American Journal of Alzheimer's
Disease & Other Dementias®
Volume 21 Number 4
August/September 2006 242-248
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10.1177/1533317506290589
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Insight and Cognitive Impairment

Effects on Quality-of-Life Reports From Mild Cognitive Impairment and Alzheimer's Disease Patients

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This study follows previous work to determine the effect of patient insight and cognitive impairment on the reliability and validity of self-reported quality of life (QOL) from patients diagnosed with Alzheimer's disease (AD) and mild cognitive impairment (MCI). AD and MCI patients (N = 68) and their caregivers participated. Patients with impaired insight provided QOL ratings that were less reliable than those provided by patients with better insight. Patient-caregiver agreement for QOL reports was used as an index of validity. Neither better insight nor lesser cognitive impairment suggested better agreement. Thus, even when patient insight is intact, patient reports are unlikely to agree with caregiver reports. Patient and caregiver reports about patient QOL may represent 2 unique, yet potentially valid, perspectives.

Keywords: mild cognitive impairment; Alzheimer's disease; quality of life; caregiver; insight; reliability; validity; self-report

Our previous research found discrepancies between patient and caregiver reports of quality of life (QOL) in patients with Alzheimer's disease (AD) and mild cognitive impairment (MCI).[1] Informants rated global QOL significantly lower in AD than in MCI, but patient self-reports did not differ between the 2 groups. Thus, patient reports differed from caregiver reports because they did not reflect lower QOL in AD relative to MCI, as one might expect.

In this study, we explore 2 reasons patient-reported QOL might differ from caregiver-reported QOL, namely, patient insight and degree of cognitive impairment. We also determine the effects of insight and cognitive impairment on the reliability of patient-reported data. To accomplish our goals, we measured patient- and caregiver-reported QOL, as well as patient lack of insight and cognitive impairment. Lack of insight was conceptualized by awareness of situation, memory deficit, functional deficits, and disease progression. Previously, we found that cognitive impairment and patient insight were not correlated with patient ratings of QOL.[1] However, specific effects of insight and cognitive impairment on the reliability and validity of patient reports and patient-caregiver agreement were not determined.

Lack of insight is common in AD[2,3] and MCI,[4,5] but there are large individual differences in awareness in these populations.[6-9] Presumably, patients with more impaired insight will be less able to provide reliable and valid self-report data about their symptoms. While the latter statement seems intuitively obvious, there are little empirical data to support this assertion. The finding that there are large individual differences in lack of insight in AD and MCI is a further complicating factor. Some patients may have the ability to report on their symptoms and experiences, despite presence of mild to moderate cognitive impairment.

For some symptoms and signs of dementia, patients' ability to provide self-report data is not of paramount importance. For example, there are standardized neuropsychological tests that provide information regarding the nature and severity of cognitive impairments. However, information regarding subjective constructs, such as patient QOL, are not easily gathered from sources that are external to the patient. It has been asserted that the best source for such subjective judgments is self-report data from

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Authors' Note: The project was supported by a National Institutes of Health–National Institute of Aging postdoctoral fellowship (F32AG20008-01 to R.E.R.).

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the patient.[10] Thus, whenever feasible, it seems optimal to gather reports about QOL directly from patients. Unfortunately, there are no guidelines or benchmarks available to help researchers and clinicians judge when they should gather self-report data from cognitively impaired patients and when they should not. In addition to lack of insight, effects of cognitive impairment on patient-report data also need to be considered.

The goal of this study was to determine if patient insight and cognitive impairment are factors that can guide decisions regarding the reliability and validity of self-report data from cognitively impaired persons. We hypothesized that patients with greater lack of insight and greater cognitive impairment would provide less reliable and valid data regarding their QOL. Specifically, we expected more impaired patients to provide QOL ratings with lesser internal consistency reliabilities than more intact patients. We also expected that patients with greater impairment would disagree with caregiver-reported QOL data more than would patients with lesser impairments in insight and cognition.

Methods

Participants

Participants were 68 patients diagnosed with AD (n = 34) or MCI (n = 34). Data from most (n = 56) of the sample were presented previously by Ready et al,[1] in which inclusion and exclusion criteria are described. These criteria are summarized below.

