Degree of discrepancy between self and other-reported everyday functioning by cognitive status: dementia, mild cognitive impairment, and healthy elders

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SUMMARY

Background Previous studies show individuals with dementia overestimate their cognitive and functional abilities compared to reports from caregivers. Few studies have examined whether individuals with Mild Cognitive Impairment (MCI) also tend to underestimate their deficits. In this study we examined whether degree of discrepancy between patient and informant-reported everyday functioning was associated with cognitive status.

Methods The sample consisted of 111 ethnically diverse community-dwelling older adults (46 Caucasians and 65 Hispanic individuals), which was divided into four diagnostic categories: cognitively normal, MCI-memory impaired, MCI-nonmemory impaired, and demented. Everyday functional abilities were measured using both a self-report and informant-report version of the Daily Function Questionnaire (DFQ). A Difference Score was calculated by subtracting patients' DFQ score from their informants' score.

Results DFQ Difference Scores were significantly higher in the demented group compared to normals and both of the MCI groups. However, the Difference Scores for the MCI groups were not significantly different than the normals. Further, while patient reported everyday functioning did not differ among the four diagnostic groups, informant reported functional status was significantly different across all diagnostic groups except MCI-nonmemory impaired *vs* normals. Performance on objective memory testing was associated with informant-rated but not patient-rated functional status. Demographic characteristics of the patients and informants, including ethnicity, had no association with the degree of discrepancy between raters.

Conclusions Although there may be some mild functional changes associated particularly with the MCI-memory impaired subtype, individuals with MCI do not appear to under-report their functional status as can often been seen in persons with dementia. Copyright © 2005 John Wiley & Sons, Ltd.

KEY WORDS — dementia; mild cognitive impairment (MCI); informant-report; self-report; awareness of deficit

INTRODUCTION

Within recent years the concept of Mild Cognitive Impairment (MCI) has become increasingly recognized and studied because of its associated risk for the development of dementia. Longitudinal studies

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of patients with MCI show conversion rates to dementia ranging from 10% to 30% annually (Peterson et al., 1999), and 48% to 61% over five years (Morris et al., 2001; Tuokko et al., 2003). However, there is considerable variability in the diagnostic algorithms used for MCI (Ritchie and Touchon, 2000), which can affect reported prevalence and conversion rates (Busse et al., 2003). Recently there have been increased efforts to identify subtypes of MCI (e.g. amnestic MCI, multiple domains mildly impaired) (Petersen et al., 2001). It is likely that clinical course and etiology differ within the different MCI profiles (DeCarli, 2003).

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The degree of associated functional decline in MCI also remains under debate. The initial diagnostic criteria for MCI specified intact or 'only slightly abnormal ADLs' (Petersen *et al.*, 1999). However, functional change arguably occurs over the course of MCI since it is precisely such cumulative change that leads to eventual conversion to dementia. In fact, recent studies have suggested that mild changes in daily functioning can be detected in MCI groups (Artero *et al.*, 2001; Tabert *et al.*, 2002). At present, the guidelines relating to functional change in MCI are unclear, and reflect our currently limited knowledge concerning the types and extent of functional change that occurs in these disorders.

There are several methods of measuring everyday function in older adults. Self-report is often used to obtain information regarding a patient's cognitive and functional status. However, there are now a number of studies showing that within dementia samples, self-report often differs substantially from information collected from caregivers (DeBettignies *et al.*, 1990) and does not correspond to objective measures of cognitive functioning (Michon *et al.*, 1994; Tierney *et al.*, 1996). However, there is substantial variability in the degree to which dementia patients and their caregivers differ (Reed *et al.*, 1993; Michon *et al.*, 1994). It is not yet clear to what degree patient or informant characteristics and/or relationship variables influence this difference.

While differences in self *vs* informant reporting of cognitive and functional abilities has been well studied in patients with dementia, only a few studies have examined this issue in MCI (Tierney *et al.*, 1996; Albert *et al.*, 1999; Tabert *et al.*, 2002). These studies have produced conflicting results in terms of the accuracy of self-reported cognitive and functional abilities relative to reports of informants. No study has examined self- *vs* informant-reported everyday functioning across different subtypes of MCI.

