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Questionnaire Versus Performance-Based Functional Assessment in Dementia

Questionnaire-based methods were used to assess dementia symptoms. We sought to validate the Functional Impact Assessment (FIA), a performance-based assessment, by demonstrating that it is not redundant with questionnaire-based methods. We compared the FIA scores of dementia patients (n = 16) to Dementia Deficits Scale (DDS; Snow et al., 2004) responses. A significant difference was found between the patients and controls on FIA performance, $t(28) = 6.76$, $p < .001$. The patients reported fewer functioning problems than their informants, $U = 53.50$; $p = .004$. The correlations between the FIA and the DDS informant and patient reports were nonsignificant. The FIA is sensitive to dementia and identifies an aspect of functioning not detected by questionnaire-based methods.

Dementia is a significant public health issue that is rapidly increasing in prevalence. Hebert, Scherr, Bienias, Bennett, and Evans (2003) found that approximately 5 million Americans are affected by Alzheimer's disease (AD), the most common type of dementia. Vascular dementia (VaD) is also increasing in prevalence and is currently the second most common form of dementia (The National Institute on Aging, 2007).

This increase in prevalence is most likely due to the increasing lifespan of Americans due to improved access to and quality of health care services. Research estimates that approximately 2.4–4.5 million Americans currently live with AD (The National Institute on Aging, 2009). These statistics become even more significant when it is taken into consideration that a large proportion of the adult population, the so-called "baby boom" generation, is reaching the age at which there is a heightened risk for developing dementia. With this in mind, the Alzheimer's Association (2009) estimates that nearly 16 million Americans will live with AD by the year 2050. The annual direct and indirect costs of dementia are estimated to be approximately $100 billion, with this figure expected to approach $118 billion by the year 2050 (The National Institute on Aging, 2007).

Functional impairment is a criterion for the diagnosis of dementia (American Psychiatric Association, 2000). The majority of research on functional decline relies on caregiver report (e.g., Guilmette, Temple, & Kennedy, 2008; Pratt, et al., 2007). Caregiver reports are attractive because they are considered to be valid and reliable, while also being brief and easy to administer (for further review, see Burns, Lawlor, & Craig, 2002 and Leifker, Patterson, Heaton, & Harvey, in press). In contrast, some previous research suggests that questionnaire-based assessments from informants, typically a family member or caregiver who has frequent contact with the patient, can be biased by insights, values, comparisons to previous states or other persons, and other events that may be occurring at the time that the report is given, thus making the accuracy of such reports debatable (Patterson, Goldman, McKibben, Hughs, & Jeste, 2001). Caregiver questionnaires are also susceptible to error from a number of other sources (Demers, Oremus, Perrault, Chapoux, & Wolfson, 2000), including the nature of the relationship of the caregiver to the patient (Ready, Ott, & Grace, 2004) and perceived level of distress caused by caring for the patient (Clyburn, Stones, Hadjistavropoulos, &

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Tuokko, 2000). From a sampling perspective, if there is no caregiver present, then the patient is often excluded from studies of functional decline, possibly resulting in biased samples that might exclude single people and over-sample married couples.

Previous research examining questionnaire-based methods has given rise to the notion that such methods may not provide an accurate portrayal of the deficits that the patient is experiencing. Ready, Ott, and Grace (2004) compared the reports of informants to the self-reports of controls and patients with both AD and Mild Cognitive Impairment. These reports included questions addressing quality of life, depression, perceived level of severity, distress caused by symptoms, and clinical insight. The correlation between the informant report of memory abilities and actual, objectively-observed memory abilities was 0.62 for caregivers who lived with patients but only 0.18 for caregivers who did not live with patients. The difference between these two correlations was significant, indicating that caregiver reports can vary greatly depending on whether or not the caregiver lives with the patient.

