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**Judgments of Quality of Life of Individuals With
Severe Mental disorders: Patient Self-Report
Versus Provider Perspectives**

[Regular Article]

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Abstract

Objective: This study was an investigation of judgments regarding quality of life of individuals with severe mental disorders from two different perspectives: patient self-report versus provider. **Method:** Judgments on several dimensions of quality of life were collected from a convenience sample of 37 schizophrenic patients and their primary clinicians by using the well-known Quality of Life Index of Spitzer et al. and the more recently developed Quality of Life Index-Mental Health. Both indexes capture judgments on a number of dimensions. Patterns of concordance for the patient-provider pairs were tested by using Cohen's kappa and Pearson correlation coefficients. **Results:** The results suggest that patients' and providers' judgments are more likely to coincide on clinical aspects, such as symptoms and function, than on social aspects. Specifically, there was moderate agreement on symptoms and function, less agreement on physical health, and little to no agreement on social relations and occupational aspects of quality of life. **Conclusions:** Such differences support the notion that treatment strategies and mental health services should address a wide range of needs reflecting different aspects of quality of life perceived as important by different patients.

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Clinicians, clinical investigators, and policy makers in the field of mental health have recognized that quality of life is an important measure of outcomes in patient management, cost-effectiveness evaluations, clinical trials, and treatment outcome studies. Increasingly, improving quality of life is seen as the major goal in the provision of mental health services [1,2]. In the past two decades, a number of quality of life instruments have been developed for persons with mental illness [3-9]. Unfortunately, there is little consensus about what constitutes quality of life or how to measure it. Quality of life is often defined in terms of subjective perceptions of life satisfaction, happiness, social relations, physical health, and psychological well-being [10-12]. Some researchers, however, have stressed more objective indicators, such as income, quality of housing, and physical function [13]. Still others have focused on ability to function as the key component.

In addition to this conceptual disagreement, the quality of life instruments previously available

for use in mental health settings have another, major limitation. Most of the instruments for assessing quality of life that are used in mental health rely on a single respondent. Either the patient or the clinician is queried, but rarely both. It is obvious that different respondents may have different information and views on the patient's clinical status and life quality. The limitations of the existing quality of life instruments have made it difficult to systematically analyze these differences.

Compounding this focus on a single point of view is the fact that few quality of life instruments cover the broad range of domains that have been shown to be related to quality of life. Assessment areas that are most important to clinicians in judging quality of life might be very different from those judged important by patients, and even among patients there are likely to be major differences about the relative importance of different domains. Ability to work might be most important to one patient, while a sense of physical health and the concomitant absence of medication side effects might be most important to another.

The emerging consensus in the health field that personal values and the patient's preferences are important in monitoring the quality of medical care outcomes makes it even more important to assess both the patient's and the provider's perspectives [14-18]. Quality of life is a personal and subjective value. Therefore, personal values must be incorporated into the measurement of quality of life if it is to reflect individual values and experience. Little is known about patients' values and preferences in mental health. As noted by Ware, "Information from patients about their experiences of disease and treatment is not routinely collected in clinical practice. This information is not part of the medical record, not available for analysis and not part of the health care database" [19]. To incorporate the patient's point of view into medical decisions and into mental health planning, patient values must be accurately measured and quantitatively expressed.

CONCORDANCE BETWEEN PROVIDERS AND PATIENTS

There are two potential kinds of discordance between providers' and patients' views of quality of life. The first discordance occurs when there is disagreement about what is important. For example, the provider may heavily weight ability to function, while the patient may give more weight to a subjective sense of well-being. A different kind of discordance occurs when both parties are judging the same domain but disagree about the measurement. For example, the patient could feel that he is functioning well while the provider may feel that the patient has considerable functional impairment; the discordance thus reflects different reference systems.

These sources of disagreement may be obscured by both researchers and clinicians. It is possible that some providers might implicitly formulate their own judgments of quality of life, which might differ from their patients' judgments. Indeed, one group of researchers has suggested that concordance between medical providers and patients is the exception rather than the rule [20]. This should be no surprise. As Freidson wrote, "The separate worlds of experience and reference of the layman and the professional worker are always in potential conflict with each other" [21]. While this problem has long been recognized, few studies, if any, have addressed it directly as far as judgments of quality of life are concerned. Previous research on concordance between physicians and patients has focused on perceptions of physical health status [22] or on specific aspects of the medical encounter [20]. Few studies have dealt with concordance on quality of life

judgments for patients with mental illness.