The purpose of the current study was to examine the discrepancies between self- and informant-reported everyday functioning across groups of healthy older adults, individuals diagnosed with MCI, and those diagnosed with dementia. Because MCI is a heterogeneous diagnostic group, we further subdivided MCI into those with a prominent memory deficit (MCI-memory impaired type), and those with mild deficits in cognitive domains other than memory (MCI-nonmemory impaired). We also examined whether certain patient and informant characteristics and relationship variables were associated with the degree of discrepancy in reported everyday decline between the two raters. Participants in the study were

made up of a culturally diverse sample of community dwelling Caucasian and Hispanic individuals and so we were particularly interested to identifying whether ethnic group status related to self- *vs* informant-reporting discrepancies.

METHODS

Participants

The sample consisted of 111 community-dwelling older adults (46 Caucasian and 65 Hispanic individuals) and their informants. Hispanic participants that were bilingual were given the choice as to whether they wanted to complete research testing in English or Spanish. Forty-six percent of the participants completed the functional and neuropsychological instruments in Spanish and 54% in English. The sample was recruited using a community survey based upon a commercially obtained list of individuals living in Woodland, California, a city of about 50,000 near Sacramento. Individuals on the list were categorized according to whether they had Latino surnames. Randomly selected individuals from the list were first mailed a letter describing the study. They were then contacted by telephone and invited to participate. For those with non-Latino surnames, 31.7% of the list could not be contacted, had died, or were not eligible (e.g. were under 60 years of age or didn't speak English or Spanish). Of those who were contacted and eligible to participate, 60.5% completed testing. For those with Latino surnames, 50.5% could not be contacted, were deceased, or were ineligible; 54.9% of those who were contacted and eligible completed testing. Informed consent was obtained from all study participants in accordance with the local Institutional Review Board.

Instruments

Assessment of everyday functioning. The Daily Function Questionnaire (DFQ) was used to measure everyday functioning in the primary analysis of this study. The DFQ is a 22-item rating scale assessing an individual's ability to complete everyday cognitive and functional tasks. It was based, in part, on the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE; (Jorm and Jacomb, 1989) but was significantly expanded to sample a wider range of everyday functional changes at both ends of the ability spectrum. A Spanish language version has been created using back-translation methods. The content

of the instrument is weighted toward assessing functional tasks related to memory, but also includes items that assess a wide variety functional tasks dependent on other cognitive abilities such as language, visuospatial abilities, and higher-order reasoning and problem solving. There are also items assessing more basic activities of daily living including dressing and feeding. Each item is rated on a three-point scale that compares current performance on a given task to the patient's ability to perform the task ten years earlier. In this way, patients serve as their own control. Ratings ranged from: 0 = performs the task the same or better than 10 years ago; 1 = performs the task a little worse now; 2 = performs the task a lot worse now. This response format has proven useful across different ethnic groups and is generally insensitive to level of education (Del-Ser et al., 1997; Morales et al., 1997; Farias et al., 2004). An Average Item Score was calculated by summing the scores from each completed item and dividing by the number of items completed. A Total Score can also be derived by summing all items. Patients completed a selfreport version, and a person familiar with the patient completed an informant-report version of the instrument. A difference score was calculated by subtracting the patient-reported DFQ Average from the informant's score. A higher score indicated that the informant was reporting more impairment. The informant report version of the DFO is significantly correlated with other measures of functional impairment such as the Blessed Roth Dementia Rating Scale (Blessed et al., 1968) (r = 0.65) and measures of global cognitive impairment such as the Folstein Mini Mental Status Exam (Folstein et al., 1975) (r = -0.61), but has a negligible correlation with education (r = -0.16) (unpublished data).

The IQCODE (Jorm and Korten, 1988; Jorm and Jacomb, 1989; Jorm et al., 1991) was used as a measure of functional change in the determination of clinical diagnosis. This is a 26-item interview-based questionnaire completed by an informant familiar with the participant. Both the English and Spanish versions of the IQCODE have been published in their entirety elsewhere (Jorm et al., 1994a; Morales et al., 1995). The IQCODE has been shown to have high internal consistency, with alphas ranging from 0.93 to 0.95 (Jorm and Jacomb, 1989) and good test-retest reliability, both over a few day period (r = 0.96) and over one year (r=0.75) (Jorm and Jacomb, 1989; Jorm et al., 1991). A number of studies have shown that it is a sensitive indicator of dementia (sensitivity = 0.86 and specificity = 0.80) (Jorm et al., 1991; Morales et al., 1997).

