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Assessing Everyday Functioning in Schizophrenia: Not all Informants Seem Equally Informative

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Abstract

Self reports of everyday functioning on the part of people with schizophrenia have been found to be poorly correlated with the reports of other informants and with their own performance of tests of cognition and functional abilities. However, it is not clear which informants are best for providing accurate reports of everyday functioning. This study examined the convergence between self-reports on the part of people with schizophrenia (n=193), who real-world functioning was rated by a friend or relative (n=154), or a high contact clinician (n=39) across 6 functional status rating scales. In addition, correlations between these reports and patient's performance on neuropsychological tests and a performance-based measure of functional capacity were also calculated. For convergence between raters, friend or relative informants and patient reports were significantly correlated for 4/6 rating scales. For the smaller sample of clinician informants, the correlations were significant on 2/6 scales. In the analyses of convergence between patient performance scores and functioning ratings, only 1/12 correlations between patient report and performance were significant, while friend or relative reports also were only correlated with performance on one rating scale. In contrast, clinician reports of functioning were correlated with patients' functional capacity performance on 4/6 rating scales and with neuropsychological test performance on 2/6. High contact clinicians appear to generate ratings of everyday functioning that are more closely linked to patients' ability scores than friend or relative informants. Later analyses will determine if there are differences between friend or relative informants.

Impairments in everyday functioning are a commonly observed in patients with schizophrenia. Through the course of their illness, these patients experience deficits in social (Wiersma et al., 2000), residential (Auslander et al, 2001), and occupational (Ho, et al., 1997) domains, even when their psychotic symptoms are in remission (Leung et al., 2008). In contrast to the general population, milestones such as marriage or a similarly stable relationship, full-time employment, and self-supported living less frequently occur in patients with schizophrenia (Harvey et al., 2009). More subtle aspects of real world

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functioning, including the real-world performance of functional skills (e.g., household management, social contacts, attempts to seek employment and financial management) have been previously rated with a variety of methods, including self-report (McKibbin et al., 2004), informant report (Bowie et al., 2006; 2008), and performance based assessments of the ability to perform everyday living skills (Patterson et al., 2001), often referred to as "functional capacity".

Similar to impaired self-evaluation of the origins and severity of symptoms in people with schizophrenia (Amador et al., 1993) lack of insight has also been documented in self-reports of real-world functioning and performance on objective tests. These impairments in selfassessment of performance are found in studies of self-assessment of cognitive functioning and real-world functional outcomes. For instance, people with schizophrenia provide implausible reports of their social functioning (Patterson et al., 1997) and their adherence to medication (Byerly et al., 2007). In addition, reports of their everyday functioning overlap poorly with reports by other informants (Bowie et al., 2007). In a study by Keefe et al. (2006), the correlation between self-reported cognitive deficits and performance on a neuropsychological (NP) assessment was r = 0.06 in a sample of 60 patients with schizophrenia. In contrast, informant reports of cognitive impairment, collected by informants unaware of patient's NP performance, was correlated at r = 0.42 (p <.01) with NP performance. The evaluators' ratings, based on self and informant report, were even more strongly correlated with patients' performance (r = .54, p < .001). In a study by Bowie et al (2007), case managers were asked to complete the same everyday functioning rating scale as their patients with schizophrenia, with the patient group also examined with a NP and a functional capacity assessment. In each of three domains of everyday outcomes (social, vocational, and residential), there was very poor correlation between case manager and patient reports (r's ranged from .20 to .29, all p>.05). Correlations were also calculated between case manager and self-reports of functioning and patients' performance on NP and functional capacity assessments, showing that case manager reports of everyday functioning were significantly (p=.04) more strongly correlated with patients performance on indices of functional capacity (r=.42, p<.05) than self reports of everyday functioning on the part of patients (r=.15, p>.20).

