A New Patient Focused Index for Measuring Quality of Life in Persons with Severe and Persistent Mental Illness
Author(s): M. Becker, R. Diamond, F. Sainfort
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A new patient focused index for measuring quality of life in persons with severe and persistent mental illness

M. Becker,* R. Diamond, and F. Sainfort

Center for Health Systems Research and Analysis, University of Wisconsin-Madison
WARF Building, 610 Wainut Street, Madison, WI 53705, USA (M. Becker, F. Sainfort);
Department of Psychiatry, University of Wisconsin-Madison, Clinical Science Center,
600 Highland Avenue, B6/212, Madison, WI 53792, USA (R. Diamond).

The quality of life in persons with severe and persistent mental illness is often poor. Most treatment programmes have the goal of increasing quality of life. Unfortunately, existing methods to assess qualtiy of life are cumbersome and oriented towards research rather than clinical settings. This study describes preliminary steps in the development, testing and application of a new patient focused index for measuring quality of life in persons with severe mental illness. The Quality of Life Index for Mental Health (QLI-MH) differs from existing instruments in that it is based on an easy to use, self-administered questionnaire that assesses nine separate domains that together encompass quality of life. Each domain can be individually weighted depending on its relative importance to the patient. Different parts of the instrument solicit information from the patient, the primary clinician and, when available, the family. The instrument and its scoring system address limitations of previous approaches to quality of life measurement.

Key words: Mental health, schizophrenia, mental illness and quality of life.

Introduction

Quality of life (QOL) has become an increasingly important concept in assessing clinical change in persons with severe and persistent mental illness. This increased attention is due in part to the inadequacies in the customary measures of treatment outcome. The two most commonly used outcome measures, rates of hospital recidivism and psychiatric symptomatology, are easy to determine and seem to be reasonable markers of improvement, but both have major problems.

Hospital recidivism has as much to do with characteristics of the mental health system as with the clinical status of the individual, and symptoms are a surprisingly poor measure of either how well someone is able to function or how they feel about their life.[1-4] Equally important, most community-based treatment programmes have the stated goal of improving quality of life. Treatment programmes have shifted their aim from elimination of disease to maintenance of functioning and increasing patients' quality of life.[5-7] Compliance may be influenced by patient perceptions about whether treatments increase or decrease their quality of life.[8] Finally, regulatory authorities increasingly require assessment of quality of life for everything from approving new medications to funding of new programmes.[9,10]

Unfortunately, there are major problems with existing instruments available for the clinical assessment of QOL in persons with serious and persistent mental illness. An instrument is either limited in the domains of QOL that are assessed, or is so cumbersome that it is more appropriate for research rather than clinical settings. Furthermore, there is disagreement about what should be included in a QOL assessment and how the different parts of an instrument should be weighted to obtain a global QOL assessment. Finally, most QOL instruments rely on information from a single responder, making validity a significant concern when the patient, clinician and family may all have very different kinds of information, perceptions, or evaluations of particular domains. This paper presents the development and preliminary field testing of a new patient-focused measure of QOL which is responsive to the needs and constraints of clinical practice and research.

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* To whom correspondence should be addressed

Rationale for a new index

In the past two decades, several QOL instruments have been developed for persons with mental illness.[11-17] However, each of these measures have major limitations in both general strategy and in application to patients with severe and persistent mental illness. Furthermore, few of the available measures were developed with careful attention to principles of test construction or with patient input.

Measurement strategies have been inadequate

There is little consensus regarding domain content for QOL assessment and the appropriate method of aggregation or scoring for domains. Existing scoring systems do not allow for cultural diversity or reflect the fact that various aspects of life are not equally important to everyone. Giving equal weight to different individual domains implicitly assumes that all the domains have equal value. This method of aggregation does not allow for the fact that patients' needs, values and the importance they ascribe to them may change with time, age, level of illness, or culture. By failing to allow patients to evaluate separately the importance and level of satisfaction of each domain, available instruments miss important information. Lack of agreement about QOL assessment methods can be attributed in part to differing views about what is important to patients,[18] the aims of the researchers involved, and different opinions about the appropriate roles of patients and their families.[19]

Approaches have been restrictive

Many QOL assessment instruments used in mental health rely on a single respondent. Either the patient or the clinician is queried, but rarely both. Families are even less often solicited for information about quality of life. This is unfortunate as different respondents may have very different information and views of the patient's clinical status and life quality. Existing instruments generally do not allow patients to speak for themselves and they usually avoid the use of open-ended questions. Informal caregivers' responses regarding patients QOL have usually not been elicited. Most researchers have preferred QOL interviews of patients to self-administered questionnaires because of an underlying assumption that patients with severe mental illness cannot reliably complete these questionnaires. This bias has not been examined and probably applies only to a small subset of the mentally ill population.