All patients were required to participate with a caregiver. Most patient-caregiver dyads were recruited from an outpatient hospital-based memory disorder clinic, but 8 MCI patients were recruited from the community. Dementia severity for all patients was rated by a neurologist (B.R.O.) or neuropsychologist (R.E.R.) according to the Clinical Dementia Rating scale (CDR).[11] Mental status of all participants was tested with the Mini-Mental State Examination (MMSE).[12] AD was diagnosed according to National Institute of Neurologic and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association criteria.[13] All AD patients had a CDR rating of 0.5, 1, or 2, indicating "very mild," "mild," and "moderate" dementia severity, respectively.

MCI was diagnosed according to criteria published by Petersen et al,[14] which are memory complaint, memory and other cognitive impairments on objective testing greater than expected for age, no evidence of functional deficits in activities of daily living, and not demented. All MCI patients had a CDR rating of 0.5. All patients and caregivers signed an informed consent form prior to participation, which was approved by the Internal Review Board at Memorial Hospital of Rhode Island.

Data from control participants were not included in this report because, by definition, there was no variability in insight ratings for controls. Our interest was the reliability and validity of QOL reports from patients who were high or low in insight.

Measures

Dementia Quality of Life Scale. The Dementia Quality of Life Scale (DQoL)[15] is a 29-item scale plus 1 global item ("Overall, how would you rate your quality of life?") that has 5 subscales: Positive Affect, Negative Affect, Feelings of Belonging, Self-esteem, and Sense of Aesthetics. Ratings are made on 5-point, Likert-type scales. Internal consistency reliabilities for subscales are 0.67 to 0.89 (median = 0.80). Two-week test-retest reliability ranged from 0.64 to 0.90 (median = 0.72). Convergent validity was indicated by correlations with the Geriatric Depression Scale.[15]

The Clinical Insight Rating Scale. The Clinical Insight Rating Scale (CIR) is a 4-item scale in which awareness of situation, memory deficit, functional deficits, and disease progression are each rated by a clinician on a 3-point scale (0-2) to yield scores ranging from 0 (*fully aware*) to 8 (*totally unaware*). The CIR demonstrated high interrater reliability ($r = 0.91$) and good internal consistency (Cronbach's $\alpha = .85$)[16] and has been used in several previous studies of insight in AD.[2,17,18] For this study, scores on the CIR were reversed, so that higher values indicated better insight (ie, 8 = *high insight*).

Procedure

Patients and caregivers were interviewed separately about the patients' QOL. Caregiver QOL ratings were not substituted judgments of the patients' QOL but rather were ratings of the caregiver's own opinion of the patient's current QOL. A substituted judgment is different because it asks caregivers to rate how they think the patient views his or her own

QOL (ie, caregivers are instructed to "substitute a judgment" for the patient). All interviews were conducted by a neuropsychologist (R.E.R.). The MMSE was administered, and insight was rated by a neurologist (B.R.O.) or by a neuropsychologist (R.E.R.).

Data Analyses

The goals of analyses were to investigate the effects of patient lack of insight on the reliability and validity of QOL ratings. Reliability was measured by internal consistency (ie, Cronbach's α). The sample was split to create 2 patient groups that were high and low in insight, and reliabilities of reports from these groups were compared. Validity was indicated by the degree of agreement between patient and caregiver ratings of patient QOL, and analyses were run to determine the effects of insight and cognitive impairment on agreement.

Analyses were conducted on the entire sample, rather than separately for MCI and AD. This approach was used because the primary variable of interest was insight and not diagnosis. Insight is found in both patient groups to varying degrees. Including the full sample in analyses increased statistical power to detect significant effects. Furthermore, MCI patients were of the amnestic subtype,[19] most of whom will progress to AD.[20] Preliminary follow-up data for our sample confirm this assertion. A subset of 16 MCI patients was followed for an average of 19.6 months after their participation. Thirty-one percent were diagnosed with possible or probable AD. An additional participant was diagnosed with mixed vascular dementia and AD. The remainder of the patients were still diagnosed with MCI, approximately half of whom showed some evidence of decline, although the decline was not sufficient to warrant a diagnosis of dementia. Thus, the MCI group in our sample is largely conceptualized as a preclinical AD group.

