

Integrating Patient and Informant Reports on the Cornell-Brown Quality-of-Life Scale

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Patients with mild cognitive impairment and mild to moderate Alzheimer's disease can provide information about their quality of life. This study determined whether aggregating patient and informant quality-of-life reports on the Cornell-Brown Scale for Quality of Life in Dementia can provide a broader perspective on the quality of life relative to patient or informant reports separately. Aggregated Cornell-Brown Scale for Quality of Life in Dementia scores were hypothesized to correlate more strongly with both patient and informant perspectives of patient's memory, function, and neuropsychiatric symptoms than the unaggregated measures. Results

indicated that aggregated Cornell-Brown Scale for Quality of Life in Dementia scores reflected a blend of patient and informant perspectives on patient function. This study contributes to a growing line of research that recommends integrating patient and informant perspectives to achieve the most complete assessment of quality of life.

Keywords: quality of life; mild cognitive impairment; Alzheimer's disease; neuropsychiatric symptoms; instrumental activities of daily living; memory problems

The assessment of quality of life (QOL) in mild cognitive impairment (MCI) and Alzheimer's disease (AD) is fraught with challenges. There are many definitions of QOL, and a wide variety of instruments, which range in breadth and depth, have been developed for its assessment in older patients with memory disorder.¹ There is no gold standard measure against which different instruments can be compared; the external criteria for validating QOL measures often are disease indicators (eg, dementia severity, functional impairment).² Disease indicators are the best available data against which the QOL measures can be validated, but they are problematic indicators of QOL, nonetheless. That is, if QOL is

merely considered to indicate greater disease severity, then QOL measures would not be needed in the first place. An implicit and valuable assumption in QOL research is that QOL must serve to indicate more than just disease severity, and knowledge about QOL can be a useful complement to other sources of information about patients with dementia.

However, there is one issue regarding QOL assessment that is particularly intractable. This most challenging characteristic of QOL research involves the source of QOL data, specifically, whether or not the patients have the ability to provide information about the quality of their own life. It is disconcerting to imagine that QOL can be assessed without input from the person about whom the assessment is targeted. After all, one point of agreement among all QOL researchers, who may slightly disagree on other points, is that QOL, at least in part, is subjective.²⁻⁷ However, persons with dementia experience impairments in memory, awareness, and insight that could limit their ability to report about their own QOL.^{8,9}

The issue of patient impairments and how they might affect QOL assessment has been handled in

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different ways by different investigators. Some assume that patients cannot participate in the assessment process and rely solely on proxy data.^{7,10} This approach seems particularly defensible when patients are in the moderate to severe stages of disease and when they have lost the ability to communicate.¹¹

Patients with milder dementia and patients in preclinical stages of memory loss are better able to participate in formal assessment of QOL. Many patients with AD and MCI can provide reliable information about their QOL^{2,12} and can even acknowledge that informants might have a different opinion regarding their QOL.¹³ Furthermore, data clearly indicate that patients with AD and caregivers do not agree regarding patients' QOL, even among mildly impaired patients, and that patients routinely report better QOL than caregivers.^{4,14} Thus, there is converging evidence that patients have something to say about their QOL, and this information can be valuable because it differs in important ways from the informant perspectives.

Fortunately, methods to facilitate patient's input into QOL assessments have been developed. Some investigators aggregate patient and informant reports, with the assumption that each source of data provides unique and valid insight into the patient's QOL and that validity might be maximized by combining reports from different sources.^{15,16} Brod et al¹⁷ went further in empowering patients and developed an instrument specifically for assessment of QOL from the patient's perspective.

The Cornell-Brown Scale for Quality of Life in Dementia (CBS) is another instrument that was designed to solicit patient's input for the assessment of QOL. The CBS differs from previous instruments because it is an interview-based scale that is administered by a health care professional.⁵ To date, patient and informant data have not been analyzed separately⁵ because the intention of creating the CBS was to develop a QOL instrument that combined patient and informant data to produce the most valid and reliable measure of patient QOL. However, in previous research, patient and informant responses were used by a clinician to reach a consensus on QOL ratings; it is not known whether aggregating patient and informant responses provides a more valid measure than relying on either source separately. The current study investigated a scoring procedure for the CBS that combined patient and informant data obtained from separate interviews, similar to previous research.¹⁶

We expected that the aggregate measure of the CBS would provide a more balanced perspective than the unaggregated reports on QOL and would correlate significantly with both patient and informant perspectives of patient function (ie, memory problems, instrumental activities of daily living, and neuropsychiatric symptoms). In contrast, due to shared method variance, we expected that patient-report CBS would exhibit preferential correlations with function measures from the patient perspective, and that informant-report CBS would exhibit strong correlations specifically with informant-report measures of patient function.