Other studies also have raised questions about the validity of informant reports. Burke and colleagues (1998) observed that perceived level of burden and severity of patient symptoms strongly influenced the reports of informants. Another study concluded that age and physical/health status influenced the differences that were found between informant and self-reports of health related concerns associated with old age (Boyer, Novella, Morrone, Jolly, & Blanchard, 2004). Using the Assessment of Motor and Process Skills (AMPS; Doble, Fisk, & Rockwood, 1999), Boyer and colleagues found that family members were equally likely to overestimate functional impairment as they were to underestimate functional impairment. The researchers did conclude, however, that impairment was more likely to be overestimated in cases of mild rather than severe impairment. Similar findings from other researchers support the conclusion that informant report of functional impairment varies according to factors other than functional impairment itself (Zanetti, Geroldi, Frisoni, Bianchetti, & Trabucchi, 1999; Arguelles, Lowenstein, Eisdorfer, & Arguelles, 2001).

Performance-based assessment has the advantage of directly assessing functional capacities without concern for the biases of questionnaire-based methods. Performance-based assessment examines a participant's ability to perform everyday activities (Instrumental Activities of Daily Living, or IADLs), such as cooking, financial management, and shopping. Furthermore, the use of performance-based assessment can be used to assess patients who do not have a close friend or family member to serve as an informant. Recent attempts

have been made to develop reliable and valid instruments of everyday functioning, including the Texas Functional Living Scale (TFLS; Cullum, et al., 2001), the Independent Living Scale (ILS; Loeb, 1996), and the Naturalistic Action Test (NAT; Giovannetti et al., 2007). Although each of these measures is still an indirect, clinic-based measure of everyday functioning, their validity is supported by data indicating that they are predictive of real-world functional indicators such as dementia status (Cullum et al., 2001), clinically-rated disability (Schwartz, Segal, Veramonti, Ferraro, & Buxbaum, 2002), unemployment (Heaton et al., 2004), and informant ratings of functional impairment (Cullum et al., 2001). Most of these instruments also have evidence for acceptable internal and test-retest reliability (Cullum, et al., 2001; Loeb, 1996; Giovannetti et al., 2007). These instruments tend to be relatively easy to administer. However, a consistent weakness in many of these measures is that they do not comprehensively assess key domains of everyday functioning.

Heaton and colleagues (2004) devised a battery based on previously-published functional tests and newly-developed tests with the goal of assessing the key functional domains of cooking, financial management, medication management, shopping, and work skills, for use in a younger neurologically impaired population. The previously published instruments included the Direct Assessment of Functioning (Lowenstein et al., 1989), the Medication Management Test (Albert et al., 1999), and a standardized work sample (Valpar International Corporation, 1986, 1992). For the present study, we modified and supplemented the Heaton and colleagues functional impact assessment (FIA) for use in an elderly population. We added the Communications subtest of the Direct Assessment of Functioning because it is sensitive to functional decline in dementia (Lowenstein et al., 1989), and we eliminated the work sample because it is not relevant to these retired and severely disabled patients. The FIA is more comprehensive than previously-published batteries because it samples a wide range of behaviors: financial management, medication management, cooking skills, communication skills, and shopping ability.

Not only are most of the extant performance-based assessments limited in comprehensiveness, but the extant literature contains few studies exploring the relationship between questionnaire-based methods and performance-based assessment (e.g., Kempen, Stevernick, Ormel, & Deeg, 1996; Reuben, Siu, & Kimpau, 1992). The current study focuses on informant reports of functional deficits and seeks to explore the question of validity of such reports by comparing the scores obtained on questionnaire-based methods to performance-based assessment. In addition, we seek

to compare the reports of both the patient and the informant to the FIA to determine the degree of inaccuracy of questionnaire methods by directly comparing them to performance-based assessment.

While previous studies (e.g., Evans et al., 2003) do indicate that performance-based assessment generates meaningful data, issues regarding the validity and reliability of performance-based assessment do exist. Miller and Linn (2000) argue that for a performance-based test to generate truly reliable data, a large number of tasks must be included in the test battery. Otherwise, the test might be biased to particular demographic groups. One of the advantages of the FIA over previous performance-based assessments (e.g., Albert et al., 1999) is the breadth of skills that are assessed.