One study [23] compared self-reported ratings of life satisfaction with ratings made by trained judges to evaluate the validity of the self-report measure. However, in their conclusion the authors themselves challenged the assumption that the raters' judgments are a suitable criterion against which to judge other instruments. A second study addressed a similar, yet different, problem (2): the authors compared life satisfaction indicators collected through interviews to "objective" life conditions. The subjects were mentally disabled residents living in a board-and-care home, and the objective measurements related to the conditions of the home. All of the statistically significant findings indicated a positive correlation between objective and subjective quality of life measures. The correlations were rather low, however, and the authors suggested that these indicators measured different aspects of quality of life. The paper concluded with the recommendation that interviews, as well as objective indicators, should be used in quality of life assessment. None of these studies, however, directly examined the relationship between judgments of quality of life made by patients and by providers when they were specifically asked to rate the same dimensions of quality by means of similar instruments. The objective of this study was to fill that gap.

DEVELOPMENT OF THE QUALITY OF LIFE INDEX-MENTAL HEALTH

The Quality of Life Index-Mental Health was developed in an attempt to overcome some of the shortcomings of previous instruments. On the basis of previous research, our clinical experience, and recommendations from an advisory board convened to develop the index, we defined quality of life as made up of the following nine domains: 1) life satisfaction, 2) occupational activities, 3) psychological well-being, 4) physical health, 5) social relations, 6) economics, 7) activities of daily living, 8) symptoms, and 9) goal attainment.

The instrument development and its validity and reliability have been described elsewhere [24]. The index contains three separate questionnaires that collect information from the patient, the provider, and the family. Only patient and provider data were collected for this study. While the patient questionnaire collects information on all domains, the provider questionnaire does not gather information on subjective personal views about which the patient is the only source of information. Perceptions of life satisfaction, psychological well-being, and economics are provided exclusively by patients. For both questionnaires, the scoring procedure is hierarchical: first, items (or questions) are scored; second, items within the same domain are aggregated to produce a domain score; third, domain scores are averaged, leading to an overall quality of life score. Thus, within this hierarchy, identical items in the patient and provider questionnaires can be compared, as can domain scores and overall quality scores.

The identical items in the two questionnaires include those from the Quality of Life Index created by Spitzer et al. [25]. This short survey, which has been widely used, is completed by the provider and consists of five specific items, each addressing one of five quality of life domains, and a sixth global item-the "uniscale"-which captures overall judgment of quality of life. The five items cover the five following domains: occupation, function, physical health, social support, and symptoms.

To allow direct comparison of provider and patient judgments, new directions for the Spitzer et

al. scale were created so that it could be self-administered by the patient. The modification was minimal; each of the directions was simply reworded to address the patient directly. For example, while the original version for the provider reads, "During the past week, this person has ..." ("generally felt calm and positive in outlook"; "been having some periods of anxiety or depression"; "generally been confused, frightened, anxious or depressed"), the new patient version reads, "During the past week, you have ..." (same answers as for provider's question).

The first five items of both the provider-administered and the patient-administered scales can be combined into an overall summary measure of quality of life, the quality of life index (ranging from 0 to 10) by simply adding the item ratings. Thus, the Quality of Life Index-Mental Health allows direct comparison of patient and provider ratings on the five specific items of the Spitzer et al. scale, the uniscale, and the following aggregate measures: the five quality of life domains, the Spitzer et al. summary index, and the overall score (average of domain scores).

METHOD

Subjects and Procedure

Local mental health providers known to us recruited a convenience sample of 40 patients who each had a DSM-III-R chart diagnosis of schizophrenia. All were living in the community, all had been ill for some years, and all were judged to have severe illness with substantial ongoing impairment. The study was approved by both the University of Wisconsin and the institutional human subjects review board of the community mental health center where the patients were treated. Patients' and providers' written informed consent statements were obtained after the procedures had been fully explained. The patients and their primary clinicians were asked to independently fill out their respective versions of the Quality of Life Index-Mental Health. Filling out the form required 10-20 minutes for the clinicians and 20-30 minutes for the patients. As part of the study, the clinicians were asked to report on the amount of assistance patients required to complete their questionnaires. A patient's ability to complete the questionnaire was determined in four ways: 1) by the general appearance of the completed questionnaire, which was checked for rote, incomplete, or systematic answering; 2) by examining the patient's Brief Psychiatric Rating Scale item score for thought disorder; 3) by clinician judgment; and 4) by an internal logic check that compared the patient's answers with answers to similar questions that are asked in different parts of the instrument. Most patients were able to fill out the questionnaire with minimal help. Of the first 40 patients studied, one returned a questionnaire too disorganized to be considered reliable and two others had considerable amounts of missing data. Data on the remaining 37 patients are reported in this paper. The majority of patients (N equals 27, 73%) were male; 35 (95%) were Caucasian, and two (5%) were black. Their ages ranged from 25 to 75 years; the mean was 41 years. The average education level was 13 years, and the range was 6 to 16 years. Eleven percent of the subjects were married (N equals 4), 11% were reported to be in common-law living situations (N equals 4), 27% were divorced (N equals 10), and 51% had never been married (N equals 19). The average age at onset of illness was 21 years (range equals 12-29).