It has been reported that many people with schizophrenia do not have informants available to report on their functioning (Patterson, et al., 1996), suggesting that informant reports might not be a suitable means to acquire information on current functioning or treatment response. However, three recent large-scale studies (n>195) have illustrated that it is possible to recruit sufficient samples of patients, all of whom have informants available and willing to participate in research (Bowie et al., 2008; Harvey et al., 2011; Harvey et al., in press). With successful recruitment of informants, the next research task is to examine the possibility of differential validity of reports from various types of informants. We do not yet know whether there are differences in relative convergence between reports of everyday functioning across various types of informants (e.g., friends or family members vs. clinicians) and, if there are discrepancies between informant reports and self reports, we do not know if they are similar across functional domains. Also, as there are multiple realworld rating scales available to rate functioning (Leifker et al., 2011), it is important to determine which, if any, real-world functioning rating scales display suitable convergence between informant reports and objective indices, such as performance-based measures of cognition and functional capacity. This paper presents the results derived from data collected in a study, Validation of Everyday Real-World Outcomes (VALERO; Leifker et al., 2011; Harvey et al., in press), that addressed these questions.

The on-going VALERO study aimed to validate assessments (self-report and informantbased reports) of real world functioning completed by a sample of people with schizophrenia

and their available informant, either a high-contact clinician or a friend or relative. Patients were also examined with a neuropsychological assessment battery adapted from the MATRICS consensus cognitive battery (MCCB; Nuechterlein et al., 2008) and a performance-based assessment of functional capacity, the UCSD Performance- based skills assessment, brief version (UPSA-B; Mausbach et al., 2008). The overall results of the first phase of VALERO (Harvey et al., in press) indicated that a comprehensive real-world functioning assessment, using self-report, informant report, and interviewer best judgment across 6 different real-world functioning rating scales, demonstrated substantial overlap with performance-based ability measures. To address the questions presented above, we used the VALERO study phase I database and hypothesized that: 1) self-reported real-world functioning on the part of people with schizophrenia would be poorly convergent with reports generated by informants, 2) the convergence between patient and informant ratings would be different across various types of informants, and 3) informant reports would be

more strongly correlated with patients' own performance on the cognitive and functional

capacity measures than patients' self reports.

Methods

Subjects

The study participants were patients with schizophrenia who were receiving treatment at one of three different outpatient service delivery systems, two in Atlanta and one in San Diego. In addition, informants were interviewed for each of the patients, with these informants either being a high-contact clinician (case manager, psychiatrist, therapist or residential facility manager) or a friend or relative. All of research participants (including informants) provided signed, informed consent, and this research study was approved by local IRBs. In Atlanta, patients were either recruited at an intensive psychiatric rehabilitation program (Skyland Trail) or from the general outpatient population of the Atlanta VA Medical Center. The San Diego patients were recruited from the UCSD Outpatient Psychiatric Services clinic, which is a large public mental health clinic, from other local community clinics, and by word of mouth. Among the clinician informants, 22 were case managers and 16 were facility managers or clinicians.

All patients with schizophrenia were administered either the Structured Clinical Interview for the DSM-IV (SCID; First et al., 1995: Atlanta sites) or the MINI International Neuropsychiatric Interview (MINI; Sheehan et al., 1998: San Diego) by a trained interviewer. All diagnoses were subjected to a consensus procedure at the local site. Patients were excluded for a history of traumatic brain injury with unconsciousness >10 minutes, brain disease such as seizure disorder or neurodegenerative condition, or the presence of another DSM-IV-TR diagnosis that would exclude the diagnosis of schizophrenia. None of the patients were experiencing their first psychotic episode. Substance abuse was not an exclusion criterion, in order to capture a broad array of patients, but patients who appeared intoxicated were rescheduled. Inpatients were not recruited, but patients resided in a wide array of unsupported, supported, or supervised residential locations. Informants were not screened for psychopathology or substance abuse. Descriptive information on patients and informants is presented in Table 1.