Methods

Participants

Participants were 63 patients diagnosed with AD ($n = 33$) or MCI ($n = 30$) and their caregivers or, for patients with MCI, knowledgeable informants. Participants have been characterized in previous publications.^{12,18} The majority (89%) of patient-informant dyads were recruited from an outpatient hospital-based memory disorder clinic. As described by Ready et al,¹² most patients and informants were Caucasian (91% and 92%, respectively) and women (57% and 71%, respectively). Informant relationship types were spouse (51%), child (30%), sibling (3%), and other (16%). The majority of informants (62%) lived with the patient.

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).¹⁹ Mental status of all participants was assessed with the Mini-Mental State Examination (MMSE).²⁰ Alzheimer's disease was diagnosed according to National Institute of Neurologic and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association criteria.²¹ Patients with AD had CDR ratings of 0.5 ($n = 11$), 1 ($n = 15$), or 2 ($n = 7$), indicating very mild, mild, and moderate dementia severity, respectively. Mean MMSE for patients with AD was 21.6 ($SD = 4.7$). Mild cognitive impairment was diagnosed according to the criteria published by Petersen et al.²² All patients with MCI had a CDR rating of 0.5. Mean MMSE for patients with MCI was 27.4 ($SD = 2.0$).

Measures

Cornell-Brown Scale for Quality of Life. The CBS is a 19-item semistructured interview to assess QOL that is conducted by a trained health care professional.⁵ Each item has a negative and a positive pole and is rated based on patient's feelings and behaviors that occurred over the past month. The CBS is a modification of the Cornell Scale for Depression in Dementia,²³ and the depressive items anchor the negative pole for each item. If the negative pole is not endorsed or observed, the positive pole is assessed. The CBS items assess mood, ideational disturbances, behavioral disturbances, physical signs, and cyclic functions. The CBS demonstrates adequate internal consistency reliability and construct validity.⁵ Patients and informants provided independent responses on the CBS.

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 $\alpha = 0.85$)²⁴ and has been used in several previous studies on insight in AD.^{8,9,25} For this study, scores on the CIR were reversed, so that higher values indicated better insight (ie, 8, high insight).

Short-Memory Questionnaire. The Short-Memory Questionnaire (SMQ) is a 14-item memory questionnaire.²⁶ Higher scores reflect greater memory ability. The scale demonstrates good internal consistency reliability (Cronbach $\alpha = 0.85$) and construct validity. Informants and patients completed the SMQ independently.

Instrumental Activities of Daily Living Scale. Instrumental activities of daily living were measured by the Instrumental Activities of Daily Living (IADL) scale.²⁷ The scale measures independence in performing 8 activities. Patient performance of each activity is rated on a 3-point scale (2, independence; 1, need for assistance; 0, dependence). Patients and informants provided independent ratings of IADLs.

Neuropsychiatric Inventory Questionnaire. The Neuropsychiatric Inventory Questionnaire (NPI-Q) is a 12-item questionnaire that assesses neuropsychiatric

symptomatology in neurologic patients.²⁸ Respondents are asked whether a symptom is present and if so, to rate the severity of the symptom on a 3-point scale (1, mild; 3, severe). Patients and informants independently provided severity ratings. Informants also indicated how much each symptom, if present, was distressing to him or her on a 6-point scale (0, not at all distressing; 5, extremely or very severely distressing). The NPI-Q demonstrates adequate test-retest reliability and convergent validity with the full-length interview version of the Neuropsychiatric Inventory (NPI).

Procedure

Patients and informants were interviewed separately by R.E.R. and asked about the patients' QOL, IADLs, neuropsychiatric symptoms, and memory problems. The MMSE was administered to all patients, and insight was rated by a neurologist (B.R.O.) or by a neuropsychologist (R.E.R.). Mild cognitive impairment and AD data were analyzed together, as in our previous research.¹²

Results

Patient and informant data on the CBS exhibited comparable internal consistency reliability (Cronbach $\alpha = 0.83$ for patients and 0.84 for informants). As stated previously, the goal of analysis was to determine whether an aggregate CBS score, produced by combining patient and informant reports, would exhibit broader associations with patient functioning than unaggregated CBS reports. Aggregated reports were expected to correlate significantly with both patient and informant perspectives of patient function. In contrast, due to shared method variance, patient-report CBS was predicted to exhibit preferential correlations with functional measures from the patient perspective (eg, memory problem, IADLs), and the informant-report CBS was expected to exhibit the strongest correlations with informant-report measures of patient function.