We hypothesized that the FIA scores will be lower in the dementia group than in the control group. We also hypothesized that there will be a significant difference between the reports of the patients versus the informants in terms of functional ability. We expect that informant report will be more accurate than patient report when compared to performance-based assessment. We expect that the patients will be more likely than their informants to overestimate functional ability. That is, patients will be more likely than the informants to report normal functioning when impairment actually exists. For the purposes of this study, we assume that the FIA is a more accurate reflection of real-world functioning, although we recognize that this assumption is not directly addressed by the data in this study. Last, we expect that questionnaire methods will explain less than half of the variation in performance-based assessment.

Method

Participants

Participants included a mixed sample of dementia patients with either AD ($n = 8$) diagnosed according to NINCDS-ADRDA criteria or VaD ($n = 8$) diagnosed according to California ADDTC criteria. In addition, 16 demographically-matched control participants were recruited from both the Veteran's Administration and from the community. Patients were diagnosed by a neurologist or a neuropsychologist in a clinical evaluation that was independent of this study. The Mini-Mental Status Exam (MMSE; Folstein, Folstein, & McHugh, 1975), which was administered as part of our test battery, mean score for the patient group was 20.38 (4.30), suggesting mild to moderate impairment.

Informants ($n = 16$) were defined as a family member (usually a spouse or child) or caregiver who spends at least 5 hours of contact per week with the patient. Patient and informant demographic information is provided in Table 1. Information regarding the nature of the relationship between the patient and the informant is provided in Table 2.

Participants were recruited from nearby Veteran's Administration Memory Disorders and Neurology clinics, referrals, and from the community. If the patients were deemed too impaired to give informed consent, the legal representative of the patient consented on behalf of the patient. Patients were compensated $45 for the initial visit; informants were not compensated. All research was conducted at a state Veterans Administration Health Care System.

Measures

Demographic questionnaire. All participants completed a demographic questionnaire about relevant information such as age, education, and ethnicity in addition to questions pertaining to both individual medical and disease history and histories of his or her family.

The Mini Mental Status Exam (MMSE). To gauge the severity of dementia, the MMSE was administered

TABLE 1

Demographic Information

	Patients	Patients' Informants	Controls	Controls' Informants
N	16	16	15	15
Age	80.38 (9.12)	65.63 (17.04)	76.73 (6.28)	65.29 (12.38)
Education	14.44 (3.10)	14.67 (2.02)	15.00 (2.30)	15.21 (2.64)
Ethnicity (% Caucasian/ Non-Hispanic)	81.3%	68.8%	86.7%	92.9%
Sex (% Male)	93.8%	6.2%	80.0%	21.8%

to all participants. The MMSE is a widely used cognitive screening instrument that is sensitive to dementia. It has a maximum score of 30 (Folstein, Folstein, & McHugh, 1975).

The Dementia Deficits Scale (DDS). The Dementia Deficits Scale (Snow et al., 2004) informant and patient versions were administered to both the patients and controls and their informants. The DDS includes four subscales: meta-awareness (e.g., "Do you/your friend or family member think that you/your friend or family member have an illness affecting your memory?"), cognitive deficits (e.g., "Do you/your friend or family member ever get confused about where you/your friend or family member are?"), emotional deficits (e.g., "Do you/your friend or family member feel as though you/your friend or family member have emotional or psychological problems?"), behavioral deficits (e.g., "Are you/your friend or family member often more suspicious or less trusting than you/your friend or family member should be?"), and functional deficits (e.g., "Would you/your friend or family member be able to handle a small household emergency such as a plumbing leak or a small fire?") There is a total of 35 questions on the DDS and questions are presented in a "yes" or "no" format. One point is given if the answer reflects the belief of impaired functioning. Higher scores on both the patient and informant versions indicate higher perceived levels of impairment.

Past research examining the reliability and validity of the DDS has concluded that the DDS is both reliable and valid. Furthermore, the DDS is favorable because it examines not just cognitive deficits, but emotional, functional, behavioral, and meta-cognitive deficits (Snow, et al., 2004). The DDS is a useful measure of awareness of one's impairment because a patient's report of problems can be compared to an informant report using the parallel patient and informant versions. In this study, we compared patient and informant reports of problems in this manner, and we also compared the accuracy of informant reports relative to objective estimates of functional impairment (the FIA).

