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Quality of life measurement in schizophrenia: reconciling the quest for subjectivity with the question of reliability

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ABSTRACT

Background. The patients' ability to appriase their quality of life in schizophrenia was studied by examining the reliability and the validity of self-rated quality of life estimates.

Methods. Sixty-three symptomatically stable patients with schizophrenia (DSM-IV) receiving maintenance treatment were evaluated over a 4-week period. The subjects were asked to appraise their quality of life at weekly intervals on a single item global quality of life measure, as well as the self-administered sickness impact profile. The patients' quality of life was also rated by a clinician using the social performance schedule and the global assessment scale of functioning; and clinical aspects such as the severity of psychotic symptoms, neurocognitive deficits, dose of medications, and side effects were documented with standardized measures.

Results. The results indicated that the patients' self-reports were highly consistent over the 4 weeks, and the quality of life ratings correlated significantly with the clinician's estimates. The patients' quality of life was predictably influenced by the severity of their symptoms, side effects, cognitive deficits and the dose of their antipsychotic medication, but the reliability of their reports was not materially affected by these factors.

Conclusions. It is concluded that clinically compliant and stable patients with schizophrenia can evaluate and report their quality of life with a high degree of reliability and concurrent validity, implying that self-report measures are potentially useful tools in clinical trials and outcome studies.

INTRODUCTION

Quality of life is an all inclusive, convenient summary phrase capable of capturing the multitude of impairments and consequences that often compound a chronic illness such as schizophrenia. Quality of life, in view of its inherent subjective nature, is also better equipped to capture the subjective dimension of this complex illness and underscore its overall impact on the individual. In view of these advantages, quality of life has been increasingly used as a screening and outcome measure in the rehabilitation of chronic mental patients, and more recently as an outcome measure in clinical trials involving newer antipsychotic medications (Lehman, 1983; Meltzer *et al.* 1989; Awad, 1995; Lancet, 1995).

However, the application of quality of life in the field of schizophrenia does not run parallel to similar developments occurring in other branches of clinical medicine (Spilker, 1996). The use of quality of life measures, especially the subjective or self-rated measures, may pose some problems that are unique to the field of psychiatric disorders (Gill & Feinstein, 1994). The key problem here is the credibility of patients' self-reports, which is often not questioned in patients affected by other medical (physical) disorders. There has been a wide-

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spread notion among clinicians and researchers that schizophrenic patients are unreliable historians and doubts about the credibility of patients' self-reports have been raised in the context of history-taking, treatment adherence and also insight into their illness (Small *et al*. 1969; Davidhizar, 1985; Amador *et al*. 1993). Past research on the self-appraisal of social functioning in schizophrenia has produced inconclusive results. Some reported that patients with schizophrenia have a tendency to underestimate their psychosocial functioning, while others observed that patients' quality of life estimates were disproportionately high, or just accurate (Weissman *et al*. 1978; Glazer *et al*. 1980; Sullivan *et al*. 1991). These were incidental observations arising out of larger surveys that were not specifically designed to address the issues of reliability and validity of patients' self-reports.

The present study was based on a premise that subjectivity is the central aspect of quality of life measurement, and a reasonable method of capturing the subjective dimension is through the use of appropriate self-report measures. This presumption, however, is only valid if the patients' self-reports of their quality of life are proven to be credible, through establishing their psychometric characteristics such as reliability and validity. So the aim of the study was to establish the credibility of patients' quality of life appraisals, through administering self-rated quality of life measures on consecutive weeks, and by examining how far the weekly ratings correlate with each other, and also correlate with a clinician's independent ratings of quality of life. Also, an attempt was made to identify the impact of symptom severity, neurocognitive deficits and treatment related factors on the credibility of patients' self-reports.

Two aspects of the study require a special explanation: first, no attempt was made to define 'quality of life (QOL)' for the purpose of this work. The phrase was used in a broader meaning of the concept which includes notions such as 'health related quality of life (HR-QOL)', 'health status' and 'psychosocial adjustment'. Accordingly, the chosen battery of rating scales with their differing scope and emphasis may represent any of these categories. Secondly, a note on the usage of the terms 'reliability' and 'validity' in this article. Conventionally, these terms are employed in the literature to describe the performance of a rating scale, with an implicit assumption that the test subjects' appraisals are always accurate and consistent. However, in the context of the present study this assumption was reversed, and the concepts were employed to characterize the credibility of patients' self-reports. Through selecting standardized rating scales with sound reliability and validity, the objective was to identify the inconsistencies and inaccuracies in patients' quality of life appraisals.