The quality of life mental health index (QLI-MH)

In developing the Quality of Life Index for Mental Health (QLI-MH), we have tried to address the major limitations of existing measures. Following Ferrans,[20,21] we define quality of life as 'a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her.' We conceptualize QOL as a complex, multidimensional construct that includes both subjective (ie. patient-rated) and objective components. Instead of trying to reduce this complexity and assess QOL with a single scale, the QLI-MH instrument assesses nine different domains or content areas. To incorporate input about patient values each domain is weighted according to the patient's evaluation of its importance. Having separate domains for important areas of life quality allows the interrelationship between QOL components such as symptoms and function, or physical, psychological, and social domains to be explored. In our view, individual weighting is necessary because a statistical aggregation of conventionally agreed indices with predetermined weights will not produce an accurate representation of the patient's life quality or allow for an understanding of the process underlying change in functioning and quality of life at the patient level.

Methods

Index development

The QLI-MH index was initially developed to enhance a cost–effectiveness study of clozaril for persons with treatment-resistant schizophrenia. The goal of that project was to expand the clorazil treatment outcome evaluation beyond a simple pre-post analysis of cost and symptom reduction to an evaluation that included the effects of treatment on quality of life and caregiver burden. We also wanted to develop a means of evaluating patient change over time and to examine the inter-relationship between different components

of quality of life. At the same time, we wanted our new index to be useful to clinicians and practical to administer within the staffing constraints of a typical mental health centre.

In keeping with the recommendations of other researchers,[22] we decided to use patient self-report QOL information as the core of the instrument. Family and clinician assessments are used to supplement patient reports, examine discrepancies between patient and caregivers and assess family burden. To help ensure adequate validity of the index we used a combination of empirical item derivation/refining strategies and theoretical approaches to item selection. When possible, we adopted scales already in use with known psychometric properties and reliability. Domains for the QLI-MH index were identified in earlier research as important to an understanding of quality of life[23-30] and information in some of the domains has been shown to be predictive of outcome in schizophrenia.[31,32] Candidate questions for the new index were reviewed by a research advisory group that included patients, family members and mental health professionals. To assure that the QLI-MH index was culturally sensitive we sought additional review and consulation from African–American and Hispanic clinicians at the Medical

University of South Carolina and University of Puerto Rico. The review groups were asked to help ensure that each question met Feinstein's criteria for scale development including sensibility, consistency, sensitivity, suitability for diverse populations, and potential to measure meaningful change.[33]

Index description

The measurement model of the QLI-MH allows information to be collected from multiple points of view, over multiple periods of time, organized within multiple separate domains. This allows the QLI-MH index to present a rich picture of each individual (Figure 1).

The nine domains of the QLI-MH include: (1) satisfaction level for different objective QOL indicators; (2) occupational activities; (3) psychological well-being; (4) physical health; (5) social relations; (6) economics; (7) activities of daily living (ADL); (8) symptoms; and (9) goal attainment. Each of these domains is discussed in more detail below. Sample questions from each domain are shown in Table 1. The QLI-MH index contains separate questionnaires for the collection of information