Correlation analysis partially supported the hypotheses (Table 1). Evidence of preferential correlations, possibly due to shared method variance, was found for patient-reported and caregiver-reported QOL. Specifically, patient CBS correlated with patient-report SMQ but not with informant-report SMQ; the converse was true for informant-report CBS. The

Table 1. Correlations Between the QOL and Various Indicators of Disease Severity for Patient, Informant, and Aggregate Reports on the CBS (N = 63)^a

Patient Factors	CBS Source		
	Aggregate	Patient	Caregiver
Patient SMQ	0.27 ^b	0.42 ^b	0.06
Caregiver SMQ	0.42 ^c	0.23	0.51 ^b
Patient IADLs	-0.21	-0.25	-0.13
Caregiver IADLs	-0.36 ^c	-0.28 ^b	-0.36 ^b
Patient NPI severity	-0.58 ^c	-0.61 ^c	-0.42 ^c
Caregiver NPI severity	-0.59 ^c	-0.37 ^c	-0.65 ^c
Caregiver distress on NPI	-0.57 ^c	-0.35 ^c	-0.65 ^c

Note: QOL = quality of life; CBS = Cornell-Brown Scale for Quality of Life in Dementia; SMQ = Short Memory Questionnaire; IADLs = instrumental activities of daily living; NPI = Neuropsychiatric Inventory.

a. Aggregate ratings are the average of patient and caregiver CBS scores.

b. $P < .05$.

c. $P < .01$.

aggregate CBS score correlated strongly with both patient and informant SMQ measures. Additionally, caregiver-report CBS correlated significantly with caregiver-report activities of daily living (ADLs) but not with patient-report ADLs.

An unexpected finding was that patient-report CBS correlated significantly with caregiver-report ADLs ($r = -0.28$; $P < .05$) rather than with patient-report ADLs ($r = 0.25$; $P < .10$). However, despite the fact that one correlation was significant and the other was only a trend, the magnitude of the difference between the correlations was negligible. Furthermore, although cross-informant correlations were found for CBS reports and for NPI scores, within-group associations were somewhat stronger than cross-group associations. The generally strong associations between the CBS and NPI support previous research, indicating that neuropsychiatric symptoms are robust correlates of QOL.^{2,4,29-32}

As hypothesized, aggregated CBS reports reflected a blend of patient and caregiver reports with respect to correlations with patient characteristics. There were significant associations between the aggregate CBS score and all reports on patient memory, function, and neuropsychiatric symptoms, except patient-report ADLs. There was no restricted range in patient-report ADLs (mean = 11.25; SD = 4.93), which might explain the lack of a significant effect. However, another reason for a nonsignificant finding

Table 2. Partial Correlations Between the QOL and Various Indicators of Disease Severity for Patients With Poor Insight (N = 21)^a

Patient Factors	CBS		
	Aggregate	Patient	Caregiver
Patient SMQ	0.40	0.45 ^b	0.26
Caregiver SMQ	0.35	0.23	0.39
Patient IADLs	-0.15	-0.23	-0.02
Caregiver IADLs	-0.26	-0.21	-0.25
Patient NPI severity	-0.80 ^c	-0.72 ^c	-0.68 ^c
Caregiver NPI severity	-0.61 ^b	-0.39	-0.70 ^c
Caregiver distress on NPI	-0.61 ^b	-0.40	0.69 ^c

Note: QOL = quality of life; CBS = Cornell-Brown Scale for Quality of Life in Dementia; SMQ = Short Memory Questionnaire; IADLs = instrumental activities of daily living; NPI = Neuropsychiatric Inventory.

a. Mini-Mental State Examination scores were controlled in correlation analyses. Aggregate ratings are the average of patient and caregiver CBS scores.

b. $P < .05$.

c. $P < .01$.

might be due to patient insight, which has been shown to affect the psychometric properties of QOL reports.¹²

Thus, analyses were rerun after the sample was split into 2 groups based on CIR scores: patients with poor insight and patients with better insight. Specifically, CIR scores were converted to z-scores (mean = 0; SD = 1) within the sample; patients with scores below zero were categorized into a poor insight group (n = 21), and patients with scores above zero were categorized into the higher insight group (n = 36). Internal consistency reliability for the CBS was comparable for the 2 insight groups (low insight alpha = .87; high insight alpha = .80). Overall, there were more associations between CBS scores and patient memory, function, and neuropsychiatric symptoms for the higher versus lower insight group. Thus, for patients with lower insight, it might be harder for patients and caregivers to rate QOL, at least as it pertains to symptoms of AD. Results of correlation analyses also indicated a pattern for the aggregate CBS ratings to exhibit correlations with the characteristics of the patient that reflected a balance between patient and informant report, whether patients are with higher or lower insight (Tables 2 and 3). Thus, aggregation might be warranted even for patients with poor insight into their dementia severity. However, similar to the results for analyses on the entire sample, patient-report ADL had the lowest associations with CBS reports.