The Function Impact Assessment (FIA).
Last, the patient was administered the FIA, which included tasks requiring the participant to balance a checkbook, make change, manage medications according to verbal and written instructions, dial a telephone, prepare a letter for mailing, pick groceries from a mock store from memory after both oral and written presentations of a shopping list, and prepare a mock meal of vegetables, bread, and pasta. Participants were rated according to standardized procedures on the basis of completeness of the task and preciseness of follow-

ing the instructions. High scores on the FIA indicate lower levels of functional impairment. When scored, one point is given for proper completion of each of the major steps necessary to complete a given task. For example, when completing the financial management portion of the FIA, the participant is given one point for signing the check, one point for properly addressing the recipient of the check, one point for completing the numeric and written amount correctly, and one point for writing the date in the proper spot on the check. Previous studies of the FIA and its component subtests indicate that it is a reliable and valid measure of functional impairment in HIV infected persons (Heaton et al., 2004; Albert et al., 1999), and patients with dementia (Lowenstein et al., 1989).

Procedures
Prior to the scheduled visit, informants were mailed a packet of questionnaires that included the informant version of the DDS for completion before the scheduled visit. When the participant and the informant arrived for the study visit, informed consent was obtained according to procedures approved by the university's Human Research Review Committee. A short quiz was administered to assure that the participant understood the consent forms. If the patients were too impaired to give informed consent, the legally authorized representative of the patient gave consent on behalf of the patient. The questionnaires then were reviewed with the informant for clarity and completeness. With another examiner in separate room, the patient completed the patient version of the DDS along with the MMSE and the FIA.

Statistical Analyses
An independent samples *t* test was used to assess the differences between the controls and the patients on the percentage correct on the FIA. Because the assumption of homogeneity of variance was not met, a nonparametric Mann-Whitney U test was used to assess the degree of agreement between the patients and informants on the DDS. When seeking to determine the accuracy of self- versus informant-report, a Chi Square test was used within the patient group, comparing informant to patient group on presence or absence of functional impairment. Again, because the assumption of homogeneity of variance was not met, a nonparametric Spearman's correlation was used to correlate the patient and informant reports with the percentage correct that the patient obtained on the FIA.

Results
Participant data
The patient and the control group were of similar age

with similar levels of education (see Table 1). Because most of the patients were recruited at a VA medical center, most patients and controls were male veterans with female informants. The informants of the patients reported more contact hours per week than was the case with the controls, most likely due to fact that the patients were likely to require more care than the controls.

Sensitivity of FIA to Dementia

We hypothesized that the control group would display less functional impairment than the patient group as measured by the FIA. The current data supports this conclusion. In terms of the percentage correct on the FIA, the control group obtained a mean of 81.76 ($SD = 8.44$) while the patient group obtained a mean of 45.00 ($SD = 18.68$). Based on these means, a large effect size was found ($d = 1.57$). An independent samples t test shows that the difference between the controls and the patients in terms of FIA performance was statistically significant, $t(28) = 6.75$, $p < .001$.

Informant Versus Patient Self-Report

We also hypothesized that there would be a significant difference between the reports of the patients versus the informants in terms of functional ability. As seen in Table 3, the informant and patient reports revealed significant differences for meta-cognitive deficits, cognitive deficits, functional deficits, and total score, with the informants reporting higher levels of impairment than the patients with dementia. There was no difference in reported emotional deficits.

TABLE 2

Informant Characteristics

	Patients	Controls
Mean duration of relationship (in years)	37.69 (21.51)	33.14 (26.32)
Mean number of contact hours per week	95.69 (72.42)	56.00 (61.27)
Nature of relationship	Spouse: 56.3 % Child: 18.8% Friend: 12.5% Other relative: 6.3% Paid caregiver: 6.3%	Spouse: 50.0% Child: 14.3% Friend: 21.4% Other relative: 7.1% Other: 7.1%

TABLE 3

Means, Standard Deviations, and U-Values

	Patients		Informants		*U*	Sig (2-Tailed)
DDS Meta-Cognitive Ability	2.63	(1.86)	4.38	(1.82)	65.50	.017*
DDS Cognitive Deficits	4.25	(3.70)	7.63	(4.41)	69.50	.026*
DDS Emotional Deficits	1.00	(1.32)	1.31	(1.50)	113.50	.565
DDS Functional Deficits	1.06	(1.24)	3.06	(2.08)	53.50	.004**
DDS Total Score	8.94	(6.42)	16.19	(7.55)	57.00	.007**

Note. DDS= Dementia Deficit Scale. Higher score reflects greater impairment.
  *Significant at the .05 level.
** Significant at the .01 level.