Q_{ij} = Evaluation of a particular domain with respect to a particular responder.
Q_i = Evaluation of domain across time.
Q_j = Evaluation across domains.
$Q_{..}$ = Evaluation of Quality of Life as a whole (perceived QoL).
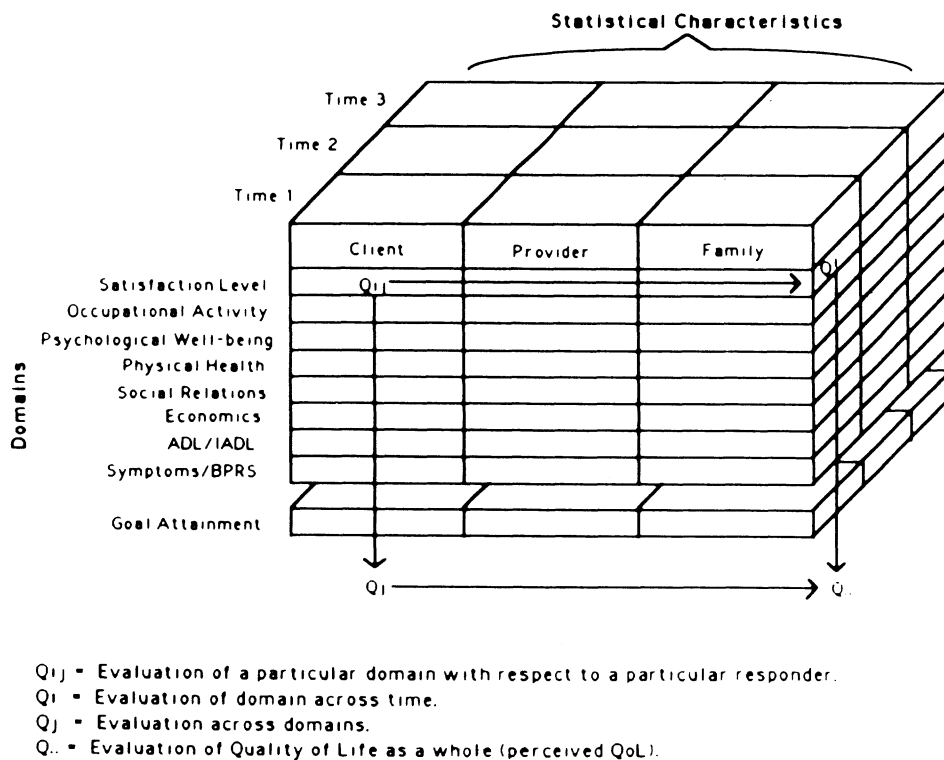
Figure 1. Measurement model for evaluating quality of life.

Table 1. Sample Questions for Domains

Domain	Question and response options
Satisfaction Level (10 questions)	How satisfied are you with the way you spend your time? □ Very dissatisfied □ Moderately dissatisfied □ A little dissatisfied □ Neither satisfied nor dissatisfied □ A little dissatisfied □ Moderately dissatisfied □ Very dissatisfied
Occupational Activities (6 questions)	Do you feel you are working or are in school... □ Less than you would like □ As much as you want □ More than you would like
Psychological Well-Being (12 questions)	In the past six months, would you say that your mental health has been: □ Poor □ Fair □ Good □ Very Good □ Excellent
Physical Health (12 questions)	In the past year, would you say that your physical health has been: □ Poor □ Fair □ Good □ Very Good □ Excellent
Social Relations (5 questions)	How do you feel about how you get along with other people? □ Very dissatisfied □ Moderately dissatisfied □ A little dissatisfied □ Neither satisfied nor dissatisfied □ A little dissatisfied □ Moderately dissatisfied □ Very dissatisfied
Economics (2 questions)	How do you feel about the amount of money that you have? □ Very dissatisfied □ Moderately dissatisfied □ A little dissatisfied □ Neither satisfied nor dissatisfied □ A little dissatisfied □ Moderately dissatisfied □ Very dissatisfied
Activities of Daily Living (24 questions)	During the past week, you have: □ not been managing personal care and/or not leaving home or institution at all □ been requiring assistance for daily activities and transport, but performing very light tasks □ been self-reliant in daily tasks; using public transport or driving
Symptoms (36 questions)	Since you have been taking your medication, how have your symptoms been? □ Substantially worse □ Much worse □ Somewhat worse □ No change or same □ Somewhat better □ Much better □ All better
Goal Attainment (6 questions)	What did you hope to accomplish as a result of your mental health treatment? Goal 1: _____ Goal 2: _____ Goal 3: _____

from the client, clinician and family. This allows different points of view to be represented in our measurement model. In addition to a total score, the QLI-MH produces subscale scores for each of the domains.

Satisfaction level. Life satisfaction has been extensively studied. Research shows that people respond to QOL questions with a discussion of life satisfaction, therefore satisfaction has been interpreted by some to be synonymous with QOL.[24,25] The items in the QLI-MH client's satisfaction domain are the same 15 indicators of life quality validated and used by Andrews and Withey.[24] Items cover a broad array of issues and refer to such things as the client's satisfaction with their living environment, housing, amount of fun, food, clothing, and mental health services.

Each indicator is rated on an ordinal scale ranging from 'very dissatisfied' to 'very satisfied'. Each indicator is also rated for importance on a scale ranging from 'not at all important' to 'extremely important'. Five response categories are used in the importance scale to maintain meaningful distinctions between response categories. An odd number of response categories is used throughout the index so that responders will not be artificially forced by the scale to respond in a positive or negative direction. The score for each item is determined by multiplying each patient's satisfaction response with the importance response. Values for component items are then summed to obtain the domain score.

The index also includes a global question for rating feeling about life as a whole. Responses are made on a seven-point scale ranging from 1 (very unhappy) to 7 (very happy). Although simplistic, and not sufficient to measure the complex construct of QOL, this global question documents beliefs of the individual about overall QOL and serves as a reference check for the QOL total score.