Data Analytic Techniques

The objective of the study was to examine the level of concordance between patient and

provider on the five specific items of the Spitzer et al. Quality of Life Index, the Spitzer et al. uniscale, the five quality of life domains, the Spitzer et al. summary quality of life index, and the overall score on the Quality of Life Index-Mental Health. Different statistics were used to estimate the level of concordance, depending on the nature of the variable examined.

As previously described, each item of the Spitzer et al. scale is rated as an ordinal variable from 0 (low or poor) to 2 (high or good). The pairs of responses for each item were arranged in a two-way contingency table, and the patient and the provider were considered to agree on a given item if both assigned the same rating to it. For such variables, three measures of concordance were calculated: percentage agreement, Cohen's kappa, and weighted kappa [26]. To interpret the strength of agreement, we followed the guidelines proposed by Landis and Koch [27], so that a kappa value between 0 and 0.20 indicated "slight" agreement, a value between 0.21 and 0.40 indicated "fair" agreement, and a value between 0.41 and 0.60 indicated "moderate" agreement.

Since the uniscale is a 10-point scale, we used a Spearman rank-order correlation coefficient to examine concordance between patients and providers. All other variables consisted of the normalized aggregated ratings of their constituent items. The number of items included in the five patient domains in this study ranged from two (for the symptom domain) to seven (for the occupation domain). The number of items included in the five provider domains in this study ranged from two (for the occupation domain) to 35 (for the symptom domain). Because of the different numbers of items in the domains, comparison of patient and provider scores on these domains is not as directly meaningful and interpretable as the comparison of scores on individual items. Corresponding patient and provider domains may indeed measure not only different perspectives but, more important, different aspects of quality of life. For these variables, Pearson correlation coefficients were calculated to measure the linear association between patients' and providers' ratings. In addition, for the five quality of life domains, t tests of the difference between patient and provider means were performed to examine differences in the ratings of these dimensions.

RESULTS

(Figure 1 shows contingency tables for the function and social support items of the Spitzer et al. scale. As can be seen in the ratings of function, most pairs (N equals 23, 66%) fell on the diagonal, indicating perfect agreement between these pairs of patients and providers. On the other hand, for social support only 15 (42%) of the pairs fell on the diagonal. A fair proportion of patients (17%, N equals 6) rated their social support as high, while their providers rated it low. Fewer patients (8%, N equals 3) rated their social support low while their providers rated it high. The percentage agreement, the Cohen's kappa, and the weighted kappa are reported in Table 1 for all five of the items on the Spitzer et al. scale.