Results

Participant and Informant Descriptive Statistics

Patient and caregiver descriptive statistics are presented in Table 1. Most patients and caregivers were White (91.2% and 92.6%, respectively) and female (57.4% and 72.1%, respectively). Caregiver relationship types were spouse (48.5%), child (33.8%), sibling (2.9%), and other (14.7%). Most caregivers (60.3%) lived with the patient.

Table 1. Descriptive Statistics for Patients and Caregivers

	$\bar{x}$	SD
Patient		
Age, years	77.9	7.2
Education, years	12.7	3.4
MMSE score	24.4	4.5
Duration of impairment, years	3.4	2.6
Insight	2.6	2.6
Caregiver		
Age, years	65.9	14.6
Education, years	14.1	2.9
Relationship length, years	47.5	17.8

Note: N = 68. MMSE = Mini-Mental State Examination (possible range, 0-30).

Internal Consistency Reliabilities

Effect of patient insight. Internal consistency reliabilities were calculated for patients with relatively intact (CIR = 8 or 7; n = 33) and more impaired insight (CIR = 0-6; n = 35). The sample was dichotomized in this manner to ensure relatively equal numbers in each group and because it separated patients with intact or only minor lack of insight from patients with more marked lack of insight. For example, to be in the impaired group, a patient had to have complete lack of insight into at least 1 symptom domain (eg, cognitive, functional) or mild impairment in at least 2 different domains.

Internal consistency reliability descriptors were unacceptable (less than 0.70), fair (0.70-0.79), good (0.80-0.89), and excellent (0.90 and greater).[21] Results indicated that reliabilities for patients with relatively intact insight include only 1 unacceptable value, whereas reliabilities for patients with impaired insight have 4 of 5 values that are unacceptable (Table 2). Internal consistency reliability was significantly ($P < .05$) greater in the intact insight group than in the impaired insight group for Positive Affect ($F = 2.6$, $df = 34, 32$) and Negative Affect ($F = 2.0$, $df = 34, 32$).[22]

Internal consistencies were calculated for caregivers. There were no trends for caregivers of patients with more impaired insight to provide QOL ratings that were less reliable than caregivers of patients with better insight (Table 2).

Table 2. Internal Consistency Reliabilities for Patients With High and Low Insight

DQoL Subscale	High Insight	Low Insight
Patient report		
Aesthetics	0.70 fair	0.55 unacceptable
Self-esteem	0.75 fair	0.65 unacceptable
Positive Affect[a]	0.85 good	0.61 unacceptable
Negative Affect[a]	0.88 good	0.76 fair
Feelings of Belonging	0.58 unacceptable	0.63 unacceptable
Caregiver report		
Aesthetics	0.74 fair	0.69 unacceptable
Self-esteem	0.76 fair	0.83 good
Positive Affect	0.84 good	0.89 good
Negative Affect	0.85 good	0.90 excellent
Feelings of Belonging	0.77 fair	0.66 unacceptable

Note: N = 68. DQoL = Dementia Quality of Life instrument.
a. Alpha significantly higher for high versus low insight ($P < .05$).

Effect of patient insight and level of cognitive impairment. It is possible that the lower internal consistency reliabilities for patients with impaired versus intact insight were driven, at least in part, by the fact that patients with lower insight tend to have more cognitive impairment. In fact, in the present sample, the MMSE and CIR were significantly correlated ($r = -0.63$, $P < .01$). Thus, in exploratory analyses, we examined internal consistency reliabilities in patients with impaired versus relatively intact insight, who were further classified as having higher (score greater than 25) or lower (score of 25 or lower) scores on the MMSE. The MMSE cutoffs were determined by a median split of the sample. Results are presented in Table 3 and should be regarded with caution because of small sample sizes. However, an interesting pattern to the results emerges. Impaired insight may have a more detrimental impact on the internal consistency of reliability of QOL data than cognitive impairment. Reliabilities are generally higher for the patients with intact insight but lower MMSE score than vice versa. However, we must again stress that these results are exploratory and preliminary, and more research is needed with larger samples in each cell.