Study design

The design and key features of the present study were as follows.

(i) The reliability of patients' judgements was established by measuring their self-reported quality of life at weekly intervals over a period of 4 weeks, and examining the strength of correlation between paired weekly ratings. Thus, the study employed a repeated-measures, within-subject design.

(ii) Issues related to the validity were addressed through examining the strength of relationship between independently recorded patients' and clinician's ratings of patients' quality of life.

(iii) To examine the potential influence of illness and treatment-related factors on quality of life appraisal, subjective responses and attitudes towards drug therapy and a side-effects (akathisia and dyskinesia) were also documented.

METHOD

Patients

Sixty-three subjects were included in the study, and the sample was drawn from an out-patient clinic attended by over 150 patients treated for schizophrenia and other psychotic disorders. The inclusion criteria of the study consisted of an established diagnosis of schizophrenia (DSM-IV), patients of either sex with age ranging between 18 and 65 years, symptomatically stable clinical status during 6 months prior to inclusion in the study, and an ability to comprehend written and spoken English. Patients who were not competent to provide written informed consent and those with an associated diagnosis of mental retardation, organic psychotic con-

Table 1. *Summary of evaluation methods*

Dimension of measurement	Scale/source	Brief description
1 Subjective multidimensional quality of life	Sickness Impact Profile (SIP) (Bergner *et al.* 1981)	A multi-dimensional, generic health status measure; contains 64 items grouped into six categories (modified version); self-administered in about 10–12 min.
2 Subjective global quality of life	Single Item Global Measure (Gurin *et al.* 1960)	A single question aimed at eliciting global quality of life, rated on a 5-point Likert scale; extensively used in general population surveys.
3 Objective multidimensional quality of life	Social Performance Schedule (SPS) (Stuart & Wykes, 1987)	Designed to measure subject's performance in eight accepted roles; performance scored by a clinician based on 15–20 min of semi-structured interview.
4 Objective global quality of life	Global Assessment Scale of Functioning (GAF) (Endicott *et al.* 1976)	A single item rating scale, for use by clinicians, to rate the overall psychosocial functioning of patients; scores range between 0–90; axis V in DSM-IV.
5 Severity of psychopathology	Positive and Negative Syndromes Scale (PANSS) (Kay *et al.* 1987)	A 30-item scale to rate the profile and severity of schiz. symptoms; yields separate scores for positive, negative and general symptoms; scored on the basis of a 45 min interview with patient and informant.
6 Side effects (dyskinesia)	Abnormal Involuntary Movements Scale (AIMS) (Guy, 1976)	A 10-item scale to rate the severity of abnormal movements in seven areas of body; yields a total score; requires about 5–10 min for examination and scoring.
7 Side effects (akathisia)	Hillside Akathisia Scale (HAS) (Fleishhacker *et al.* 1989)	A five-item (two subjective and three objective) rating scale to quantify frequency and magnitude of akathisia; requires 5–10 min for completion.
8 Attitudes toward treatment	Drug Attitude Inventory (DAI) (Awad, 1993)	A 10-item scale designed to elicit patients' subjective responses and attitudes towards drug therapy in schizophrenia; requires about 2 min.
9 Neurocognitive functioning	COGLAB (Spaulding *et al.* 1989)	A computer administered cognitive test battery, consisting of six tests of information processing; requires about 20–30 min for administration.

ditions, alcohol and substance abuse or secondary mood disorders were excluded. Patients with visual, language and communication difficulties, and those suffering from additional handicaps such as severe physical disabilities were also excluded. A total of 153 subjects were screened for the study, through performing chart reviews and preliminary interviews. Patients who fulfilled the selection criteria were given an explanation about the study and a written informed consent was obtained.