Cognitive functioning. Neuropsychological functioning was assessed using the Spanish and English Neuropsychological Assessment Scales (SENAS; (Mungas et al., 2000; Mungas et al., in press a, b) and the The Modified Mini-Mental State Examination (3MS) (Teng and Chui, 1987). The SENAS is a neuropsychological test battery developed using psychometric methods associated with item response theory (IRT) (Baker, 1985; Hambleton et al., 1991). The goal of psychometric matching called for highly similar measurement properties of the English and Spanish versions of the same scale, but also for similar measurement properties of all scales within each language version. SENAS development and validation are described in detail elsewhere (Mungas et al., 2000; González et al., 2001; Mungas et al., in press a, b).

Six measures of cognitive ability taken from the SENAS were used in the primary analysis: (1) Object Naming; (2) Verbal Attention Span; (3) Verbal Comprehension; (4) Spatial Localization; (5) Verbal Memory; and (6) Nonverbal Memory. Object Naming is a confrontation naming task. Verbal Attention Span assesses forward digit span. Verbal Comprehension is a measure of the ability to follow commands of increasing length and complexity. Spatial localization measures the ability to perceive and reproduce spatial relationships. The Verbal Memory measure was derived from the Spanish and English Verbal Learning Test (SEVLT; (González et al., 2001), a component of the SENAS. The SEVLT uses a 15-word list that is presented for five learning trials in a standard word-list learning test format, followed by presentation of a distracter task, and then by free recall of the initial list. The Verbal Memory measure was a composite measure combining scores from the learning trials and delayed recall trials such that psychometric characteristics were matched to the other non-memory SENAS scales. The Nonverbal Memory measure was derived from a multi-trial learning format in which the task was to learn colors of regions on a map that contained 12 differently colored regions. The Nonverbal Memory measure was a composite scale, similar to the Verbal Memory measure, that also was matched psychometrically to the other five scales. Scale format and content is described in greater detail elsewhere (Mungas et al., in press a, b). Five SENAS tests were used in the process of establishing a clinical diagnosis. These included Verbal Memory, Verbal Attention Span, and Object Naming described earlier. The two additional tasks were Verbal Abstraction (a measure of abstract reasoning) and Pattern Recognition (a measure of visuospatial abilities).

Table 1. Demographic Information by diagnostic group

	Age	Gender (% female)	Education (years)	Ethnicity (% Hispanic)
Normal $(n = 59)$	72.12 (8.27)	39%	8.68 (5.75)	55%
MCI-memory impaired $(n = 21)$	76.54 (8.41)	47.6%	9.52 (6.49)	76.2%
MCI-nonmemory impaired $(n = 25)$	73.73 (7.35)	56%	9.92 (6.23)	56%
Demented $(n = 6)$	74.83 (3.83)	50%	13.67 (4.35)	33.3%

The Modified Mini-Mental State Examination (3MS) (Teng and Chui, 1987) was used as an independent measure of global cognitive functioning for the purpose of aiding in clinical diagnosis. This is a 100-point scale that was designed to expand the range of measurement and increase the sensitivity of the Mini-Mental State Exam. It is widely used in epidemiological studies.

Determination of diagnostic syndrome

Individuals were classified as cognitively normal, MCI with memory impairment (MCI-memory), MCI with nonmemory impairment (MCI-nonmemory), or demented using the following process. First, cases were identified as potentially having dementia if they met any one of the following criteria: (1) demographically adjusted score or raw score on at least one of the five SENAS neuropsychological tests used in clinical diagnosis at or below the 10th percentile of a non-demented normative sample and functional change as measured by an IQCODE > 3.4; (2) impairment below the 10th percentile (raw or adjusted) on four or more neuropsychological tests, or (3) IOCODE > 4.0. Cases meeting these criteria were then adjudicated by a neurologist (WJ) and neuropsychologist (DM) based minimally upon the IQCODE, 3MS, and the SENAS scales and a syndrome diagnosis of demented or non-demented was determined. A diagnosis of dementia required impairment in two cognitive domains (as measured by the SENAS and 3MS) and significant impairment of independent function (as measured by the IQCODE). Cases who were not demented were classified as normal, MCImemory impaired, or MCI-nonmemory impaired. Individuals were classified as MCI-memory impaired if they attained a demographically adjusted score on Verbal Memory that fell below the 10th percentile. Individuals were classified as MCI-nonmemory impaired if at least one of four demographically adjusted non-memory measures (Object Naming, Pattern Recognition, Verbal Abstraction, Verbal Attention Span) was below the 10th percentile. Those who had neither memory nor nonmemory impairment

