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Associations among measures of awareness of cognitive deficits in dementia

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Abstract

Background—To examine the relationships among various measures of awareness of cognitive deficits in dementia, and investigate the unique association between clinician rating and alternative approaches to assessing awareness.

Methods—Participants were 108 patients with very mild ($n = 50$) or mild ($n = 58$) dementia. Awareness of cognitive difficulties was assessed by clinician rating, informant rating, patients' report of cognitive difficulties, discrepancy between patients' and informants' report of cognitive difficulties, and patients' perception of performance on neuropsychological tests. Correlational analyses were used to assess associations among these measures of awareness; and ordinal logistic regression was used to examine the unique relationship between clinician rating of awareness and the other approaches.

Results—All measures of awareness were significantly correlated with one another, with coefficients ranging from 0.26 to -0.64 . Patients categorized as being unaware by either clinicians or informants reported fewer cognitive difficulties. Of the awareness measures evaluated, clinician rating had the strongest correlation with a measure of global cognition. In the regression analysis, only informant global rating and patients' report of cognitive difficulties were significantly associated with clinician rating. The model's classification accuracy was satisfactory for patients in the "intact awareness" and "severe unawareness" categories, but not for those in the "mild unawareness" category.

Conclusion—Though they likely share overlapping variance, measures of awareness are not interchangeable. Each potentially elucidates unique aspects of the complex phenomenon of awareness, with clinician assessment most suited for ambiguous cases. Even so, when clinician assessment is not feasible, informant rating (but not patient-informant discrepancy) would be a valid substitute.

Keywords

dementia; awareness; clinician rating; Cognitive Difficulties Scale

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1. Background

Dementia is characterized by frank cognitive, behavioral, and functional impairments that manifest over the course of the disease [1]. However, patients with dementia frequently fail to fully appreciate their deficits [2,3]. Such impaired awareness of deficits is observed even in the earliest stages of dementia and worsens as the disease progresses [4–6]. Impaired awareness of deficits has implications for diverse aspects of patient care such as timely self-presentation for treatment [7], compliance with treatment [8], personal safety [9], financial autonomy [10], caregiver distress [11], and nursing home placement [12].

Awareness of deficits is a complex phenomenon. This is evidenced by the lack of consensus concerning its etiology, structure, clinical correlates, and prognostic utility despite the attention it has received in the literature [13–16]. Likewise, there currently exists no gold standard for assessing awareness in dementia; and the information obtained from the various approaches is not always coincident [17–19]. Nonetheless, clinician determination of awareness is generally considered the most reliable approach given that clinicians are comparatively better trained at ascertaining levels of awareness, particularly for ambiguous cases. In addition, the interview format of clinician assessment provides opportunities to clarify questions, query responses, and ensure that comprehension difficulties are not mistaken for unawareness [17,19,20].

Despite these advantages of clinician ascertainment of awareness, there arise occasions when such assessment is either impossible or impractical, such as when the logistics of a research study does not permit the extensive interview that informs clinician determination of awareness. Although a number of studies have examined awareness of deficits in dementia using a combination of methodologies [17,18,21], to our knowledge, no study has attempted to determine which alternative approaches to awareness assessment best predict clinician rating. This represents a knowledge gap, because such an examination has the potential to uncover time-efficient yet reliable ways of obtaining the same sort of information available via extensive clinical assessment.

In this study, we assessed awareness of deficits in dementia using clinician global rating, informant global rating, patients' report of cognitive difficulties on a questionnaire, discrepancy between patients' report on the questionnaire and informants' report on a parallel version of the questionnaire, and patients' rating of their performance on a neuropsychological battery. We first sought to understand the bivariate, and potentially overlapping, relationships among these measures of awareness. Then, we attempted to assess the unique association between clinician global rating and the other measures of awareness.