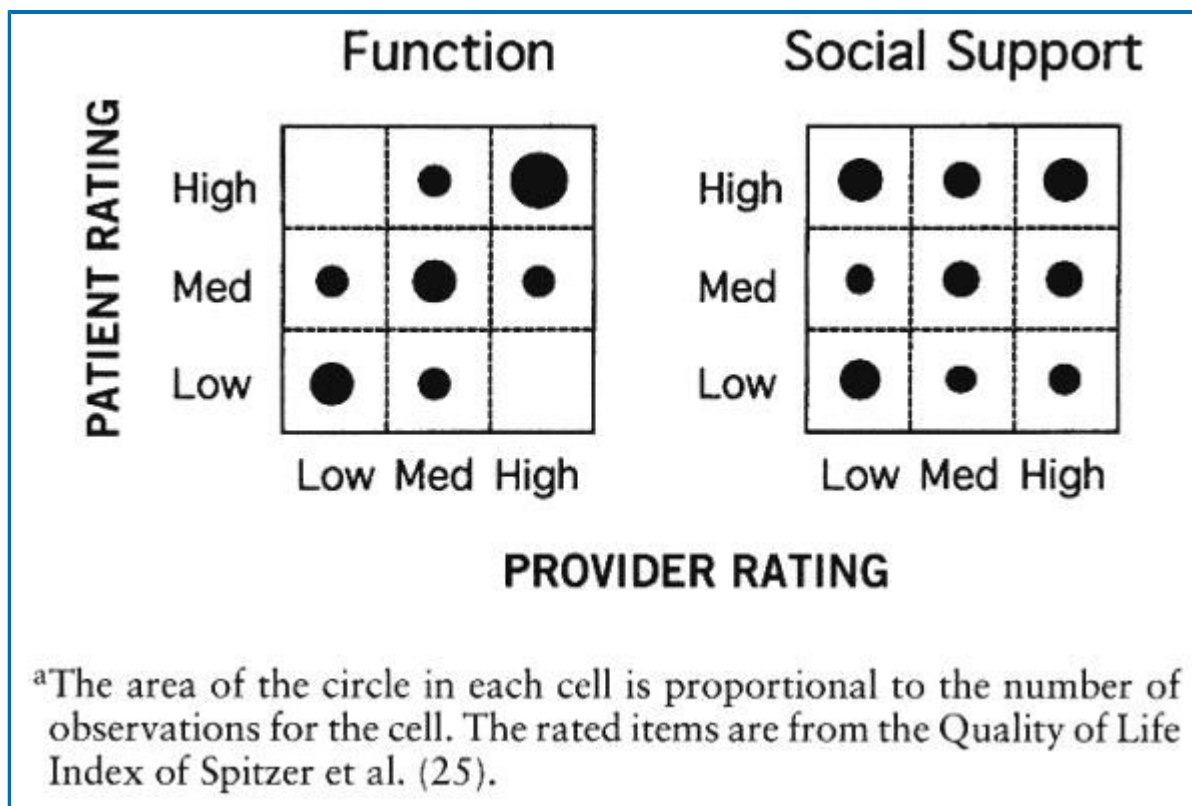


Figure 1. Overlap in Patients' and Providers' Ratings of Function (N equals 35) and Social Support (N equals 36) for Individuals With Severe, Chronic Schizophrenia sup a

Domain	Percentage Agreement	Cohen's Kappa		Weighted Cohen's Kappa	
		Kappa	SD	Kappa	SD
Occupation	44.4	0.08	0.12	0.14	0.15
Physical health	56.8	0.32	0.12	0.43	0.11
Social support	41.7	0.12	0.12	0.10	0.14
Function	65.7	0.48	0.12	0.60	0.10
Symptoms	63.9	0.43	0.12	0.43	0.13

^aThe rated items are from the Quality of Life Index of Spitzer et al. (25). The number of subjects varied among domains.

Table 1. Three Measures of Agreement Between Patient and Provider Ratings of Quality of Life Domains for 37 Individuals With Severe, Chronic Schizophrenia^a

The data suggest that patients and providers agree moderately on assessment of function and symptoms, agree only fairly on physical health, and slightly agree on occupation and social support. For the Spitzer et al. uniscale, the Spearman correlation coefficient was 0.32 and was only significantly different from zero at the 0.10 level. Thus, the level of agreement between patients and providers on quality of life as measured by a global question was low.

Pearson correlation coefficients for the relation of patient and provider scores, as well as p

values, were calculated for each of the five common domains. The patient and provider ratings of physical health were not significantly correlated (r equals 0.15, df equals 35, p more than 0.10). The ratings of occupation (r equals 0.30, df equals 35, p less than 0.05), social relations (r equals 0.24, df equals 35, p less than 0.05), and symptoms (r equals 0.36, df equals 35, p less than 0.01) were slightly correlated. The ratings of activities of daily living (r equals 0.55, df equals 35, p less than 0.001) were moderately correlated. In addition to examining correlations, we investigated differences in the mean ratings of these five domains between patients and providers. These results are shown in Figure 2.