were classified as Normal. Those with memory impairment (regardless of non-memory status) were classified as MCI-memory, and those with nonmemory impairment only were classified as MCI-non-memory.

Table 1 includes basic demographic information on patients and their informants. There were no significant differences in age, distribution of gender or ethnicity, or years of education across the four groups (p-values = 0.18--0.54). In terms of the informants, 63.4% of the informants were spouses, 34.8% adult children or children-in-law of the patient, and 1.8% were friends of the patient. On average, informants spent 83.4 hours per week with patients. There were no significant differences across the groups in terms of the type of relationship with informant or the amount of time informants and patients spent together (p-values = 0.86 and 0.52, respectively).

RESULTS

Self and informant-reported everyday function by diagnostic group

Table 2 presents the Average and Total DFQ scores for each diagnostic group. A multivariate analysis of variance was used to determine if both patient and informant-reported decline significantly differed between the four diagnostic groups. Patient-reported everyday function did not differ across diagnostic

Table 2. Informant and patient-reported everyday functioning by diagnostic category

	Average DFQ	Total DFQ
Informant-reported DFQ		
Normal	0.10 (0.12)	2.22 (2.54)
MCI-Memory	0.18 (0.17)	3.81 (3.74)
MCI-Nonmemory	0.13 (0.17)	2.76 (3.66)
Demented	0.78 (0.29)	17.17 (6.04)
Patient-reported DFO	, ,	, ,
Normal	0.17 (0.21)	3.66 (4.65)
MCI-Memory	0.20 (0.18)	4.43 (4.03)
MCI-Nonmemory	0.14 (0.18)	3.08 (3.92)
Demented	0.23 (0.17)	5.00 (3.69)

Table 3. DFQ Difference Scores for each diagnostic group

Diagnostic group	DFQ Difference Score	
Normal MCI-memory MCI-nonmemory Demented	-0.065 -0.025 -0.012 0.553	

Positive scores indicate the informant is reporting more impairment than the patients.

groups. In contrast, diagnostic groups were significantly different based on informant-reported everyday functioning (p < 0.0001). Follow-up comparisons using t-tests revealed that informants reported significantly more everyday functional change in the demented group vs the normals [t(63) = -11.49, p < 0.0001], and in the demented group compared to both the MCI-memory impaired group [t(25) = -6.44, p < 0.0001] and the MCI-nonmemory impaired group [t(29) = -7.29, p < 0.0001]. Further, informants reported more everyday dysfunction in the MCI-memory impaired group compared to normals [t(78) = -2.24, p = 0.028], but did not report more functional impairment in the MCI-nonmemory group when compared to normals.

Table 3 presents the mean DFQ Difference Scores for each diagnostic group. An analysis of variance was used to examine whether the degree of discrepancy between informant and patient-reported functional abilities differed across the four clinical diagnostic groups. The overall F statistic was significant (p < 0.0001). Follow-up post hoc comparisons using t-tests revealed that the Difference Score was significantly higher in the demented group compared to healthy controls [t(63) = -6.93, p < 0.0001], as well as the MCI-memory group [t(25) = -6.064,p < 0.0001 and the MCI-nonmemory group [t(29) =-5.79, p < 0.0001]. However, the Difference Scores for both MCI groups as compared to healthy controls did not significantly differ. Examination of the mean Difference Scores suggest that individuals with dementia tend to underreport their level of everyday functional impairment compared to their informants. Interestingly, individuals in both MCI groups reported slightly more functional change than their informants. This slight over-reporting was also observed within the cognitively normal group.