Evaluation methods

The scope of measurement involved two aspects: performing quality of life assessments, and documenting simultaneously a range of illness and treatment related issues which could potentially affect patients' ability to judge their quality of life. The comprehensive strategy for measuring quality of life involved two key dimensions – self-rated (subjective) and clinician-rated (objective) evaluations, as well as global and domain-specific rating methods. The subjective domain-specific dimension was captured with the sickness impact profile (SIP), the subjective global dimension with Gurin's single-item measure, the objective domain-specific dimension with the social performance schedule (SPS) and the objective global dimension with the global assessment scale of functioning (GAF). The second category of assessments involved the measurement of illness and treatment related factors which could potentially affect patients' self-appraisals. Various rating scales and evaluation methods used to quantify these aspects are summarized in Table 1.

Data collection

The study protocol for each patient spanned 4 weeks, consisting of assessments at weekly intervals. The initial assessment on week 1 involved three components – completion of self-administered scales (Gurin's global quality of life measure, SIP and DAI) by the subject, a standard psychiatric interview and examination by a clinician to complete the social performance

scale, global assessment scale of functioning, positive and negative syndrome scale, abnormal involuntary movement scale and Hillside Akathisia scale. This was followed by a neurocognitive evaluation with the aid of COGLAB. The average time period required for all evaluations was about 90 min for each subject. On week 2 and week 3 the evaluations consisted of completion of SIP and Gurin's global quality of life measure by the patient. On week 4 the subjects completed the SIP and Gurin's global quality of life measure, and the clinician re-administered the positive and negative syndrome scale to document any changes in clinical status.

Data analysis

The test–retest reliability of subject's self-reports was established by examining the strength of association between paired weekly ratings of scores obtained on the SIP, as well as Gurin's global quality of life measure. The concurrence between patients and clinicians ratings of patient's quality of life was addressed by examining the strength of association between the SIP and Gurin's quality of life measure scores, and the scores obtained on the social performance schedule (SPS) and global assessment scale of functioning (GAF). Pearson's product moment correlations were computed to examine test–retest reliability and concurrent validity. The influence of illness and treatment on the reliability of patients' self-reports was determined by examining the reliability coefficients in subgroups of patients, using repeated measures analysis of variance (ANOVA).

RESULTS

The results are presented under four headings: sample characteristics, reliability and validity data, and effects of illness related factors on patients' self-appraisal. The sample profile is indicative of a predominantly male, Caucasian, young-adult, educated, unemployed, unmarried patient population who tended to live alone (Table 2). Illness onset was in their early 20s, duration was about 9 years, and the psychopathology was of mild to moderate degree with a slight predominance of negative symptoms. All were maintained on antipsychotic medication with evidence of milder side effects and an overall positive attitude towards treatment. Indices of psychosocial functioning and neurocognitive tests revealed moderate degree of disability and deficits (Table 3).

Reliability of quality of life self-reports

Reliability coefficients were positive and statistically significant for the SIP scores ($r = 0{\cdot}80$–$0{\cdot}87$, $P < 0{\cdot}0001$) as well as patients' ratings on the Gurin's global quality of life scale ($r = 0{\cdot}68$–$0{\cdot}87$, $P < 0{\cdot}0001$) (Table 4). These findings support the key hypothesis that schizophrenic patients' self-appraisals of their quality of life were highly consistent on repeated measurements over 4 weeks; and the degree of reliability was evident on global as well as multidimensional measures.

Factors influencing the reliability of patients' ratings

In order to determine the influence of illness severity and treatment related factors on the reliability of patients' self-reports, each of the potential contributory factors (symptom severity, neurocognitive deficits, drug dosage, severity of side effects and attitudes towards treatment) were considered one at a time, and their association with reliability coefficients of the SIP was examined. Based on the clustering of scores obtained on each of these scales, the sample was divided into 3 or 4 equal subgroups, and the

Table 2. *Sociodemographic characteristics of the sample* (N = 63)

Variable		Frequency	%
1 Age	(Mean)	32·4	
2 Sex	Male	41	65·07
	Female	22	34·92
3 Race	White	37	58·70
	Black	11	17·46
	Asian	6	9·52
	Others	9	14·20
4 Education	Primary	6	9·52
	Secondary	45	71·43
	University	12	17·46
5 Employment	Employed	9	14·28
	Employable	10	15·87
	Unemployed	44	69·84
6 Marital status	Single	50	79·36
	Separated etc.	9	14·28
	Married	4	6·34
7 Living arrangement	Alone	40	63·49
	Shared	8	12·6
	Family	15	23·80

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Table 3. *Clinical profile and indices of quality of life*