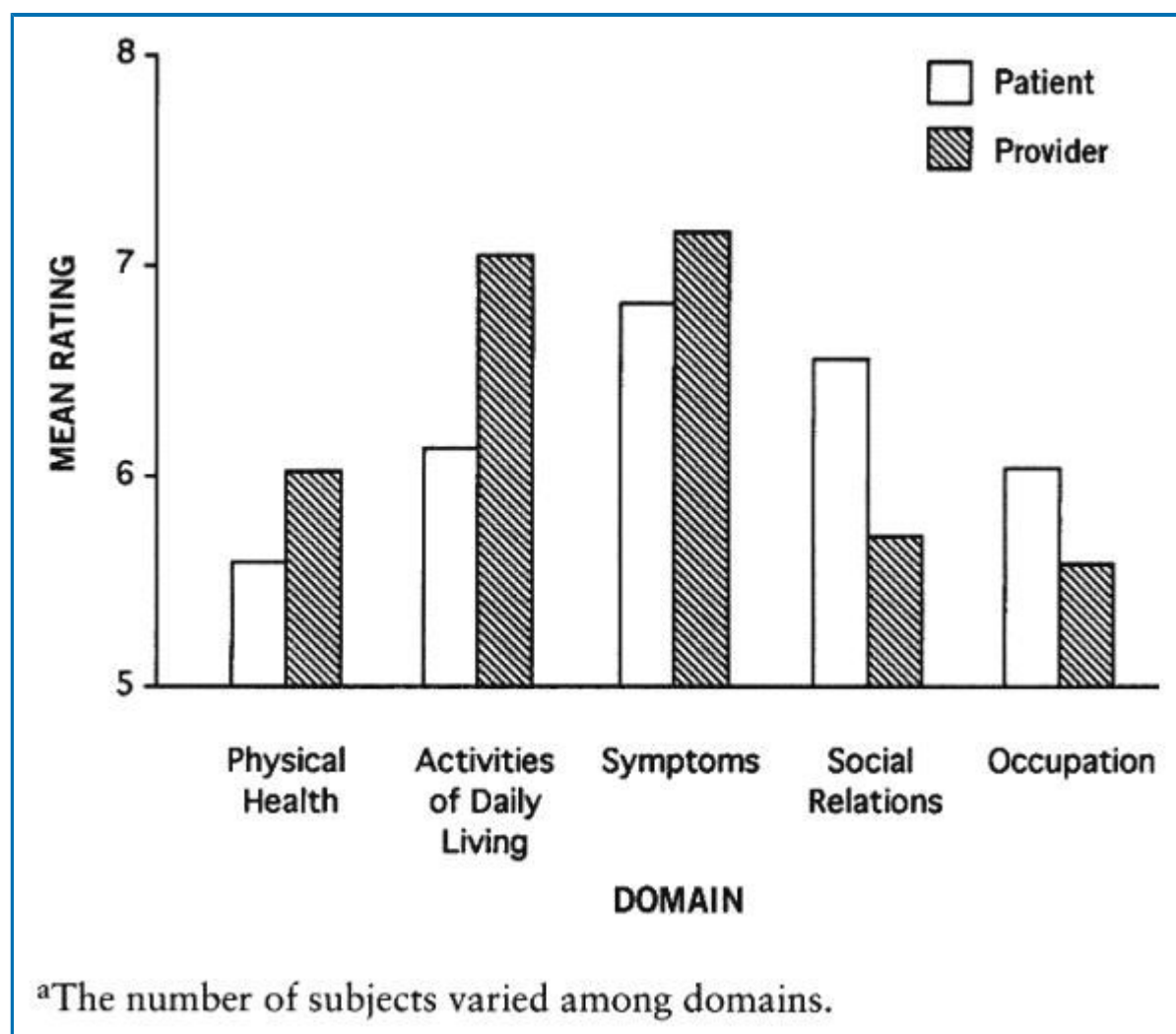


Figure 2. Patients' and Providers' Mean Ratings of Quality of Life Domains for 37 Individuals With Severe, Chronic Schizophrenia^a

The mean ratings of the providers for physical health, activities of daily living (function), and symptoms were higher than those of the patients, and the providers' mean ratings for occupation and social relations were lower than the patients' ratings. However, a t test of the difference between means for each domain showed a significant difference between mean ratings at the 0.10 level for two domains only: activities of daily living and social relations. Since we found a moderately high correlation for activities of daily living, it seems that providers rate function higher than patients do in a systematic fashion. On the other hand, while the overall rating for social relations was higher for patients than for providers, we found a low correlation; thus, no such

systematic over- or underrating seemed to occur for this domain.