2. Methods

2.1. Participants

Participants were 108 consecutive patients who presented with cognitive complaints to the Neuropsychology Program at the Rhode Island Hospital, Providence, Rhode Island, and were subsequently diagnosed with very mild (CDR 0.5, $n = 50$) or mild (CDR = 1, $n = 58$) dementia on the basis of medical history, family reports, neurological examination, neuroradiological findings, and neuropsychological testing. Persons with a differential medical (e.g., uncontrolled diabetes, end-stage renal failure), neurologic (e.g., ruptured aneurysm, brain tumor), or psychiatric (e.g., major depression, bipolar disorder) condition that might account for their cognitive difficulties were excluded.

By definition, the CDR 0.5 subgroup likely included persons who meet criteria for mild cognitive impairment (MCI) [22]. However, group membership for this study was defined on the basis of the CDR (very mild or mild dementia), to be consistent with the clinical characterization of our patients and to circumvent the controversies surrounding the overlap between CDR staging and MCI case definition [22–24]. The CDR 0.5 subgroup was comprised of persons with suspected incipient Alzheimer's disease (52%), vascular dementia (28%), mixed Alzheimer's disease and vascular dementia (8%), frontotemporal dementia (6%), olivopontocerebellar atrophy (2%), alcohol-related dementia (2%), and dementia NOS (2%). The dementia subtypes in the CDR 1 subgroup included Alzheimer's disease (79.3%), vascular dementia (5.2%), mixed Alzheimer's disease and vascular dementia (5.2%), frontotemporal dementia (3.4%), Lewy body dementia (3.4%), and Parkinson's disease dementia (3.4%). All dementia diagnoses were made using applicable criteria, such as the National Institute of Neurological and Communicative Disorders and Stroke–Alzheimer's Disease and Related Disorders Association criteria [25] for Alzheimer's disease. The local Institutional Review Board approved all study procedures. Table 1 details patient characteristics.

2.2. Informants

Each patient came to the evaluation with an informant whom the patient identified as appropriately knowledgeable concerning the patient's cognitive and functional abilities. Informants were mostly patients' spouses (42.6%) or children (40.7%), who have known the patients for 44.38 ± 14.40 years, and spend 10.91 ± 9.48 hours with them each day. Most informants (73.7%) reported receiving no assistance with caregiving. Informants' mean Zarit Burden Inventory [ZBI; 26] score was 20.17 ± 13.98 , which is below the threshold for significant burden.

2.3. Measures

2.3.1. Demographics—Patients' age, gender, race (all participants were Caucasians), and years of education were determined through study questionnaires.

2.3.2. Global cognitive status—This was assessed with the Modified Mini Mental State Examination [3MS; 27]. The 3MS is an extended version of the Mini Mental State Examination [MMSE; 28]. Relative to the MMSE, the 3MS samples a wider variety of cognitive functions using a more refined scoring algorithm. In dementia samples, it has excellent test-retest reliability ($r = 0.93$) and satisfactory sensitivity (88%), specificity (90%), positive predictive value (29%), and negative predictive value (90%) [29]. Possible scores range from 0 to 100.

2.3.3. Depressive symptoms—The presence of depressive symptoms was assessed using the Beck Depression Inventory-II [BDI-II; 30]. The BDI-II has good psychometric properties: [internal consistency = 0.92, test-retest reliability = 0.93, construct validity = .71 (i.e., correlation with the revised Hamilton Psychiatric Rating Scale for Depression [31])]. Possible scores range from 0 to 63.

2.3.4. Awareness—Awareness was assessed in various ways. First, a clinician assigned the patient an awareness score based on information gathered from the patient and their informant, during the clinical interview, regarding the nature, extent, and everyday impact of the patient's cognitive problems. Possible scores were (1) intact awareness, (2) mild unawareness, or (3) severe unawareness [21,32]. Second, the informant completed an awareness measure [33] wherein they assigned the patient a rating, indicating the patient's global level of awareness of cognitive difficulties. Possible ratings include (1) shows an acceptable level of awareness of his/her strengths and disabilities, (2) shows fairly good

awareness, but limitations in awareness of disability sometimes causes problems, (3) is about halfway there in reaching an acceptable level of awareness, (4) has a little awareness of disabilities, but is very limited, or (5) shows no awareness or almost no awareness of disabilities.