Insight and QOL Agreement

To test the effects of cognitive impairment and lack of insight on patient-caregiver agreement, regressions were run with caregiver DQoL ratings as the dependent variable and patient DQoL ratings as the independent variable. The standardized residuals of the regressions were saved and were used as the measure of agreement. Positive residuals indicate that caregivers reported higher scores on a subscale than patients did. Negative residuals indicate that caregivers rated the subscale lower than patients did. Next, moderated multiple regressions were calculated to determine if (1) MMSE predicted patient-caregiver agreement (ie, standardized residuals); (2) insight was a significant predictor of agreement, after controlling for MMSE; and (3) insight moderated the effect of MMSE on agreement.

Dependent variables in the moderated regressions were the standardized residuals, described above. Predictors were entered in a stepwise fashion. First, MMSE was entered to determine the effect of global cognitive impairment on QOL agreement. Next, CIR was entered to determine if insight could significantly account for variance in agreement beyond the MMSE. The significance of the change in R^2 was used to measure the effects of insight on agreement. Finally, the interaction between MMSE and insight (ie, MMSE × CIR) was entered into the regression equation to determine if there were interaction effects between MMSE and insight on agreement.

Results indicated that MMSE was a significant ($P < .05$) predictor of patient-caregiver agreement (ie, standardized residuals) for global QOL, and there was a trend ($P < .10$) for Self-esteem (Table 4). Greater MMSE scores were associated with more positive residuals (ie, caregivers reported higher QOL than patients did).

Results also indicated that after controlling for MMSE, CIR contributed significantly ($P < .05$) to prediction of patient-caregiver agreement for Self-esteem, and there was a trend ($P < .10$) for the global rating (Table 4). Better insight was associated with more positive residuals (ie, caregivers reported higher QOL than patients did).

There also were significant ($P < .05$) interaction effects between the CIR and MMSE in predicting agreement for Self-esteem, Positive Affect, and Feelings of Belonging (Table 4). Greater CIR and MMSE scores were associated with more positive residuals (ie, caregivers reported higher QOL than patients did), and lower scores were associated with more negative residuals (ie, caregivers reported lower QOL than patients did).

Table 3. Internal Consistency Reliabilities for Patient-Reported QOL by Level of Insight and Cognitive Impairment

	Impaired Insight		Intact Insight	
DQoL Subscale	Lower MMSE (n = 25)	Higher MMSE (n = 10)	Lower MMSE (n = 10)	Higher MMSE (n = 23)
Aesthetics	0.52 unacceptable	0.64 unacceptable	–0.07 unacceptable	0.81 good
Self-esteem	0.72 fair	0.39 unacceptable	0.83 good	0.71 fair
Positive Affect[a]	0.61 unacceptable	0.64 unacceptable	0.81 good	0.89 good
Negative Affect[a]	0.71 fair	0.83 good	0.87 good	0.88 good
Feelings of Belonging	0.63 unacceptable	0.71 fair	0.77 fair	0.43 unacceptable

Note: DQoL = Dementia Quality of Life instrument; MMSE = Mini-Mental State Examination. Patients with impaired and relatively intact insight were categorized based on Clinical Insight Rating scores (intact CIR = 7 or 8; impaired CIR = 6 or lower). Higher MMSE scores were 26 or greater; lower MMSE scores were 25 or lower.

Table 4. Moderated Multiple Regression Analyses Predicting Patient-Caregiver Agreement: Effects of Global Cognitive Impairment and Insight

	Independent Variables		
DQoL Scale	MMSE, R^2	CIR, ΔR^2	MMSE × CIR, ΔR^2
Aesthetics	0.01	0.03	0.00
Self-esteem	0.04*	0.10***	0.12***
Positive Affect	0.02	0.02	0.12***
Negative Affect	0.00	0.03	0.02
Feelings of Belonging	0.00	0.02	0.09**
Global QOL	0.10**	.04*	0.03

Note: DQoL = Dementia Quality of Life instrument; MMSE = Mini-Mental State Examination; CIR = Clinical Insight Rating Scale; QOL = quality of life.
$^*P < .10$. $^{**}P < .05$. $^{***}P < .01$.