The relationship between patient and informant-rated everyday function and specific domains of cognition

Pearson correlations were used to examine the degree of association between various neuropsychological measures and both informant-rated and patient-rated everyday functioning. Due to the number of correlations, a Bonferroni correction was applied. Verbal memory was the only neuropsychological test to be significantly associated with any of the measures of everyday functioning. Further, verbal memory was only significantly correlated with the informant-rated measure of everyday functioning (r = -0.35, p < 0.0001). Patient-reported everyday function was not significantly associated with any of the objective cognitive tests.

To explore neuropsychological correlates of the discrepancy between raters, Pearson r correlations were also computed between the Difference Score and the cognitive tests. After using a Bonferroni correction there were no statistically significant correlations between the neuropsychological measures and the Difference score. There was a non-significant trend for Verbal Memory to be modestly associated with the degree of discrepancy between patient and informant reported everyday functioning (r = 0.19).

The relation between patient and informant characteristics and discrepancy between raters

Next, we examined the bivariate relationship between degree of discrepancy among raters and various patient and informant characteristics, as well as several relationship variables. Patient characteristics examined included: the patient's age, gender, level of education, and ethnicity. None of these patient characteristics were related to the DFO Difference Score. Informant characteristics that we examined in association with the discrepancy included: informants' age, gender, level of education, and ethnicity. Again, none of these variables were related to discrepancy between raters. Finally, the relationship variables examined included: type of relationship (i.e. spouse, adult child, etc.), duration of relationship, and frequency of contact between the two parties (as measured in hours per week). None of these factors were associated with the discrepancy between

To further investigate any possible differences in reporting as a function of ethnicity, a multivariate analysis of variance was used to determine if there were differences in either patient-reported functional status, informant-reported functional status, or the Difference Score across the two ethnic groups (Caucasians and Hispanic Spanish-speakers). No significant differences were found (*p*-values = 0.88–0.63) suggesting there were no systematic differences in rating sources across the two ethnic groups. Similar

analyses were also run examining possible group differences as a function of language of test administration with essentially the same results.

DISCUSSION

Self-reported functional status did not significantly differ across the four diagnostic groups. This was in large part due to the fact that the dementia group tended to very significantly underestimate their functional losses compared to the reports of their informants. Interestingly, the individuals in the MCI groups, along with the normal controls, tended to report slightly more functional changes than their informants did. As opposed to self-report, informant ratings of everyday functioning did differ across diagnostic groups. Specifically, informants reported more everyday functional decline within the demented group as compared to the cognitively normal or either MCI group. Informant ratings also showed significantly more functional change within the MCI-memory impaired group compared to healthy controls. Thus, the MCI-memory impaired type does show mild functional changes relative to the healthy control group, but as expected, much less severe than within the demented group. There was no significant difference in informant-rated everyday functioning between the MCI-nonmemory group and normal controls. Thus, it appears that there may be little to no functional change in the MCI-nonmemory group as perceived by the informants.

We next more directly examined discrepancies between self- and informant-report using the DFQ Difference Score. The dementia group showed a significantly higher Difference Score than the cognitively normal and both MCI groups. That is, demented participants rated themselves as having much less decline in everyday cognitive and functional abilities than their informants reported. Such results likely reflect a decreased awareness of deficit on the part of the demented patients. Supporting this interpretation, only the informant ratings were significantly correlated with objective measures of cognition, while patient-rated everyday functioning was unrelated to any objective measure of cognition. These findings are consistent with other studies that have shown that caregivers of dementia patients tend to be more accurate observers of patients' cognitive abilities (Koss et al., 1993; Tierney et al., 1996) and self-care (Kuriansky et al., 1976) than patients themselves. Difference scores were not significantly different in either MCI group compared to the cognitively normal group. Thus, self-report ratings of everyday functioning within the MCI groups do not appear to be more discrepant from their informants' ratings than the degree of discrepancy observed between normal controls and their informants. Other groups have also failed to find a significant discrepancy between self-and informant-reported functional abilities within an MCI group (Tabert *et al.*, 2002). In fact, as noted above, in the current study of community dwelling elders, the MCI groups as well as the normals tended to report slightly more functional change than their informants. Similarly, Tabert and colleagues (2002), reported that MCI patients with a Clinical Dementia Rating (CDR) of 0 tended to slightly over-report functional change in comparison to their informants, while MCI patients with a CDR of 0.5 showed the opposite pattern.