In addition to the measures described above, at the end of the neuropsychological evaluation patients were asked to assign themselves a rating, on a 1 (very poorly) to 10 (very well) analog scale, indicating their perception of performance on the tests administered. Furthermore, patients completed the Cognitive Difficulties Scale [34,35], a 38-item questionnaire that inquires into everyday inefficiencies in attention, concentration, language, praxis, memory, orientation, and daily functioning. Responses were made on a 5-point scale: (0) not at all, (1) rarely, (2) sometimes, (3) often, or (4) very often. Because some patients found some questions inapplicable and, thus, did not complete them (e.g., “I have trouble sewing or mending”), it became necessary to control for variability in the number of items duly completed by each patient. This was accomplished by computing a mean CDS rating for each patient by dividing the sum of the items completed by the number of items completed. Informants also completed a parallel version of the CDS, describing patients’ deficits. A mean CDS rating was computed for each informant for the same reason, and in the same manner, as for patients. A CDS discrepancy score was obtained by subtracting a patient’s mean CDS ratings from their informant’s mean CDS ratings. Thus, a positive discrepancy score indicated that, on average, the patient rated himself as having milder deficits than the informant did.

2.4. Statistical analysis

The bivariate associations among the measures of awareness utilized in this study were examined using Pearson’s coefficients (or Spearman’s rho for correlations involving clinician rating). Ordinal logistic regression was used to assess the unique association between clinician global rating and the other measures of awareness. In this regression analysis, clinician global rating of awareness was the dependent variable and the other indices of awareness (i.e., informants’ global rating, patients’ rating on the 10-point scale, patients’ mean CDS ratings, and CDS discrepancy) were the independent variables. The proportional odds assumption was tested for this regression model.

All analyses were performed using SPSS 16 (SPSS Inc., Chicago, IL), and only test findings that met an alpha of .05 (2-tailed) threshold were considered significant.

3. Results

3.1. Summary statistics for study measures of awareness

Table 2 presents summary statistics for the measures of awareness employed in this study. Clinicians assigned the majority of patients an awareness rating of “mild unawareness.” On the informant global rating measure, most patients were either characterized as having “acceptable” or “fairly good” awareness. Patients’ perception of performance on the neuropsychological tests administered tended to be positive. Consistent with this perception, patients generally reported few cognitive difficulties on the CDS. Overall, informants described the patients as having more cognitive inefficiencies than the patients did.

3.2. Associations among measures of awareness

Table 3 presents bivariate correlations among the measures of awareness. All measures of awareness were significantly correlated with one another. The strongest correlation was between CDS discrepancy and patients’ mean CDS ($r = -0.64$). However, this was not surprising given that CDS discrepancy was partly derived from patients’ mean CDS. Of

note, all correlations were in the positive direction (i.e., the measures were generally in agreement with one another) except correlations involving patients' mean CDS, which were negative. In essence, patients described as being unaware by either clinicians or informants endorsed fewer cognitive difficulties on the CDS.

Because it is conceivable that clinicians' and informants' assessments of patients' level of awareness may be in error, we also tested associations between measures of awareness and patients' performance on the 3MS, an objective estimate of patients' cognitive status. These analyses revealed significantly negative correlations between the 3MS and clinician global rating, informant mean CDS, and CDS discrepancy. In essence, patients who performed poorly on the 3MS were more likely to be rated as unaware by clinicians, more likely to be described as having considerable cognitive difficulties by their informants, and more likely to report fewer cognitive complaints on the CDS relative to their informants. In contrast, patients' mean CDS was positively, though only marginally significantly ($p = 0.069$), associated with scores on the 3MS. That is, patients who performed poorly on the 3MS tended to endorse few cognitive complaints on the CDS. These findings are also presented in Table 2. Notably, of the awareness measures examined, clinician rating had the strongest correlation with the 3MS ($r = -0.45$).