	Variable	Mean	(S.D.)	Scale range and significance
1	Illness duration (years)	9·2	5·4	
2	Age of onset (years)	22·3	4·2	
3	PANSS total score	75·72	15·32	30–210, higher score indicates more symptoms
4	Antipsychotic Drug Dose (CPZ) equivalents in mg)	818·55	326·2	
5	AIMS scores	1·30	1·99	0–28, higher score indicates more side effects
6	HAS scores	13·14	12·09	0–20, higher score indicates more side effects
7	DAI scores	3·92	4·6	−10 to +10, negative score indicates negative attitudes, and positive score indicates positive attitudes
8	Sickness Impact Profile (SIP), overall score	35·77	21·03	0–100%, higher score indicates poor functioning
9	Social Performance Schedule (SPS)	45·6	11·9	0–100%, higher score indicate poor functioning
10	Global Assessment Scale of Functioning (GAF)	55·15	16·29	0–90, higher score indicates better functioning
11	Gurin's Single Item Global Quality of Life Measure	3·2	1·19	1–5, higher score indicates better functioning
12	Wisconsin Card Sorting Test			
	(a) Perseverative errors	22·11	9·67	Higher scores indicate greater cognitive deficit
	(b) Random errors	46·64	6·36	

reliability of the SIP scores was examined in each of the subgroups across the 4 weeks. For example, based on the PANSS scores the sample was divided into four subgroups, and the reliability coefficients for these subgroups ranged between 0·81–0·97 (for the mildly symptomatic group with PANSS scores of 40 to 65) and 0·76–0·90 (for the moderately ill with PANSS scores of 86 to 111). Further, repeated measures analysis of variance (ANOVA) failed to detect any group by week interaction for the severity of symptoms ($F(9,126) = 1·37$, $P = 0·20$), side effects ($F(9,177) = 1·26$, $P = 0·12$), neurocognitive deficits ($F(3,93) = 1·73$, $P = 0·16$), anti-psychotic drug doses ($F(9,177) = 0·84$, $P = 0·58$), or attitudes ($F(9,177) = 1·70$, $P = 0·09$). The lack of such interaction indicates that SIP scores remained fairly consistent for all the subgroups across time. In other words, the subgroup of patients with higher level of symptoms (PANSS score of 86 to 111) were as reliable in their self-reports as the subgroup of patients with a lower level of symptoms (PANSS score of 40 to 65) (see Fig. 1). Similarly, the subgroup of patients with a higher degree of neurocognitive deficits (exemplifed by a perseverative error score of 30 to 122 on Wisconsin Card Sorting Task) were as reliable as the subgroup of patients with a lower degree of deficits (perseverative error score of 0 to 7·5).

These results provide further support to the hypothesis that, in a clinically stable, mild to moderately ill schizophrenic patient population, symptom severity, neurocognitive deficits and other treatment related issues do not impair patients' ability to appraise quality of life.

Validity of patients' self-reports

Concordance between scores obtained from the self-report measures and the clinician-administered measures of quality of life are presented as a correlation matrix (Table 5). The significant findings include the following. (1) Scores obtained on the two self-report measures (SIP and Gurin's global quality of life measure) correlated with each other to a significant degree ($r = 0·55$–$0·89$, $P < 0·0001$). (2) Clinician's ratings on the global and domain-specific measures (SPS and GAF) also correlated with each other ($r = 0·83$–$0·86$, $P < 0·0001$) significantly. (3) Patients' self-rated quality of life on the multidimensional measure (SIP) correlated well with clinician's ratings (with SPS, $r = 0·40$–$0·52$, $P < 0·0001$; with GAF, $r = 0·35$–$0·54$, $P < 0·0001$), but their global estimates on Gurin's quality of life measure correlated weakly with clinician's ratings (with SPS, $r = -0·15$, $P < 0·28$; with GAF, $r = 0·21$–$0·28$, $P < 0·03$). (4) Among clinical indices, severity of symptoms (PANSS), severity of akathisia (HAS), and patients' subjective experiences with anti-psychotic drugs (DAI) correlated significantly with both subjective and objective quality of life measures. Indices of subjective distress (severity

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Table 4. *Reliability coefficients of quality of life self-reports*