Accuracy of Informant Report

We also hypothesized that compared to patient performance on the FIA, informants would offer more accurate DDS reports than patients. In addition, we hypothesized that patients would be more likely than informants to overestimate functional ability as measured by the DDS. To address this issue, the mean percentage correct on the FIA for the control group was calculated (M = 81.76, SD = 8.44). One standard deviation below the mean of the control group was then established as the cut-off point for functional impairment. Using this standard, 14 out of the 16 dementia patients met the criteria for functional impairment. To establish informants who report functional impairment in the patient, a similar procedure was used for the questionnaire-based report of functional impairment. A cut-off score for the report of impairment was established using the mean DDS informant functional report for the control group (M = .21, SD = .58). Using these cut-offs, agreement or lack of agreement between informant report of functional impairment and FIA score was established. It was found that in three cases (18.75% of patient cases), the patient was found to be functionally impaired on the FIA, but the informant did not report functional impairment. In two cases (12.5% of patient cases), it was found that the informant reported functional deficits that were not supported by the FIA. In total, there was a lack of agreement between informant report and FIA percentage correct in 5 cases (31.25% of patient cases).

This procedure was then repeated to determine the agreement between patient self-report agreement and FIA score. In 8 cases (50% of patient cases), the patient underestimated his or her own level of impairment, meaning that his or her FIA score indicated impairment whereas the patient did not report impairment as defined by the cutoff score approach described above. Because the cutoff was close to the lowest score on the DDS, falling in the unimpaired range using the cutoff method on the DDS essentially means the patient was denying any functional impairment. In no cases did the patients over-report their impairment. The accuracy of informant- versus patient-reported impairment was nonsignificant, χ^2 (1, N = 15) = 3.27, p = .07.

We used two nonparametric correlations (Spearman's rho) to examine the relationship between the FIA percentage correct and the informant and the patient self-report functional DDS scores. We similarly examined the relationship between the FIA percentage correct and patient self-report (see Figure 1). While the correlations indicate that informant and patient reports of deficits were in the expected direction for the group as a whole—lower performance-based scores were associated with higher subjective reports

of functional deficits—the correlations were only modest in magnitude. Neither informant report (p = .-41, p = .12) nor patient report (p = -.47, p = .07) reached statistical significance, but did indicate a trend toward significance.

Discussion

The differences shown between the FIA performances of the two groups indicated that the FIA is an instrument that is sensitive to the presence or absence of dementia. Furthermore, correlations between the FIA and self- and informant-report of functional impairment were not significant, although the direction of the association was in the expected direction. The central hypothesis of this study, that informant report would explain less than half of the variance in performance-based assessment was supported by the finding that the correlation between informant reports and the performance-based measure were less than .5 (-.41 for informant report, -.47 for patient report, neither of which were statistically significant). If one assumes that the performance-based measure is a valid measure of everyday functioning, then one can conclude that questionnaire-based approaches may either be inaccurate estimates of real-world functioning or may estimate a different element of functioning than the FIA. As noted before, there is evidence from multiple studies that our performance-based measure is a valid predictor of real-world functioning, although it must be acknowledged that the FIA has not been validated

