changes in QoL over time, and the relationship between QoL and behavioral disturbances. Future investigations will also address the impact of the quality of the patient-caregiver interpersonal relationship on QoL, and evaluate changes in QoL with both pharmacological and behavioral treatments. The increasing recogni-

tion of QoL as an important outcome variable in research with individuals with AD, and the development of measures such as the QoL-AD, marks an important milestone in AD research, which will encourage and allow a more global and clinically relevant assessment of individuals with AD.

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