Paired measures correlated	Correlation coefficient*
1 Mean SIP overall (%) scores	
Weeks 1 and 2	0·86
Weeks 1 and 3	0·84
Weeks 1 and 4	0·86
Weeks 2 and 3	0·85
Weeks 3 and 4	0·87
2 Mean (%) scores of various SIP categories	
a Sleep and rest	
Weeks 1 and 2	0·77
Weeks 1 and 3	0·56
Weeks 1 and 4	0·59
b Home management	
Weeks 1 and 2	0·76
Weeks 1 and 3	0·63
Weeks 1 and 4	0·54
c Social interaction	
Weeks 1 and 2	0·71
Weeks 1 and 3	0·52
Weeks 1 and 4	0·57
d Alertness behaviour	
Weeks 1 and 2	0·81
Weeks 1 and 3	0·87
Weeks 1 and 4	0·91
e Communication	
Weeks 1 and 2	0·82
Weeks 1 and 3	0·79
Weeks 1 and 4	0·84†
f Recreation and pastimes	
Weeks 1 and 2	0·72
Weeks 1 and 3	0·46
Weeks 1 and 4	0·50
3 Mean scores of Gurin's Global QOL Measure	
Weeks 1 and 2	0·74
Weeks 1 and 3	0·70
Weeks 1 and 4	0·68
Weeks 2 and 3	0·87
Weeks 3 and 4	0·68

* $P < 0{\cdot}0001$ for all correlations except †, where $P < 0{\cdot}0006$.

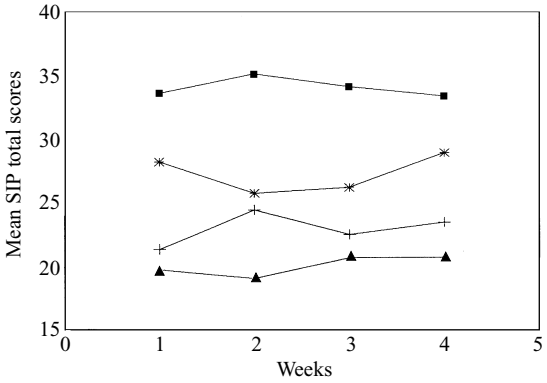

FIG. 1. Illness severity and consistency of SIP scores. (PANSS score: ▲, minimal; +, mild; ✳, moderate; ■, severe.)

Table 5. *Intercorrelations between Quality of Life Measures and Clinical Indices*†

	SIP total	Global QOL	SPS total	GAF score
Global QOL	−0·55 −0·59***	1·00		
SPS total	0·40 0·52***	−0·15 −0·24	1·00	
GAF score	−0·35 −0·54***	0·21 0·28*	−0·83 −0·86***	1·00
PANSS	0·44 0·61***	−0·39 −0·45**	0·54 0·62***	−0·72 −0·74***

† Based on Week 1 and Week 4 scores.
* $P < 0{\cdot}05$; ** $P < 0{\cdot}001$; *** $P < 0{\cdot}0001$.

of illness and akathisia) also correlated with subjective quality of life ratings, e.g. HAS and SIP, $r = 0{\cdot}39$–$0{\cdot}41$, $P < 0{\cdot}0001$; HAS and Global QOL, $r = -0{\cdot}38$ to $0{\cdot}39$, $P < 0{\cdot}001$. The association was less impressive with the objective measures (SPS and GAF).

In summary, while assessing patients' quality of life, patients' and clinician's judgements concurred more when structured measures of illness and quality of life were used; and the agreement was less impressive with the use of global measures of quality of life.

DISCUSSION

The objective of this study was to address some of the conceptual and methological issues surrounding the use of self-report measures of quality of life, and to provide a rational basis for future clinical trials and outcome evaluations involving schizophrenic patients.

The study is noted to have some limitations pertaining to the representativeness of the sample and absence of control groups. Arguably, the sample is rather homogeneous in terms of their symptom severity, treatment compliance and psychosocial functioning, and may not be representative of a broader schizophrenic population. This has been identified as a frequent problem in schizohrenia research, as the extremely ill patients are the ones who are often non-compliant and unwilling to be studied (Schreiber *et al.* 1990). However, since one of the objectives of the study was to provide a rational

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basis for future clinical trials and outcome evaluations in clinical practice, the study subjects were chosen to closely resemble a clinical trial population. Arguably, the study may have benefited from the inclusion of a non-schizophrenic control group, since the focus is on the self-appraisal ability of patients. However, choosing an appropriate control group for studies involving schizophrenic patients has been identified as a vexing problem, as the illness is complex and it is often difficult to draw a distinction between the consequences of illness and the patients' pre-morbid characteristics (Buckley *et al*. 1992).