3.3. Predictors of clinician-rated awareness

Table 4 displays the results of the ordinal regression model that examined the unique association between clinician rating and the other measures of awareness. Only informants' global rating and patients' mean CDS emerged significant predictors of clinician rating of awareness. Patients rated as having greater unawareness by their informants were also significantly more likely to be classified as being unaware by the clinician. In contrast, patients who rated themselves as having milder cognitive difficulties were significantly more likely to be classified as being unaware by the clinician. The Nagelkerke R^2 for this model was 0.43, indicating a robust effect size [36]. The analysis satisfied the proportional odds assumption.

Table 5 presents a cross tabulation of patients' actual clinician-rated level of awareness against their model-predicted level of awareness. The model attained a 73% correct classification for those the clinician adjudged to have "intact awareness" and 79% for those classified as having "severe unawareness." The hit rate for those in the "mild unawareness" category was considerable less, 42%. The figure illustrates this by presenting patients' probability of being model-assigned to their actual clinician-rated category as a function of their CDS score. For those in the "intact awareness" category, the probability of being correctly model-assigned to this category increased almost linearly with increments in CDS score; and for those in the "severe unawareness" category, the probability of being correctly model-assigned to this category virtually increased linearly with decrements in CDS score. In contrast, the probability of accurate classification for those in the "mild unawareness" group exhibited a curvilinear relationship with CDS score – it initially increased with increments in CDS score, but subsequently decreased with further increases in CDS score.

4. Discussion

In this study, we investigated associations among five measures of awareness – clinician rating, informant rating, patients' report of cognitive difficulties, discrepancy between patients' and informants' report of cognitive difficulties, and patients' perception of performance on neuropsychological tests. Because clinician rating is arguably the most reliable and widely used method for evaluating patient awareness of deficits, we also sought to understand the unique association between clinician rating and the other measures of awareness—a previously unexamined issue.

We found correlation coefficients ranging from 0.26 (between informant rating and patients' perception) to -0.64 (between patients' CDS and patient-informant discrepancy on the CDS). Of the ten correlations tested, seven were smaller than 0.40. Furthermore, with the exception of the potentially artificially inflated -0.64 correlation between patients' CDS and CDS discrepancy, all other correlation coefficients were less than 0.50. This finding of relatively modest correlations among the various measures suggests that the measures largely tap potentially distinct aspects of the complex phenomenon of awareness. As such, though they may on the surface appear alternative means of assessing the same construct, none may completely replace the other [19].

The direction of the correlations among the measures of awareness indicated that the measures were overall in agreement with one another. For instance, patients who were determined to have reduced awareness of deficits by clinicians were also likely to be deemed unaware by their informants. Exceptions to this were correlations involving patients' report of cognitive difficulties on the CDS. All correlations involving patients' CDS were negative, indicating that patients who reported fewer cognitive difficulties on the CDS were characterized as unaware by clinicians and informants (although neither clinicians nor informants had access to patients' CDS scores).

Because it is possible that informants and clinicians may misconstrue a patient's report of mild cognitive difficulties—during the clinical interview (for clinicians) or in daily life (for informants)—as unawareness of deficits, we computed correlations between measures of awareness and patients' performance on an objective measure of global cognition, the 3MS. These correlations revealed that patients who objectively had poor cognitive functioning tended to report fewer cognitive difficulties, whereas they were described as unaware by clinicians and as having considerable cognitive difficulties by their informants. Thus, it is unlikely that clinicians and informants misconstrued patients' report of cognitive functioning. The finding of a correspondence between clinician ratings of unawareness and patients' worsening cognition is consistent with reports from prior dementia studies that found that unawareness of deficits worsens as the disease progresses [4–6]. Furthermore, our finding that clinician rating had the strongest correlation with the 3MS concurs with the view that clinician rating is the most reliable and valid approach to assessing awareness [17,19,20].