Procedure

All patients were examined with a performance-based assessment of neurocognitive abilities and functional capacity. They also provided self-reports of social, residential and vocational functioning on six different functional outcomes scales, which were either administered to them as interviews by a trained rater, or completed in a questionnaire format. Informants independently completed the same six outcomes scales and reported on the functioning of

the patients. Informants were compensated \$25.00 for their time and effort. Patients received \$50.00.

Performance-based assessment

Neurocognition—We examined cognitive performance with a modified version of the MATRICS consensus cognitive battery (MCCB; Nuechterlein et al., 2008). For this study, we did not include the MSCEIT social cognition measure, as we were interested in variables that were purely neurocognitive, and there is evidence that social cognition and neurocognition may be correlated minimally (Ventura et al., submitted). We calculated a composite score, which was an average of the other 10 age and gender corrected T-scores, based on the MCCB normative program, as our critical dependent variable. Note that this is different than the composite score generated by the MCCB computer program, which compares composite scores to the performance of healthy individuals. It typically leads to lower scores in impaired populations because of the consistently lower scores on the part of patients weighted against healthy comparison individuals. See Keefe et al., (2011), for a clear comparison of the MCCB composite scores vs. individual ability domain scores and Kern et al (2011) for a description of the typical patterns of impairment seen in schizophrenia patients on the MCCB.

In addition to this modified version of the MCCB, we also had patients perform the Wide-Range Achievement Test, 3rd edition (WRAT-3;Wilkinson, 1993). This was done to ensure that all patients could read adequately to be assessed with the cognitive battery and also as an approximate index of premorbid intellectual functioning.

Functional Capacity—Participants' functional capacity was assessed using the Brief version of the UCSD Performance-based Skills Assessment (UPSA-B; Mausbach et al., 2008). The UPSA-B is a measure of functional capacity in which patients are asked to perform everyday tasks related to communication finances. During the *Communication* subtest, participants are required to role-play exercises using an unplugged telephone (e.g., emergency call; dialing a number from memory; calling to reschedule a doctor's appointment). For the *Finance* subtest, participants are required to count change, read a utility bill and write and record a check for the bill. The UPSA-B requires approximately 10–15 minutes to complete, and raw scores are converted into a total score ranging from 0–100, with higher scores indicating better functional capacity. Recently (Green et al., 2011) the UPSA-B was determined to be the most suitable short form for functional capacity assessments as a co-primary measure in clinical treatment trials.

Clinical Symptom Ratings—Clinical ratings of symptoms were collected with the Positive and Negative Syndrome Scale (PANSS; Kay, 1991) and the Beck Depression Inventory- Second edition (BDI-II; Beck et al., 1996) and are presented in Table 1, along with demographic information.

Real-World Functional Outcomes—The initial phase of the VALERO study included a RAND panel that selected 6 functional outcome scales from a much larger group of candidate scales, as most suitable for current use at the time of the panel (see Leifker et al., 2011 for detailed descriptions of these instruments). These six scales are the Heinrichs-Carpenter Quality of Life Scale (QLS; Heinrichs et al., 1994), Specific Levels of Functioning (SLOF; Schneider and Struening, 1983), Social-Behavior Schedule (SBS; Wykes and Stuart, 1986), Social Functioning Scale: (SFS; Birchwood et al., 1990), Life Skills Profile (LSP, Rosen et al., 1989), and the Independent Living Skills Survey (ILSS; Wallace et al., 2000).

There are several important features of these functional outcome scales. Two (SBS, SFS) were pure social functioning scales, while two others examined only community functioning (LSP; ILSS). The others (QLS; SLOF) were "hybrid" scales examining social, residential, and vocational outcomes. Of the six scales, 2 were administered as self-report questionnaires (ILSS and SLOF) and the others were administered as interviews using the standard instructions for the scale. Although all of these rating scales have multiple individual subscales, for the purposes of this report, early on in the analysis of this rich dataset, we examined only summary scores. This choice is based on the fact that if these scales were used as outcomes measures in a clinical trial, a single, predefined primary outcome would have to be selected and we were interested in making this information available in as timely a manner as possible. The summary scores we used were based on the means of the subscales in each of the scales.