Discussion

The current study is one of the first to address patient lack of insight and its impact on the psychometric quality of data provided by older patients diagnosed with MCI or mild AD. Patients with relatively poor insight into their cognitive and functional decline provided self-report QOL data that were less internally consistent than data provided by patients with fairly intact insight. However, it is important to note that patient insight was not the only factor that affected the reliability of patient-reported data. It is likely that cognitive impairment also contributed to lower reliabilities, especially because insight and cognitive impairment were significantly correlated. However, our data suggest that patient insight may affect reliability of QOL reports independent of cognitive impairment. More research is needed to test this intriguing hypothesis.

With regard to validity analyses, patient insight had effects on associations between patient- and caregiver-reported QOL that were unexpected. Discrepancies between patient and caregiver reports of QOL were found for patients both high and low in insight, but the differences were in opposite directions. For example, greater insight in patients was associated with higher self-esteem reports from caregivers than from patients. Lower insight in patients was associated with the opposite trend. Thus, there was not a simple, linear association between patient insight and agreement.

Insight also interacted with global cognitive impairment to predict discrepancies between self- and caregiver reports on the 3 DQoL subscales of Self-esteem, Positive Affect, and Feelings of Belonging. For patients with greater insight and less cognitive impairment, caregivers reported better QOL than did patients. For patients with lower insight and greater cognitive impairment, the opposite effect was found, with patients reporting greater QOL than caregivers. Thus, overall, better insight does not necessarily suggest better agreement between patient and caregiver perspectives on patient QOL.

Agreement is an imperfect measure of validity, and this is a limitation of this study. If a gold standard measure of QOL were available, it would be easier to determine the relative validity of patient and caregiver reports. Unfortunately, it is unlikely that an objective criterion measure will ever be available for a subjective construct such as QOL. Also, because of its inherent subjectivity, it is unlikely that an outside observer will ever have perfect access to another person's QOL. Our conclusion from this preliminary study is that it would be wise to partially weight QOL judgments in favor of self-report data, at least when patient insight is relatively intact. Scoring criteria for the Quality of Life–AD scale for combining patient and caregiver reports is an example of this method.[23]

It was surprising that caregivers rated QOL higher than patients did for the subgroup of the sample that was the highest functioning. It is a ubiquitous finding in the QOL literature that caregivers report lower QOL than patients do across a wide range of medical and psychiatric disorders[24] and especially in dementia samples.[23,25] Our data suggest there may be exceptions to this trend. Perhaps patients' awareness of their mild impairments resulted in lower self-report QOL ratings, whereas caregivers may see intact insight in a more positive light. For example, it may be easier for caregivers to take care of a person who is aware of their deficits than a person who is unaware of them,[26] and caregivers' feelings of burden may color how they perceive patient QOL.[25]

Alternately, it may be that patients' awareness of very mild deficits causes feelings of negative affect, such as uncertainty, which may serve to lower their QOL. Uncertainty and concern about one's own symptoms would, no doubt, affect self-reports about QOL more than caregiver reports would. Patients may adjust to, and be more accepting of, impairments over time, as suggested by response shift theory.[27] Of course, these speculations go beyond the current data and are issues to address in future research.

There are several limitations of this study that should be noted. Generalizability is limited by the sample, which was homogeneous with regard to race, recruited primarily from a clinical population, and relatively small. In addition, factors that may have aided in the interpretation of results, such as caregiver burden, were not measured. Finally, our data were cross-sectional, and longitudinal data would be particularly helpful to further explore reasons for patient and caregiver disagreements in QOL ratings, such as the response shift hypothesis mentioned above.

Despite these limitations, the current study makes an important contribution to the literature regarding self-report QOL data from older memory disorder patients. It is one of the first studies to address how patient insight may affect the psychometric quality of data provided by patients diagnosed with MCI or mild AD. Results suggest that when patient insight is intact, patient-report QOL is important to assess. Even when patient insight is intact, however, patient reports are unlikely to agree with caregiver reports. It is possible that both caregiver and patient reports have validity and may be regarded as 2 unique and independent perspectives on the patient's QOL and that both should be considered when making treatment decisions for the patient.[23]

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