Occupational activities. Six questions are devoted to patients' work, school, or day programming. A sample question from this domain is: 'Do you feel you are working or are in school. . . less than you would like; as much as you would like; more than you would like?' Other questions in this domain relate to patients' capacity to work in their usual manner and to the type of occupational activity they have.

Psychological well-being. The domain contains individual questions relative to patients' sense of

emotional well-being. We have included the Bradburn Affect Balance Scale (ABS) within the QLI-MH.[34,35] The ABS is a widely used and well validated scale that has been used by other researchers attempting to operationalize and study psychological well-being.[34] The ABS includes separate assessments of negative and positive affect. It seemed particularly important to include this because of research data and theoretical speculation suggesting an association between negative affect, health complaints, and perceived life satisfaction.[36] The information about positive and negative affects can be used to investigate the possible confounding effects of affect on quality of life assessment. In addition to the ABS, the patient is asked to rate their mental health on a scale ranging from poor to excellent, and how they feel about what they do for fun.

Physical health. Questions in this domain ask about patients' perceptions of their physical health. For example, patients are asked to rate their physical health in the past year on a 5-point scale from poor to excellent. Another question asks responders to rate their physical health in the past week. Although physical health has often been measured by a combination of diagnostic, descriptive, and functional information related to patients' ability to perform self-care activity, in the QLI-MH index health-related functional information and evaluation of patients' basic living skills are specifically addressed in the Activities of Daily Living (ADL) domain. Because self care and ability to function independently are such crucial areas of concern for persons with severe mental illness, we decided that ADL evaluations warranted their own domain.

Activities of daily living (ADL). After reviewing the strengths and weaknesses of a large number of instruments developed to assess ADLs we decided to incorporate the entire Life Skills Profile (LSP) developed by Rosen *et al.*[14] The LSP was tested in a large sample of subjects with schizophrenia. Research data show this scale to be reliable and sufficiently sensitive to detect clinically significant differences in patients' functioning. The LSP was incorporated into the QLI-MH provider questionnaire. Specific psychometric properties and data regarding the validity and reliability of the LSP are reported elsewhere.[14]

To obtain additional information on functional status we also incorporate the QL-Index developed

by Spitzer *et al.*[37] This index has been extensively tested with a variety of populations including patients with mental illness. The QL-Index has been shown to produce a reliable and valid assessment of persons' activity and response to serious illness.[38] The QL-Index consists of five questions which have 3-point responses each scored as 0 (activity essentially absent), 1 (activity partially present), and 2 (activity fully present). The QL-Index was originally designed for providers, so the instructions have been modified for patient self-administration.

In the family questionnaire we included questions about the amount of ADL assistance required by the patients from family or significant others and ask caregivers about their feelings in relation to providing the needed assistance. Elicited information can be used to measure patients' need for caregiver assistance, to monitor changes in the level of assistance required, as well as assessing caregivers' feelings about providing that assistance.

Social relationships. Social relations and social skills have been deemed essential to the determination of clients' QOL.[32] These are often affected by severe mental illness and are areas where patients typically need assistance. Given the fact that much psychiatric rehabilitative work is oriented toward improving patients' social relationships, this domain has particular importance for mental health research. For the index we define social relationships as active participation with others. However, we have included questions in the questionnaire which cover activities that take place in a social context but may or may not represent social relatedness (i.e. going to a movie or participating in a sport). These questions will be analysed separately to evaluate their importance to patients but are not included in the domain score.

Items in the social relationships domain build on earlier research[31] and on the ground-breaking work of the International Pilot Study of Schizophrenia (IPSS). Specifically, the index includes the entire IPSS outcome scale related to frequency and type of social contact.[32] Because the IPSS questions about social contact do not assess how the responder experiences the social event, we have added two questions that specifically ask responders to rate the amount of support they experience from their relationships (see Table 1) and about the patients' perceived satisfaction with their social relations.

Economics. Socioeconomic status is an important variable in mental health research and is predictive of outcome in schizophrenia.[39,40] It has been hypothesized that lack of money and other material resources may be associated with lowered QOL because poor people are subject to more environmental stressors and have fewer resources to enable them to cope.[41] Domain questions ask about the adequacy of patients financial support and about their satisfaction and the importance of the amount of money they have.