FIGURE 1

Scatter plot and correlation of patient self-report and informant report of functional deficits versus performance-based assessment of everyday functioning (FIA).
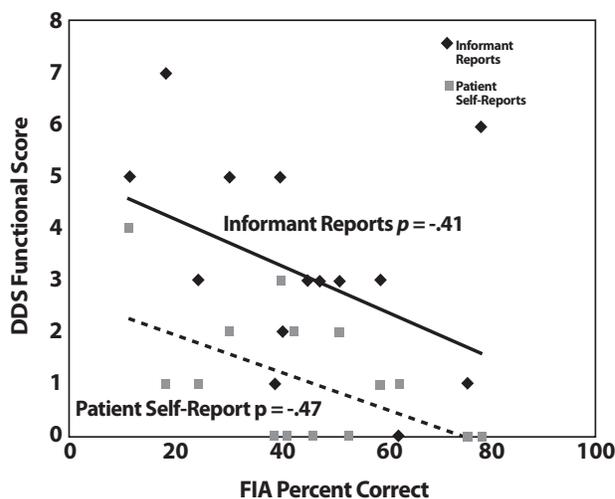
with direct observation of patients' completion of daily tasks. Therefore, our data provide only indirect support for the conclusion that questionnaires are imperfect measures of real-world functioning. Considering the practical problems with observing patients' actual daily functioning in their homes, and the fact direct observation is rarely performed in research or clinical arenas, our data reflect the best possible estimates given such limitations.

The data also show that almost one third of the informants are either overestimating or underestimating functional impairment, while the patients are strictly underestimating impairment. The informant and patient reports were discrepant for meta-cognitive deficits, cognitive deficits, functional deficits, and total score with the informants reporting higher levels of impairment than the patients with dementia. There was no difference in reported emotional deficits, probably reflecting the low rate of self- and informant-reports of emotional dyscontrol in this sample. Because dementia affects one's cognitive abilities, a plausible conjecture may be that dementia patients are not reporting accurately due to the fact that the patients have deficits in terms of meta-cognitive skills. It may be the case that those with dementia are simply too impaired to perceive their own deficits. Because of this possible lack of self-awareness and ability to self-assess, direct assessment of functional capacities or informant report should be used when assessing a patient's functional and cognitive status. It is worth noting that about two thirds of the informants were accurate in their report of impaired patient functioning. It could be useful to determine if certain informant characteristics could predict whether or not they are accurate. It would also be useful to employ a questionnaire with a wider range than the DDS cognitive scale so that degree of accuracy of the informant report could be more reliably assessed.

The FIA is limited by the fact that the test is administered in a laboratory setting and may therefore not be an accurate reflection of how the patient functions within his or her home. Another possible limitation of the current investigation is that the sample size was small, thus limiting the power. However, this small sample size did not prevent statistically significant findings between patient and control groups. It is possible that a larger sample would result in the correlations between questionnaire methods and performance-based measures being statistically significant, but a larger sample size would probably not change the modest magnitude of the correlation.

Future studies should employ a more demographically diverse sample (especially with more women than were obtained by this primarily military veteran sample) to improve generalizability of these findings. Future

consideration should also be given to establishing a test that assesses the participant within his or her home.

Further research is also necessary to examine the test-retest reliability of this new performance-based functional battery, so that such a battery can be incorporated into longitudinal studies of disease progression and treatment. It will also be interesting to use the FIA to further build on past research that investigates the role of patient and informant depression, and perceived level of caregiver distress and how it affects the validity of reported symptoms, as some of the previously-mentioned studies have noted. Larger sample sizes will be needed to examine the effect of informant demographic variables such as age, level of education, and gender, in addition to other variables of interest such as duration of relationship with the patients, length of time spent caring for the patient, and severity of the patients' symptoms, on the reliability of informant reports. Future research may also focus on these variables and their effect on the accuracy of reporting functional impairment.

Past research looking at varying topics and populations within clinical psychology suggest that use of multiple methods and data collection techniques is optimal because it allows researchers to rule out possible alternative explanations to findings while also examining research questions that may not otherwise be possible when using a single method or data collection technique (e.g., Anastasi, 1997). Our findings provide support for the notion that studies of functional impairment are likely to have better accuracy by including a performance-based measure of everyday functioning when used in conjunction with other methods such as questionnaires and/or neuropsychological testing. Especially in studies of disease progression and treatment effects, reliance solely on informant reports may lead to incorrect estimates in change over time. As the number of people with cognitive disorders of aging increases, the need for accurate estimates of disease burden is a significant public health issue. Improved methods of estimating functional impairment could lead to better planning for future health care needs and more accurate estimates of the effectiveness of treatments.

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