Some of these instruments were modified by deletion of some of their subscales following the suggestions of the RAND panel. For instance, the social acceptability and personal care subscales of the SLOF were not used in calculation of the total SLOF scores and, for the QLS, the intrapsychic foundations subscale was not included in the analyses of the data because it measures deficit (i.e. negative) symptoms.

Analyses—To address the first hypothesis, we compared the summary scores of each of the real-world functioning measures between the patients and their respective informants using paired t-tests. Paired t-tests were used because the samples were dependent, because both sets of ratings were aimed at the patient. For the ILSS and the QLS, the informant and patient subscales had different metrics. We standardized the scores within the patient and informant samples and calculated the t-tests on those z-scores. The second hypothesis was addressed by first calculating the correlations between patient and informant reports. Separate correlations between patients and informants (i.e., friends/family and clinicians). We did not perform a direct comparison of the magnitudes of these correlations between both patient and informant reports of real-world functioning and the patient's performance on the measures of neurocognition and functional capacity. These two sets of correlations (i.e., patient vs. friend/family & patient vs. clinicians) were then statistically compared.

Results

Table 1 presents the demographic and clinical characteristics of the patient samples as a function of the type of informant. As we examined the convergence in reports between patients and informants as a function of the different informant types, we were interested in whether these samples of patients who had different informants were different from each other. Patients who were rated by clinicians were more likely to be Caucasian, were younger, and had more years of education (all $p \le 0.03$). These patients also had lower scores on the BDI-II than the patients rated by a friend or relative, and higher WRAT-III reading scores (both $p \le 0.02$). PANSS total scores did not differ between the groups (p = 0.47).

Table 2 presents the paired t-tests between informant ratings and self-reports across the six real-world functioning rating scales. In a preliminary analysis to ensure comparability of the patient samples in reported functioning across the types of informant, we compared the functional outcomes impairment scores for patient self-reports and informant reports across the 6 rating scales across groups of patients who had the different types of informants. Neither patient self reports (all t<1.55, all p>0.13) nor informant reports (all t<0.35, all p>0.73) differed in severity across any of the 6 rating scales as a function of the type of

informant who rated the patient. Thus, overall severity of functional impairment was similar in the two subsamples of people with schizophrenia.

For the LSP, the severity scores did not differ between patients and friend or relative informants, or between patients and clinician informants. The correlations between patients' self-reports and both types of informants were not significant. For the SBS, friend or relative informants reported greater impairment than patients did, but clinician and patient reports did not differ. There was a significant correlation between patient reports and friend or relative informant reports, but not between clinician informants and patient self-reports. For the ILSS, there were no severity differences between patient and informant reports, across both types of informants. There was a significant correlation between patient reports and friend or relative reports, but not between clinician informants and patients. Similarly, there were no severity differences between patient and informant reports on the QLS manifested a significant correlation with patient self reports. For the SFS and the SLOF, there was no difference among the severity scores on reports of patients and both types of informants. Correlations between patients and both informant types were non-significant on both scales. Interpretation of this table should be tempered by the difference in sample size across these two groups of patients.

Table 3 presents the correlations between patient self reports, informant reports and patient's performance on the NP assessment battery and the UPSA-B. The mean score for the sample on the UPSA-B was 76.66 (SD=13.14) and for the modified MCCB, the mean of the individual t-scores score was 37.90 (SD=6.95). Patients' performance on both the UPSA-B, t(194)=0.38, p=0.70, and the MCCB, t(194)=0.13, p=0.90, did not differ as a function of the type of informant. The overall correlation between the UPSA-B and MCCB was r=0.62, p<0.001. For patients with a clinician informant, there was only one significant correlation between patient self-reports and their performance on the MCCB or UPSA-B: self-reported functioning on the ILSS and performance on the UPSA-B. In contrast, clinician informant reports of functioning on four of the six rating scales (ILSS, QLS, SFS, & SLOF) were significantly correlated with performance on the UPSA-B. Further, clinician rated functioning was significantly (p<.05) correlated with MCCB performance on two of the six rating scales (ILSS & QLS) and manifested a trend-level (p<.10) relationship with the two scales that were found to be correlated with UPSA-B performance (SFS and the SLOF). For the patients with a friend or relative informant, only one of 12 correlations between selfreported real-world functioning (SFS) correlated with modified MCCB performance. That correlation accounted for 3% shared variance. Friend or relative informants generated ratings that were correlated with patients' performance on only one of the six rating scales (SFS), and these two correlations shared less than 4% variance.