Symptoms. We have incorporated the 24-item Brief Psychiatric Rating Scale (BPRS) developed by Overall and Gorham[42-44] into the provider questionnaire to measure patients' level of symptomatology. The BPRS has been shown to be a reliable and valid measure of patients' psychiatric symptomatology.[42-44] It is one of the most widely used symptom scales in schizophrenia research. Because the BPRS was used in initial clinical trials of clozaril and is frequently used in drug trials, this scale has particular value for cost–effectiveness evaluations. The symptom domain contains two additional global questions: one question asks patients to rate the overall severity of their symptoms and a second global question concerns side-effects from antipsychotic medication.

Goals for improvement with treatment. It has been noted that patients' opinions and human concerns are particularly important when an instrument is intended to measure QOL.[45] Patients' humanistic assessments are thought to be important because 'symptoms and other clinical problems and functional capacity are usually the main goals of patients seeking clinical care'.[46] Previous researchers have documented the importance of personal goals to psychological functioning[47] and Diamond[8] has emphasized the importance of patients' treatment goals to medication compliance and quality of life. Surprisingly, despite evidence documenting the importance of patients' preferences and goals for improvement with treatment, few existing QOL measures assess patients' and families' treatment goals or the degree to which patients believe they are achieving their goals.

In the QLI-MH we use an open-ended strategy that provides for evaluation of patients', providers', and families' goals for improvement with treatment. Family members and clinicians are asked to specify the three most important goals for the patient's improvement with treatment. Goals

are ranked on two ordinal scales. The first scale rates the relative importance of the goals from 1 'not very' to 3 'extremely important'. The second scale rates the extent to which the responder feels their goal has been achieved. Responses are ranked from 1 'not at all achieved' to 3 'completely achieved'.

Scale scoring

Separate scales for each domain are derived for the patient and the provider. A similar scoring strategy is used for the family instrument, although family data for this pilot set of subjects has not been collected. For existing scales (such as BPRS, ABS, LSP, SLDS, QL-Index, Uniscale, IPSS, QL-Index), we followed the scoring methods defined by the corresponding developers of these scales. For the purpose of creating the QLI-MH score, the scoring methodology consists of three steps: (1) rescaling each item, (2) aggregating items within a domain, and (3) aggregating domains to produce a final score.

The first step is necessary since each domain contains a number of items and each item is scaled and numerically coded using different response categories. Thus, each item is rescaled on a common scale through a linear transformation, assuming that each scale is an interval scale with equivalent endpoints. Therefore, the items used in any given domain correspond to questions for which the response categories can be meaningfully ordered from low to high (contribution to) QOL. A number of items have to be reversed before being linearly transformed. Once all items in a domain have been properly rescaled, the second step consists of aggregating the items together through a simple arithmetic average. The domain score produced is thus itself in terms of the same common scale. Finally, the domain scores themselves are simply averaged out to produce a final QLI-MH score. The scoring strategy that has been adopted here is the simplest one. As more data will become available, different and more elaborate scoring methods will be tested including weighting the relative importance of the different domains. The following tests and analyses have been carried out with this simple strategy.

Change in QOL across time and in response to treatment is evaluated by comparing scores from one point in time to another (see Figure 1). The resulting scores can be used to monitor clients'

progress or response to interventions, and they can be used in cost–effectiveness analysis relating costs to specific outcomes. Our scoring method provides for ongoing examination of the associations between domain specific functioning and overall QOL. This scoring method allows for the determination of what, if any, clinical significance can be assigned to overall and domain specific QOL scores.

As noted earlier, patients' needs and the importance of those needs may change. By providing patients with an opportunity to separately evaluate both the importance, and the level of satisfaction of each quality of life area, the QLI-MH identifies information that is potentially useful to clinicians. The index can be used by clinicians to pinpoint problem areas where clients have important needs that are not satisfied, that change with time, different cultural values, circumstance, or level of illness. Documenting patients' unmet or changing needs is helpful because patients' unmet needs may lead to client distress, increased morbidity, and lowered QOL (Figure 2). This scoring feature increases the utility of the QLI-MH for clinical practice.

Initial field testing

The QLI-MH index was field tested for providers and patients by using local mental health providers known to the authors. These clinicians recruited a convenience sample of 40 patients who met the Diagnostic and Statistical Manual of Mental Disorders third edition revised (DSM-III-R)[48] criteria for schizophrenia. In addition to recruiting patients and obtaining their informed consent, clinicians completed the provider questionnaire and reported on the amount of assistance required by patients to complete their questionnaire. Patient reliability in completing the questionnaire was determined (1) by the general appearance of the completed questionnaire which was checked for rote, incomplete, or systematic answering; (2) by examining the patient's BPRS item score for thought disorder; (3) by clinician judgement; and (4) by an internal logic check which compares the patient's answers to similar questions that are asked in different parts of the instrument.[49]