Using the entire sample, there was a non-significant trend for verbal memory to be associated with the degree of discrepancy between self- and informant-reported everyday functioning. No other objective measures of cognitive functioning were correlated with this discrepancy. Such findings seem to suggest that verbal memory may be one of the most important cognitive determinants of a patient's inaccuracy in reporting declines in everyday functioning.

In addition to cognitive status, we also attempted to identify patient- and informant-related variables that may influence the degree of discrepancy between selfand informant-reported functioning. Demographic variables such as the age, education, gender, and ethnicity of either the patient or informant were not associated with the degree of discrepancy between raters. To our knowledge this is the first study to examine issues related to patient vs informant reported everyday function in an ethnically diverse sample. The present results suggest that neither the patient's nor the informant's ethnic status was related to the degree of discrepancy between raters. Given the lack of association between degree of discrepancy and ethnicity, it appears likely that our overall findings generalize to both English and Spanish speakers. It should be noted that there was a modest difference in the numbers of potential participants who could not be contacted with Latino versus non-Latino surnames (50.5% and 31.7%, respectively), thus our non-Latino/Caucasian group may be slightly more representative of the general population. Finally, neither the type of relationship between informant and patient (i.e. spouse versus adult child), nor time spent with the patient (i.e. hours per week) were associated with the degree of discrepancy between the two raters. Although not intuitively obvious, our results seem to be consistent with other research (Magaziner

et al., 1988) that did not find a clear relationship between amount of contact and self- vs informant-reported functional status within a physically impaired elderly sample. Similarly, Kemp et al. (2002) found that neither the frequency of patient-informant contact nor the type of relationship between patient and informant were associated with accuracy of informant report in a heterogeneous sample of elderly. We did not examine the quality of the informant/patient relationship, which may better account for differences in reporting than just the type of relationship.

The results of this study have important clinical implications. The lack of a difference in the discrepancy between raters in the MCI groups compared to the cognitively normal group suggests that individuals with mild cognitive changes not meeting criteria for a dementia may be fairly accurate in their ability to report their functional status. Given the trend for an association between verbal memory and the DFQ Difference Score, along with the clear discrepancy between raters in the demented group, results suggest that as people gradually become more cognitively impaired their ability to accurately report their functional status diminishes. Other studies have suggested that when a discrepancy between self and informant reported cognitive or functional status is observed in patients with MCI there is an increased likelihood of eventual conversion to dementia (Tabert et al., 2002; Tierney et al., 1996). The finding that, according to informant report, there may be different levels of everyday functional loss across various subtypes of MCI, with the MCI-memory group showing somewhat more functional change than the MCI-nonmemory group, warrants further investigation. To our knowledge this is the first study to examine self- vs informant-reported functional declines across different MCI subtypes.

The individuals in this study were recruited from the community rather than from a clinical setting. Prevalence and conversion rates of MCI to dementia can differ substantially across community vs clinical samples (Busse et al., 2003). Thus, results from our community based sample may not generalize to clinical samples or older adults referred to a memory disorders clinic. Another possible limitation of this study is that the DFQ (the functional measure used in the primary analysis) and the IQCODE (the functional measure used in clinical diagnosis) were completed by the same informant and have some overlap in items across the two instruments (approximately a quarter of the items overlapped), which could artificially augment group differences in the DFQ scores. This is

likely to be a greater problem for demented cases since an impaired IQCODE was required for a diagnosis of dementia, but is less of a concern for the MCI group wherein 45 of 46 cases had a normal IQCODE score (data not shown) and therefore the IQCODE did not contribute to the differentiation between normal vs MCI. Furthermore, previous studies (Jagust et al., 2002; Wu et al., 2002) have shown structural and functional neuroimaging differences between these diagnostic groups, providing further biological validity of the diagnostic process used in this sample. A further limitation of this study was the lack of information regarding either patients' or informants' mood. Previous studies have suggested the presence of depression in the patient and informant can affect the degree of discrepancy between raters (Rubenstein et al., 1984; Epstein et al., 1989; O'Conner et al., 1990; Bolla et al., 1991). Finally, some authors have suggested that executive functioning or frontal lobe functioning may be particularly associated with a loss of awareness of deficit that can lead to discrepancies in self- vs other-reporting (Reed et al., 1993; Michon et al., 1994). The current study lacked a measure of higher-order reasoning and problem solving and this should be included in future research.

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