Discussion

Our study revealed that across six different functional status rating scales, patients generated self-reports that were modestly correlated with informant reports, including both clinicians and friend/relatives serving as informants. The severity levels of each measure were only slightly different for the two measures that differed significantly (SBS & QLS), with patients under-reporting impairment when compared to both types of informants. Overall, clinician reports were more consistently correlated with the performance of patients on cognitive and functional capacity measures than the reports of friend or relative informants, despite the larger sample size for that informant group. The relationship between clinician reports and performance-based indices for four rating scales (ILSS, QLS, SFS and SLOF) were all of similar strength.

These data have implications for current "consumer-driven" approaches to assessment. These data suggest that consumers have substantial problems in reporting their ability to perform everyday activities. These findings do not suggest that self report is not important, but rather that only certain things may be self-reported with suitable accuracy. Quality of life and mood symptoms do not seem subject to this concern (Bowie et al., 2006; 2010).

Some of the limitations encountered in this study include the fact that there is only one informant per patient and that there were differences in the two samples in several different demographic factors. The sample sizes were also different, but the smaller samples (clinician informants) were associated with larger correlations between performance-based measures and informant reports, arguing against differential power as an explanation for differences in correlations. We did not correct for multiple correlations, but the consistent correlations between clinician informant reports of real-world functioning and patient performance on functional capacity measures was very consistent with our prior studies in this area. The current study did not attempt to quantify the specific environment where the observations were performed or to examine the convergence scores for different types of friend or relative informants. Further, friend or relative informants seem more likely to themselves be affected by psychiatric conditions such as mental illness or substance abuse, which may impact on the validity of their reports. The next phase of the VALERO study will examine a new sample of patients, each of which will be evaluated with a more limited set of functional measures by two informants: a clinician and a friend or relative.

Future research trying to understand reduced convergence between self reported functioning, observer perspectives, and patient performance could be aimed at the predictors of discrepancies in reported functioning between informants, including levels of cognitive impairment on the part of patients, clinical symptom severity, and presence of depression. We will address some of these issues later ourselves. The extent and environmental context of the contacts between informants and patients may affect convergence of reports and different functional domains (i.e., social, vocational, and residential). Differences in the reports between friends and relatives may be important as well. In the next sets of analyses, we will systematically examine the differences between patients whose self-reports of functioning are over, as compared to under, estimates of their measured functional abilities. In prior studies, depression has been shown to affect discrepancies between informant reports and self reports across neuropsychiatric conditions, with less depressed patients providing self reports that reflected less severe impairment then objective measures (Bowie et al., 2007;Carone et al., 2005). This phenomenon is also seen in healthy populations (Dunning & Story, 1991) and has been referred to as the "sadder but wiser" effect (Alloy & Abramson, 1979).

These results tentatively suggest that high contact clinicians may be the optimal informant to provide ratings of real-world functioning that are related to patients' objectively measured ability. The phase of our study will be better poised to make a direct comparison between the validity of different informants' perspectives on real-world functioning of people with schizophrenia. Our findings do suggest, replicating previous findings with smaller samples, that self-reports of everyday functioning in people with schizophrenia are only minimally related to to the perspectives of informants or objective information on performance-based measures.