If a patient is thought to be unable to complete the questionnaire himself, he is interviewed and the patient questionnaire is completed as fully as
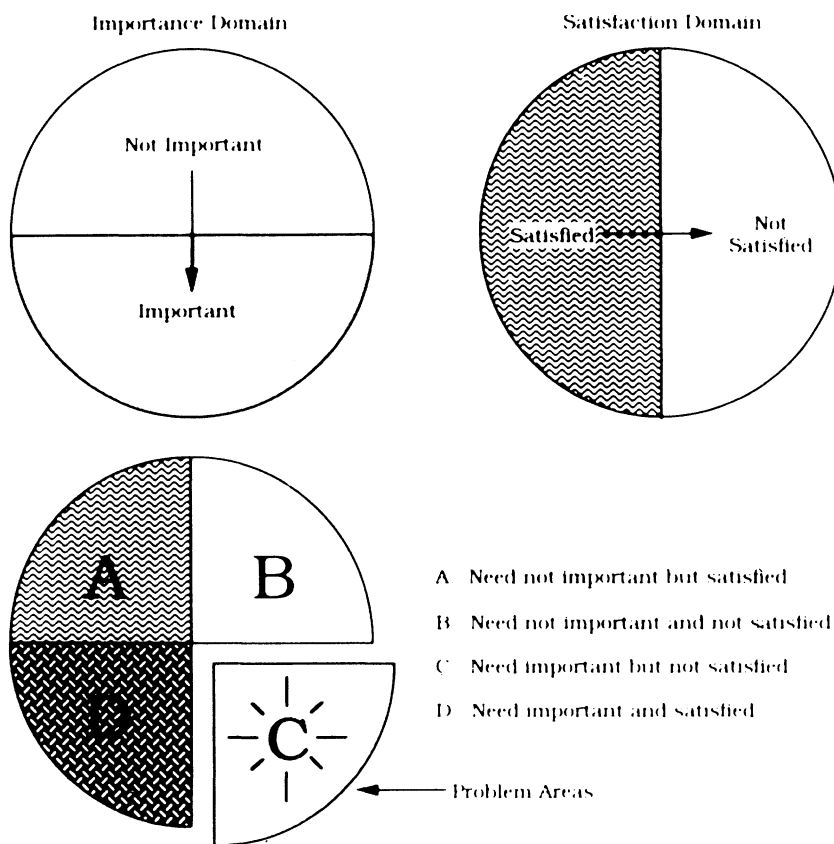
Importance Domain   Satisfaction Domain

A   Need not important but satisfied

B   Need not important and not satisfied

C   Need important but not satisfied

D   Need important and satisfied

Problem Areas

Figure 2. Needs matrix.

possible by the clinician most familiar with that person. We note that for patients who are actively and severely psychotic, information obtained in an interview is as difficult to use as self-administered self-report information. When the QLI-MH index is used, parallel information elicited with the clinician and family questionnaires can be used to supplement patient reports and to estimate patients' QOL status when patient self-report information is unusable.

Results

Patient characteristics

The majority (29, or 72%) of patients were male; 38 (95%) were Caucasian and two (5%) Black. The mean age of patients was 41 years, and average education was 13 years. Eleven per cent of subjects were married, 10% were reported to have a common-law partner, 27% were divorced and 52% had never married. The average age at onset of illness was 21 years. Twenty-three patients were

receiving clozaril and the remaining 17 were receiving other types of antipsychotic medication.

Efficacy

Patient and provider questionnaires were completed for the 40 patients recruited for the study. In general, providers required 10–20 min and patients required 20–30 min to complete the questionnaire. As would be expected, the amount of assistance required by patients varied with their degree of disorientation and attention span. In the first series of 40 assessments one client was determined to be too disorganized to answer the questions reliably and two patient questionnaires were returned with missing data, leaving 37 completed provider and patient questionnaires for analysis. The majority of patients were able to complete the questionnaire with only minor encouragement. Clinicians generally reported a favourable response to the questionnaire. Several clinicians said they felt the information elicited with the QLI-MH index would be helpful in their clinical work with patients.

Validity and reliability

Although it includes a number of existing valid and reliable scales, the QLI-MH index is a new empirically grounded indicator that has to pass several evaluation tests before it can be used for a variety of empirical studies. At least two important properties are necessary for such empirical measurements: validity and reliability. In a very general sense, the index is valid if it does what it is intended to do. Furthermore, the index is reliable if it yields the same results on repeated trials. According to Carmines and Zeller[50] there are three basic types of validity: content validity, criterion-related validity, and construct validity.