Table 3. Partial Correlations Between the QOL and Various Indicators of Disease Severity for Patients With Relatively Intact Insight (N = 36)^a

Patient Factors	CBS		
	Aggregate	Patient	Caregiver
Patient SMQ	0.16	0.31	0.01
Caregiver SMQ	0.44 ^b	0.30	0.50 ^b
Patient IADLs	-0.13	-0.04	-0.12
Caregiver IADLs	-0.34 ^b	-0.29	-0.33 ^b
Patient NPI severity	-0.42 ^b	-0.51 ^b	-0.27
Caregiver NPI severity	-0.56 ^b	-0.40 ^b	-0.61 ^c
Caregiver distress on NPI	-0.53 ^b	-0.35 ^b	-0.62 ^c

Note: QOL = quality of life; CBS = Cornell-Brown Scale for Quality of Life in Dementia; SMQ = Short Memory Questionnaire; IADLs = instrumental activities of daily living; NPI = Neuropsychiatric Inventory.

a. Mini-Mental State Examination scores were controlled in correlation analyses. Aggregate ratings are the average of patient and caregiver CBS scores.

b. $P < .05$.

c. $P < .01$.

Discussion

Our previous research demonstrated converging evidence, across QOL measures, that patients with MCI or mild AD have the capacity to report reliable and valid data about their QOL.^{5,12,14} Patient data are imperfect and are affected by factors such as poor insight¹²; informant data also are flawed and, for example, can be influenced by feelings of burden.⁴ The results of the current study imply that aggregating these 2 meaningful, yet imperfect, sources of data about patient QOL can provide a more representative and balanced measure of patient QOL than either perspective alone.

Investigators collect QOL data more often from informants or caregivers than from patients,^{7,10,28} but on the basis of data from this study and work from other researchers,^{4,16,17} omitting patient data reduces the potential validity of a QOL measure. In the current study, without patient's input, associations between QOL and patient-reported memory difficulties would have been missed, and associations between QOL and informant-report data would have been overestimated.

Patients with memory loss or mild AD have the capacity to participate in assessment exercises that are complex. For example, patients with AD can see a difference between their own view of QOL and views of their caregivers.¹³ Furthermore, patients routinely

have a more optimistic view of their lives and situations than external observers, even if these observers are close relatives or caregivers.¹⁴ Positive moods have powerful predictive power for functioning.³³ Thus, patient perspectives should not be dismissed but incorporated, whenever possible, into QOL assessment. In the current study, aggregate measures of QOL appeared better than reports from a single source, even for patients with poorer insight into their dementia severity.

Patient insight is often cited as a reason for not collecting self-report QOL data,³⁴ and, in fact, patients with poorer insight may provide QOL data with lower internal consistency reliability than patients with better insight.¹² In the current study, there tended to be lower correlations between QOL and patient characteristics (ie, memory reports) for patients with lower versus higher insight, and this pattern was true for self-report and informant-report QOL. Thus, it is possible that caregivers might have a more difficult time rating QOL for patients with poor insight than for patients with better insight. This is a novel prediction that should be pursued in future research. That is, perhaps patients with poor insight are more difficult to judge or present with contradictory behaviors (eg, acting impaired vs verbally denying problems) that make their true situation difficult to discern.

There are limitations to this study that must be mentioned. The sample was from a memory disorder clinic and thus may not be representative of the general population. Results are also specific to patients in the very mild to moderate stages of cognitive impairment, and they probably would not extend to those with severe dementia who are too aphasic and confused to communicate meaningful information about their QOL. However, results do provide important guidance for using the CBS and for further validating the approach of combining patient and informant reports on QOL.^{15,16} Thus, we hope this research will encourage persons who use the CBS or another QOL instrument to consider collecting patient data as a complement to caregiver or informant data. Aggregation of these sources of data may provide a more broad and representative measure of QOL than either perspective alone.

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