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Table 1

Demographic Information as a Functional of Type of Informant

	Clinici	m	Friend/	Relative	χ^2	d
Ζ	39		154			
% Male	69		69		0.00	66.
Racial Characteristics (%)						
Caucasian	LL		48		10.39	.006
African-American	18		44			
Latino	Ś		œ			
	М	SD	М	SD	t	d
Age	39.97	13.88	45.12	10.87	2.49	.03
Years of Education	14.34	2.65	12.56	2.34	4.04	.001
WRAT-III Reading Score	47.72	5.58	45.13	4.78	2.93	.004
Beck Depression Inventory-II Total Score	12.03	9.12	16.95	12.45	2.31	.02
PANSS Total Score	64.15	14.73	62.25	14.50	0.73	.47

Table 2

Patient and Informant Reports of Patients' Real World Functioning Across Six Rating Scales

Rating Scale	Patient		Friend Relativ	or e	Correl	lations	Group I	oifferer	Ices	Patient		Clinicia	u	Corre	lations	Group I	Differe	nces
	m	$\mathbf{p}\mathbf{s}$	М	$\mathbf{p}\mathbf{s}$	r	p	t	df	þ	m	\mathbf{p}	m	sd	r	p	t	df	p
ΓSP	26.13	2.91	25.52	3.10	0.12	0.199	1.60	153	0.112	26.78	2.51	25.45	3.15	0.12	0.549	1.85	38	0.076
SBS	0.36	0.32	0.54	0.50	0.25	0.007	-3.63	153	0.000	0.39	0.37	0.57	0.59	0.14	0.475	-1.52	38	0.140
ILSS	0.76	0.13	2.50	0.66	0.19	0.050	-0.63	153	0.711	0.75	0.15	2.49	0.73	0.24	0.206	-0.36	38	0.84
QLS	19.64	5.54	21.34	8.29	0.33	0.001	0.70	153	0.686	19.83	3.96	24.36	8.49	0.49	0.008	-1.44	37	0.16
SFS	16.77	3.01	16.19	3.53	0.48	0.000	1.827	153	0.070	15.93	3.54	14.86	4.03	0.41	0.030	1.364	38	0.184
SLOF	30.46	5.03	28.71	4.89	0.13	0.179	2.808	153	0.006	30.52	5.45	28.58	6.07	0.15	0.446	1.370	38	0.182
Note																		

Note.

LSP: Life Skills Profile: Range of Scores 17–32

SBS: Social Behavior Schedule: Range of Scores 0–1.7

ILSS: Independent Living Skills Survey: Range of Scores Patient 0.33–1.0; Informant 0.7–3.85

QLS: Heinrichs-Carpenter Quality of Life Scale: Range of Scores Patient 6-46; Informant 5-42

SFS: Social Functioning Schedule: Range of Scores 9.9–24.3 SLOF: Specific Levels of Functioning: Range of Scores 15.3–37.5 Note. Analyses for the ILSS and QLS were computed by using standard scores, because the total raw scores differed across informant and patient forms. Also, keep in mind that the sample sizes across the two groups were quite different. Sabbag et al.

Table 3

Pearson Correlations Between Ability Variables and Patient and Informant Reports of Functioning on Six Rating Scales

	Patient		Clinicia	п	Patient		Friend/J	Relative
		(n=39)				(N=154)		
	UPSA	NP	UPSA	AN	UPSA	NP	UPSA	NP
Scale								
Life Skills Profile	.13	.16	.16	.21	.06	00.	.06	.11
Social Behavior Schedule	00 [.]	.02	.20	.12	.08	.16	.08	.19
Independent Living Skills Survey	.36*	.04	.34*	.37*	.04	.16	11.	.16
Quality of Life Scale	.22	.15	.46*	.36*	II.	.13	.10	.16
Social Functioning Scale	.15	.06	.45*	.31	60.	.18*	.19*	.19*
Specific Levels of Functioning	.24	.24	.46*	.27	.16	.06	.12	.10