Content validity refers to the extent to which an empirical measure covers the domain of content of the theoretical concept. In order to ensure content and face validity in this study we based the development of the model on a comprehensive model of quality of life that includes multiple dimensions of quality as well as multiple perspectives on quality life (see Figure 1). Furthermore, both consumers and professionals considered to have expertise and extensive experience with persons suffering from severe and persistent mental illness were involved in the development, definition and choice of items and/or scales to be included to represent these multiple dimensions of quality of life. Finally, to the extent possible, existing valid scales were chosen to capture some aspects of the various domains and dimensions of quality of life.

Existing scales were included in their entirety in the instrument with no change in either the question or the respose categories. These scales include the BPRS, ABS, LSP, SLDS, QL-Index, Uniscale and IPSS. The Spitzer QL-Index[37] developed for the provider, has been reworded with minimum changes in the instructions directing the provider to answer the question from a patient's perspective. The response categories, however, are unchanged. We believe that a satisfactory level of content validity has been ensured by the development process itself. However, it should be recognized that it is never possible to determine the specific extent to which an empirical measure is considered content valid.

Criterion-related validity represents the degree of correspondence between the measure and a criterion variable. There are no known criterion variables against which the QLI-MH index can be compared to establish criterion-related validity. In effect, one of the objectives of this study is precisely to develop an index of quality of life. However, as mentioned above, Spitzer *et al.*[37] developed a short quality of life index, the QL-Index, as well as a one-item scale, the uniscale, measuring overall quality from the perspective of the provider. While the QL-index is included in the QLI-MH index (provider's perspective), the uniscale is not and has been collected to test for criterion-related validity. Furthermore, although not directly tested for validity and reliability, a QL-Index and a uniscale have also been collected from the patient's perspective.

It should be noted that the uniscale coincides with the general one-item QOL assessment used in the medical outcomes study.[51] In this context, from a patient's perspective, this uniscale has also been tested for validity and reliability, however, not with patients with severe and persistent mental illness. Table 2 shows the Pearson correlation coefficients among these measures from both patient and provider perspectives. From a patient's perspective, the correlation between the QLI-MH and the patient uniscale is 0.677, indicating an acceptable level of validity. The correlation between the QLI-MH and the QL-Index is very high at 0.908. The QLI-MH includes the items of the QL-Index, and thus a structural relationship is built in. It should be noted that the QLI-MH and the QL-Index serve very different purposes. The QLI-MH allows analysis of quality of life from multiple points of view and along multiple dimensions, while the QL Index allows a single overall 'snap-shot'.

The *patient* QLI-MH correlates with the *provider* QL-Index and uniscale, with coefficients of 0.577 and 0.500 respectively, thereby indicating criterion-related validity for the client QLI-MH. On the provider side, the QLI-MH correlates with the

Table 2. Correlation coefficients among various measures of quality of life (*n* = 37)

	QL-Index	Uniscale	QL-Index provider	Uniscale provider
QLI-MH Patient	0.908	0.677	0.577	0.500
QLI-MH Provider			0.766	0.799

Spitzer provider uniscale at a level of 0.799, thus showing a fairly high level of criterion-related validity.

Construct validity focuses on the extent to which a measure performs in accordance with theoretical expectations. In the context of quality of life, however, construct validity is not easy to establish. Based on previous research, clinical experience and theories of locus of control and quality of life[52-54] we predicted that patients' ADL functioning would have little correlation with psychiatric symptoms. The results are plotted in Figure 3. As predicted there was little correlation between symptoms and functional status. Patients with the same symptom level can experience low or high
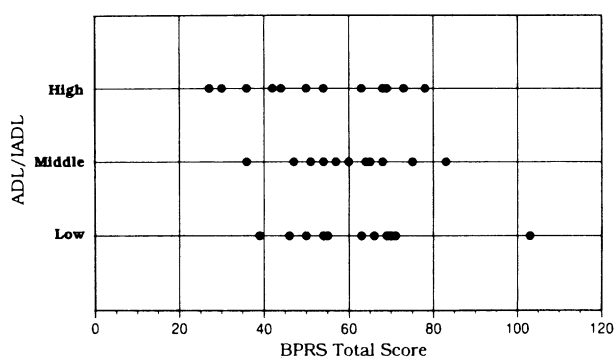
functioning. Patients with a low level of symptoms can also have a low level of function and some highly symptomatic persons can achieve a relatively high level of function.