The study has demonstrated that schizophrenic patients' self-reports of quality of life can achieve a high degree of reliability. The reliability coefficients observed in this study were generally comparable to the reliability data obtained in the original standardization studies of the Sickness Impact Profile. To establish the test–retest reliability of the SIP, Bergner *et al*. (Bergner *et al*. 1981) readministered the scale to a sample of general practice patients after an interval of 24 h, and the correlation between the scores was 0·87. In our study, the minimum interval between the re-administrations was set at 1 week, and a comparable correlation coefficient (0·86) was obtained, confirming that stabilized schizophrenic patients could be as reliable as the patients from a general practice clinic. Even though time interval chosen for the readministration was longer, it did not lower the reliability coefficients. Re-administration periods shorter than a week, however, could be associated with problems of learning and memorization (Streiner, 1989). Realistically, the 1 week interval chosen in this study is also closer to the spacing of evaluations in a practice/clinical trial situation.

The impact of schizophrenic symptoms on patients' quality of life was examined in past studies (Lehman, 1983; Simpson *et al*. 1989) but their effect on patients' self-appraisal and the measurement process has not been addressed. The present study demonstrates that the severity of schizophrenic symptoms, cognitive deficits and the sequelae of treatment did not influence the reliability of patients' self-reports in this population. Influence of more severe psychotic symptoms and the relevance of specific aspects of the illness, such as insight, require further investigation. Future studies should also examine the issue of 'responsivity' or 'sensitivity to change', which is another important prerequisite for the use of quality of life measures in clinical settings. The cross-sectional design of our study did not provide the scope to examine if patients' self-reports were responsive to changes in their lives, over time, with or without intervention. It has been recently shown that self-reports, especially in chronic institutionalized population, may not adequately reflect the effects of various interventions (Barry & Crosby, 1996). Acutely ill and ambulatory psychotic patients, who are more likely to be included in clinical trials, may perform differently in this respect.

The issue of low concurrent validity, i.e. weak concordance between patients' global assessment of quality of life and clinician's quality of life ratings, has been a recurrent theme in the quality of life literature (Slevin *et al*. 1988). The failure to achieve a higher concordance between subjective and objective quality of life measures may have been due to discrepancies at three levels – conceptualization, reporting and measurement. First, quality of life is much larger and more complex than a simple aggregate of performance and satisfaction in individual areas of life (Bush *et al*. 1982). It has been noted earlier that past experiences and personal characteristics, such as attitudes, aspirations and value systems, can lead to idiosyncratic global quality of life estimates (Campbell *et al*. 1976). Secondly, mentally ill people, similar to the general population, are also prone to a wide array of biases in self-reporting. These are variously known as 'social desirability' (Edwards, 1957; Kozma & Stones, 1987), 'acquiescence' (Couch & Keniston, 1960), 'positive skew' (Cowles & Kubany, 1959) or 'happiness barrier' (George & Bearon, 1980). Appreciating this intricate interplay of issues is useful in understanding the complexities involved in the formulation and expression of subjective quality of life ratings. Thirdly, the lack of concordance between patient- and clinician-rated quality of life could be due to the shortcomings in clinicians' own methods of assessing quality of life. Traditional rating scales or methods of assessing quality of life are unduly preoccupied with objective needs, such as housing and finances, perhaps minimizing the role of subtle subjective attitudes (Lehman *et al*. 1993). Understanding the reasons

for a low concordance between subjective and objective measures, and improving the degree of agreement, should be the research priorities to ensure a wider and meaningful clinical application of quality of life.

These results have immediate implications for clinical researchers and pharmaceutical industry. The study has demonstrated that schizophrenia and antipsychotic drugs do not impair patients' ability to appraise quality of life, lending a qualified support to the notion of using self-report quality of life measures in clinical trials and outcome studies involving schizophrenic patients. Use of descriptive, structured, self-report measures as opposed to simplified, global measures is, perhaps a more sensitive and accurate method of measuring quality of life in this population.

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