The ratings of quality of life domains, by both patients and providers, can be further aggregated into an overall score, the Quality of Life Index-Mental Health score. Similarly, the five specific items on the Spitzer et al. scale can be aggregated into an overall score, a quality of life index. These indexes, containing many items, are called "megavariable" indexes [28]. Thus, at a higher level of aggregation we can examine correlations and differences between the corresponding patient and provider scores. The Pearson coefficients for the correlations between patient and provider scores were moderately high, 0.51 (df equals 34, p less than 0.001) for the Quality of Life Index-Mental Health and 0.47 (df equals 34, p less than 0.005) for the Spitzer et al. quality of life index. The patients' mean rating on the Quality of Life Index-Mental Health was 6.23 (SD equals 1.58), and the providers' mean rating was 6.31 (SD equals 1.30), while the quality of life index scores were 5.86 (SD equals 2.75) and 5.92 (SD equals 2.71), respectively. A t test of the difference between means showed no significant difference at the 0.10 level for either index. Thus, at a high level of aggregation, ratings of quality of life by patients and providers are moderately correlated and at the same level on average. However, this moderate correlation is not extremely informative, since, as suggested by Feinstein [28], "megavariable indexes may be quite satisfactory for denoting the average ratings of a group, ... but they are seldom satisfactory for individual patients, because the main focus of clinical concern or management may be lost, obscured, or not included among all the information that surrounds it." This level of correlation between megavariable indexes of quality of life can be contrasted with the lower correlation between the direct ratings of quality of life on the individual items of Spitzer et al. and the uniscale, as discussed earlier. The uniscale is a global index in the sense that one single global item is used to measure a multidimensional concept, such as quality of life.

DISCUSSION

Clinicians often perceive symptoms to be the major indicator of patients' well-being. While this study shows that there is moderate agreement between providers' and patients' assessments of symptoms, it also shows that there is little agreement on other dimensions of well-being. This is important since it is increasingly accepted that treatment strategies need to address more than symptoms and should be designed to improve all aspects of patients' quality of life. Given that different dimensions of well-being should be evaluated, the issue of whose perspective should be considered in making treatment decisions still remains. The results of this study show that the perspectives taken may lead to significantly different judgments and therefore potentially different preferences for treatment strategies and therefore potentially different treatment interventions. Another important issue that needs to be investigated to fully capture preferences is the relative importance of the different dimensions of well-being. Differences in importance would suggest the need for prioritizing different services.

Our study data suggest that patients' and providers' judgments are more likely to coincide on clinical aspects of quality of life than on social aspects of quality of life. While the level of congruence between patients and providers is relatively high for symptoms and function and moderate for physical health, patients' and providers' judgments substantially differ for occupation and social relations. Overall, providers tended to rate social support and occupation low while patients rated them high. Reasons for such differences may include patients' greater knowledge of

their own social support and occupational functioning. Alternatively, clinicians might focus on clinical aspects because of their own expertise and skills in managing symptoms, function, and physical health, while patients, experts on issues such as their social relations and occupational activities, focus on these aspects. It also may be that patients do not focus on disease-related aspects because of a presumed lack of control or expertise while clinicians do not focus on social support and occupation for similar reasons. Alternatively, it may be that patients adapt to their symptoms and discount them or use a different yardstick when reporting the symptoms' magnitude. It should also be noted that the extent to which a provider is knowledgeable about a particular patient may be important in patterns of agreement between judgments. Furthermore, these particular findings are specific to a small group of individuals with severe mental disorders and may not necessarily apply to patients suffering from nonpsychotic disorders.

In addition to these specific findings, we observed an increase in concordance between the patients' and providers' ratings with increasing aggregation of the measures of quality of life. The multivariable indexes of quality rated by the patients and providers were correlated at higher levels than were the specific items within the indexes. Tantam [29] suggested that the advantages of multivariable indexes include the ability to either use the assessments as a profile of scores, indicating relative strengths and weaknesses, or combine them for an aggregate score. The disadvantages are that oversimplification of the construct may occur and the differences between individual items are lost. Thus, multivariable indexes lose in specificity what they gain in reliability and face validity.

Furthermore, it is also important to note that, while the providers' and patients' judgments of function correlated, the patients and providers had significantly different mean judgments of function. The providers systematically rated function higher than the patients did. This was not apparent on the function item of the Spitzer et al. scale, since the item provides for only three possible answers. On the other hand, it was apparent on the function domain of quality of life, which is a continuous scale made up of a number of items. While this may not pose a major problem regarding group averages, in the case of clinical management of individual patients clinicians need to be aware of their potential for overrating patients' function. Similarly, although we did not find it significant in this study, overrating may also exist for judgments of physical health and symptoms. In addition to disagreement on judgments of occupation and social relations, we found a significant difference in the mean ratings of social relations between providers and patients. In this case, however, the clinicians' judgments seemed on average to underrate the patients' judgments of social relations and occupation. Future research is necessary to further explore and understand such patterns.

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