In order to examine test–retest reliability, the QLI-MH was administered to a previously untested sample of ten schizophrenic outpatients and their providers. A second administration was completed within 3–10 days. We examined whether or not answers for the questions in each domain were exactly the same on the second administration. The percentage match for each domain and total score follows: satisfaction level 0.83; occupational activities 0.87; psychological well-being 0.82; physical health 0.86; social relations 0.82; economics 0.85; activities of daily living 0.82; symptoms 0.86; goal attainment 0.85; total score 0.84. The percentage agreement was high enough to give us confidence in the reliability of the QLI-MH index.

Figure 3. Relationship of functional level to BPRS score.

Individual QLI-MH domains

In order to examine the relationship between individual QLI-MH domains, Pearson correlations were performed for both patients and providers (Tables 3 and 4). Not unexpectedly, these data indicate moderate to strong correlation among

Table 3. Pearson correlation matrices for patient responses ($n = 37$)

	Satisfaction	Occupation	Psychological well-being	Physical health	Social relationships	Economics	ADL functioning	Symptoms
Satisfaction	1.000							
Occupation	0.609	1.000						
Psychological well-being	0.574	0.663	1.000					
Physical health	0.289	0.505	0.339	1.000				
Social relationships	0.586	0.696	0.644	0.464	1.000			
Economics	0.539	0.497	0.415	0.314	0.442	1.000		
ADL/IADL functioning	0.181	0.359	0.211	0.189	0.249	0.067	1.000	
Symptoms	0.433	0.449	0.589	0.455	0.582	0.238	0.335	1.000

Table 4. Pearson correlation matrices for provider responses ($n = 37$)

	Occupation	Physical health	Social relationships	ADL functioning	Symptoms
Occupation	1.000				
Physical health	0.149	1.000			
Social relationships	0.510	−0.059	1.000		
ADL/IADL functioning	0.453	0.156	0.614	1.000	
Symptoms	0.293	0.109	0.499	0.726	1.000

domains and fairly good agreement between provider and patients, given the potential for differences due to differing perspectives, values and information held by these different responders. These data are in keeping with expectations that providers would emphasize patients' symptoms and rank them higher in importance than would the patient. We predicted that patients with severe mental illness would tend to be somewhat isolated and perhaps adapted to a smaller social network. Therefore, we thought patients would be likely to view their social relationships less negatively than clinicians. This hypothesis was supported by the data. On the other hand, patients and clinicians are fairly close in their evaluations of physical health.

Discussion

We have presented a new patient focused index for measuring QOL in persons with serious mental illness and a scoring method for the index that allows for the determination of specific aspects of QOL which are most important to patients. The QLI-MH index was designed to address the major limitations of conventional approaches to QOL measurement in mental health. Specifically, the index builds upon existing scales but has the advantage of covering a broad array of objective and subjective, generic and disease-specific domains. It evaluates aspects of QOL thought to be affected by treatment and includes open-ended questions and information about patients' goals for improvement with treatment. Information is solicited from multiple sources including the patient, clinician and family. In the QLI-MH index patients individually weight the relative importance of domains in determining the QOL score. Finally, the new index is self-administered, relatively easy to use and score, and it is appropriate for clinical as well as research settings.

Although the QLI-MH index has the characteristics of an adequate instrument for measuring quality of life suggested by other researchers,[22] no single instrument can be used to assess outcome in every situation. The new index has several limitations. Although designed to be self-administered, patients who are severely psychotic, illiterate, or unable to read will require an interviewer to read and answer the questions. In addition, as has been noted by others,[53-55] mood and cyclicality of disease may effect the self-reporting of QOL outcomes. Questions in the QLI-MH are in keep-

ing with Van Dam's[56] suggestions with regard to diminshing the 'mood of the day' effect, and attempt to evaluate the individual's status over an extended period of time rather than on a given day. Additional research is needed to understand the potential confounding effect of mood on self-report evaluations of QOL. The investigators plan to continue this research by additional analysis of data that will be available from studies in progress. The QLI-MH index is presently being used to study QOL outcomes and mental health services in three states. When completed, data from these studies will be used to examine the effect of mood and other conditions on patient evaluations of QOL. Data from these ongoing studies will also be used to validate further the QLI-MH index by means of concurrent use of other validated QOL measures and by continuing the analysis of the psychometric properties of the instrument.

Comprehensive and accurate QOL assessment is useful for many reasons. QOL information can be used to monitor patients throughout the course of their disease and treatment, to identify times when patients may benefit from planned intervention, to assess the effect of new programmes or specific rehabilitative approaches and to assess quality of care. Analysis of QOL data from studies of patients with severe and persistent mental illness will be used to increase understanding of the relationship between QOL and outcomes of care.

Acknowledgment

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