The regression analysis that examined the unique association between clinician rating and the other measures of awareness revealed that only informant rating of awareness and patients' report of cognitive difficulties were significantly correlated with clinician's awareness ratings — patients described as unaware by their informants were also likely to be classified as unaware by the clinician, and patients who reported fewer cognitive difficulties were likely to be classified as unaware by the clinician. Though the effect size for this model was reasonably large, it was not overwhelming; suggesting that a sizable proportion of the information present in clinician rating of awareness is not captured by the other measures (and vice versa). This reinforces the earlier conclusion that, though the various measures of awareness may share overlapping variance, they likely provide windows into distinct aspects of this complex construct [19,37]. Of note, the regression model's classification accuracy was satisfactory for patients categorized as having “intact awareness” or “severe unawareness” by clinicians, but not for those rated as having “mild unawareness.” This raises the possibility that although non-clinician approaches to assessing awareness may reasonably detect persons at the extremes of the awareness continuum, they are less suited for ascertaining ambiguous cases; a function best performed by trained clinicians.

Several studies have examined informant report of functional [18,38,39] and cognitive [17,40,41] abilities among cognitively-impaired older adults. Results from these studies indicate that there is considerable variability in the extent to which the report provided by informants approximate patients' actual performance on objective testing. Whereas some found that informants generally provide reliable estimates of patients' actual abilities [40,41], others observed that the report provided by informants is influenced by factors such as mood [42], relationship to patient [38], and perceived burden of caregiving [43]. The present study is unique in that, in addition to utilizing the conventional method of calculating discrepancy scores from informant and patient ratings of patient's deficits, we also asked the informant to directly rate the patient's global level of awareness, an approach not employed by any prior awareness studies in dementia. Our findings suggest that global ratings of awareness provided by informants generally approximate ratings made by trained clinicians.

It is worth noting that whereas informants' global rating of awareness was a significant predictor of clinician's rating, the discrepancy between patient and informant reports of patient's cognitive difficulties only attained marginal significance. This is an interesting finding given that dementia studies routinely operationalize awareness as the discrepancy between patients and their informants [2,44,45], a methodology premised on the view that report by informants is generally more reliable than that by patients [21]. Indeed, our correlation analyses revealed that informants' mean CDS ratings were significantly correlated with patients' 3MS scores whereas patients' mean CDS ratings only tended toward significance in the *reverse* direction. Even so, the combination of a significant "informant global rating" and a marginally significant "discrepancy score" in the present study suggests that discrepancy between patients and their informants may not necessarily signal unawareness of deficits in all cases. A recent study found that neither concordance nor discordance between patients and their informants was performative indicative of patients' level of awareness [18]. Therefore, it appears that direct rating of awareness by informants may more closely approximate clinician rating than the discrepancy between informants and patients.

A limitation of this study is the use of data obtained from an ethnically-homogenous (all Caucasians) sample of patients who presented to an outpatient neuropsychology clinic. The findings may have been different if the study was conducted with an ethnically-diverse sample recruited from the community as part of a research study specifically designed to address the study's aims. Secondly, due to our modest sample, the study was not sufficiently powered to investigate its aims separately for patients with CDR 0.5 versus CDR 1. Such within-group investigation is relevant as the relationships observed may not hold equally for the two patient groups. Related to the foregoing, it would be of interest to conduct this study with persons representing a broader spectrum of cognitive functioning, from normal cognitive aging to moderate dementia. We also acknowledge that, though clinician rating is widely considered superior to other methods for assessing awareness (hence we selected it as the criterion), it is not without limitations and may not necessarily be *the* gold standard.

In summary, this study examined bivariate associations among various measures of awareness, as well as the unique association between clinician global rating and the other measures. The key finding was that though these measures share overlapping variance, they are not completely coextensive. Each likely provides distinct information concerning awareness, a conclusion supported by the complex nature of this phenomenon [13,14,46]. This study is also the first to demonstrate that, in the context of dementia, informant global rating of patient awareness is a significant predictor of clinician rating. Therefore, when clinician rating of awareness is unobtainable, informant global rating, which is relatively easier to obtain, would be a valid substitute.

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Figure. Probability of being assigned to actual clinician-rated category as a function of CDS score

○ = intact awareness, * = mild unawareness, ◇ = severe unawareness.

CDS = Cognitive Difficulties Scale.

Table 1

Characteristics of study participants.

Characteristic	Value	Sample range
Age , mean (SD)	74.68 (7.96)	51 – 88
Female , %	61.1	----
Education , mean (SD)	12.94 (3.05)	7 – 20
*3MS , mean (SD)	79.13 (11.23)	41 – 96
CDR global , %		----
0.5	46.3	
1.0	53.7	
BDI , mean (SD)	7.99 (8.00)	0–38

3MS = Modified Mini Mental State Examination; CDR = Clinical Dementia Rating Scale; BDI = Beck Depression Inventory.

* Mean (SD) Mini Mental State Examination = 24.79 (3.16); sample range = 14 – 30.

Table 2

Summary statistics for study measures of awareness.

Measure	Value	Sample range
Clinician rating		---
Intact awareness, %	26.2	
Mild unawareness, %	55.1	
Severe unawareness, %	18.7	
Informants' global rating		----
Acceptable awareness, %	32.7	
Fairly good awareness, %	34.7	
Halfway awareness, %	12.2	
Little awareness, %	14.3	
No awareness, %	6.1	
Patients' rating, mean (SD)	6.09 (1.79)	1 – 10
Patients' mean CDS, mean (SD)	1.37 (0.74)	0 – 3.42
Informants' mean CDS, mean (SD) [†]	1.73 (0.75)	0.16 – 3.58
CDS discrepancy, mean (SD)	0.36 (0.98)	-1.84 – 3.00

CDS = Cognitive Difficulties Scale; CDS discrepancy calculated as informants' mean CDS minus patients' mean CDS.

[†]This measure is not considered an index of patients' level of awareness. Its inclusion in this table is to present informant report of patients' cognitive difficulties vis-à-vis patients' report of cognitive difficulties.

Table 3

Correlations among measures of awareness and global cognition.

	1. Clinician rating	2. Informants' global rating	3. Patients' rating	4. Patients' mean CDS	5. Informants' mean CDS [†]	6. CDS discrepancy	7. 3MS
1.	1.00						
2.	0.36**	1.00					
3.	0.36**	0.26*	1.00				
4.	-0.49**	-0.32**	-0.36**	1.00			
5.	0.13	0.18	0.09	0.15	1.00		
6.	0.48**	0.37**	0.34**	-0.64**	0.66**	1.00	
7.	-0.45**	-0.13	-0.05	0.18	-0.26**	-0.33**	1.00

All correlations are Pearson's coefficients except those involving clinician rating, which are Spearman's rho.

[†] This measure is not considered an index of patients' level of awareness. Its inclusion in this table is primarily to show congruence between informant report of patients' cognitive difficulties and patients' objective cognitive status.

* correlation significant at the .05 level;

** correlation significant at the .01 level.

CDS = Cognitive Difficulties Scale; CDS discrepancy calculated as informants' mean CDS minus patients' mean CDS; 3MS = Modified Mini Mental State Examination.

Table 4

Predictors of clinician rating of awareness.

Variable	β	SE	OR (95% C.I.)	p value	Nagelkerke R ²
Informants' global rating	0.42	0.19	1.52 (1.04, 2.23)	.029	
Patients' rating	0.23	0.13	1.26 (0.96, 1.63)	.092	
Patients' mean CDS	-0.97	0.43	0.38 (0.16, 0.89)	.023	.43
CDS discrepancy	0.52	0.30	1.68 (0.92, 3.03)	.089	

CDS = Cognitive Difficulties Scale; CDS discrepancy calculated as informants' mean CDS minus patients' mean CDS; 3MS = Modified Mini Mental State Examination; CDR = Clinical Dementia Rating Scale.

Table 5

Classification accuracy of regression model

Clinician rating	Model-predicted category		
	Intact awareness	Mild unawareness	Severe unawareness
Intact awareness	73.1	26.9	0.0
Mild unawareness	32.1	41.5	26.4
Severe unawareness	5.3	15.8	78.9

Values are row percentages. For instance, of all those the clinician classified as having “intact awareness,” 73.1% were correctly assigned to that category by the regression model whereas 26.9% were assigned to the “mild unawareness” category.