

Quality of Life Assessment Project

WISCONSIN QUALITY OF LIFE ASSESSMENT MANUAL

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Preface

Quality of life (QoL) is fast becoming a standard measure of outcomes in clinical trials, cost effectiveness analysis and clinical practice. A confluence of forces including rising health care costs, concern over reported poor QoL of psychiatric patients living in the community and an awakening recognition that customary measures of treatment measures are inadequate has focused attention on the need to measure and improve QoL for persons with mental illness. Unfortunately, methods for combining clinical data with client perceptions and goals for improvement with treatment are not standardized. In addition, there are likely to be differences about the relative importance of different domains. Clinicians, families and the clients themselves may have a very different view of the client's QoL and the important goals of therapy. Quality of life is a subjective construct which varies with the population studied. It is generally conceptualized as a multi-dimensional construct made up of a number of independent domains including physical health, psychological well-being, social relationships, functional roles and subjective sense of life satisfaction. Each QoL domain can be assessed from the point of view of the clinician, client or caregiver, and the relative weighting of the importance of each domain can also vary from one observer to another.

This Quality of Life Assessment Manual is an introduction to seven QoL assessment measures developed by the Quality of Life Assessment Project at the University of Wisconsin - Madison. The manual provides an overview of QoL assessment for three distinct groups including families, older adults and adults with serious mental illness. This document also describes the conceptual framework for the instruments and illustrates some of the ways that outcome data may be presented and used. The instruments presented here embody a multi-disciplinary approach to outcomes and present the work of a diverse team of researchers from the University of Wisconsin - Madison including:

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Historical Context

The Quality of Life Assessment Tools provided in this manual were developed for clinical and research use. The first Wisconsin Quality of Life Index (W-QLI) was developed for use in mental health in response to a need to provide appropriate information in the Wisconsin Medicaid Program for reauthorization of clozaril. Clozaril was then a new and expensive antipsychotic medication. At the time of development, outcomes in psychiatric patients were being measured predominantly in terms of symptoms. In fact, the Medicaid programs in 30 of 50 states in America were using a symptom improvement criteria for reauthorization of the drug under Medicaid reimbursement. Most were using a 20 percent symptom improvement criteria based on outcome measured with the Brief Psychiatric Rating Scale.⁽¹⁾ When clozaril was approved for use, the field lacked an inexpensive, easy-to-use, comprehensive QoL assessment tool for use in busy mental health settings.

Our primary objective was to develop an inexpensive, easy-to-use, self-report and self-administered instrument that would reflect consumer values and goals for improvement with treatment. An advisory board was convened to guide the scale development and ensure that consumer needs were incorporated.

We realized that the clinical and practical usefulness of an assessment instrument would be key to its successful adoption and use in the field. Thus, we developed an instrument that could be used to assess patient status, and that could also be used for monitoring and evaluating patient outcomes over time. Important features of all QoL instruments developed by the principal investigator are their dimensionality, inclusion of consumer goals, and provisions for multiple respondents. Descriptions of the index domains and underlying conceptual frameworks are provided in subsequent sections of this manual. The multi-dimensional conceptual model for the W-QLI is found on page 5.

The Wisconsin Quality of Life Index

The Wisconsin Quality of Life Index (W-QLI) for use in mental health has been made available to investigators in community settings, academia and the pharmaceutical industry. In exchange for early access to the W-QLI, anonymous data sets have been provided to the developers for psychometric evaluation. Early application studies were primarily conducted in community support programs (CSP's). However, the W-QLI has also been used in hospital settings, clinical trials, a private doctor's office, and mental health care units of health maintenance organizations.

Studies currently in the field in the United States focus primarily on persons with chronic mental illness. The majority of responders have carried a diagnosis of schizophrenia, although the W-QLI has also been used in a populations of persons with borderline personality disorder and with major affective disorder. The W-QLI has been used for program evaluation as well as for the purpose of comparing outcomes of different service models (i.e. a Program for Assertive Community Treatment (PACT) and a Fountain House Model Program).

Validation of the Instruments

The W-QLI index was field tested for clients and providers by using local mental health providers known to the authors. Results of the initial validation work have been reported in detail elsewhere.⁽²⁾ In order to ensure content and face validity of the W-QLI, we based the conceptual framework and the development of the instrument on a comprehensive model of QoL that includes multiple dimensions as well as multiple perspectives on the client's QoL. 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 life quality. Finally, to the extent possible, existing valid scales were chosen to capture some aspects of the various domains and dimensions of QoL.

The Quality of Life Index for Older Adults and the Family Quality of Life Index are newer instruments in their initial stages of evaluation. They are designed to follow the conceptual framework of the W-QLI.

⁽¹⁾ See *The brief psychiatric rating scale*, (p. 799-812) by J. Overall, D. Gorham, 1962, Psychological Report, Vol 10.

⁽²⁾ See *A new patient focused index for measuring quality of life in persons with severe and persistent mental illness*, (p. 239-251) by M. Becker, R. Diamond, F. Sainfort, 1993, Quality of Life Research, Vol 2.

Cultural Translations

The W-QLI has been culturally adapted/translated and harmonized for use in a number of countries using accepted international guidelines. Available translations include Afrikaans, Australian, Austrian, Canadian, Canadian French, Dutch, English, Finnish, French, German, Greek, Hebrew, Italian, Japanese, Polish, Portuguese, Spanish and Russian. Efforts are currently underway in Canada, Italy and Spain to collect general population norms for the W-QLI.

Cultural Adaptation Methodology:

Cultural adaptation of the W-QLI was funded by in part by Janssen Research Foundation. Janssen wished to use the W-QLI to assess QoL of individuals suffering from schizophrenia. They contracted with Mapi Values in Lyon, France, who directed the work of the cultural adaptation using the following methodology:

- Recruitment of a QoL specialist as project manager in each of the countries involved.
- Production of two independent forward translations of the original questionnaire by two independent professional translators, native speakers of the target language and bilingual in the source language.
- A meeting between the forward translator(s) and the project manager to compare both forward translations and to establish a reconciled version.
- Production of a backward translation of the reconciled forward translation into the source language by one professional translator, native speaker of the source language and bilingual in the target audience.
- A meeting between the backward translator and the local project manager to compare the backward translation and the original, discuss discrepancies and possibly modify the reconciled translation into the target language. Discussion of the discrepancies between the back translation and original source questionnaire between the local project manager and Mapi Research Institute and agreement on the changes to be made to the reconciled translation.
- Cognitive Debriefing: the test of the target language translation established in the light of the backward translation, is usually carried out on five patients suffering from the condition being investigated and native target language speakers. However, due to the complex nature of schizophrenia and the effect that this condition has on patients who suffer from it, it was decided to recruit three healthy subjects and two subjects suffering from schizophrenia. This form of recruitment allowed for a more subjective assessment of the clarity, appropriateness and acceptability of the translated questionnaire, which was followed by integration of the results into the reconciled translation.
- An international harmonization meeting during which the translations, modified according to the outcome of the cognitive debriefing, were compared to all the other translations as well as the original in order to ensure conceptual equivalence throughout all versions.
- Establishment of a final version in the target languages according to the outcome of international harmonization.
- Revision of the lay-out to facilitate completion of the questionnaire. This was done in collaboration with Janssen Research Foundation and submitted to Marion Becker for approval.

Introduction to Coding and Scoring

This section provides an overview of the general steps to accomplish before coding, data entering and scoring the QoL questionnaires covered in this manual.

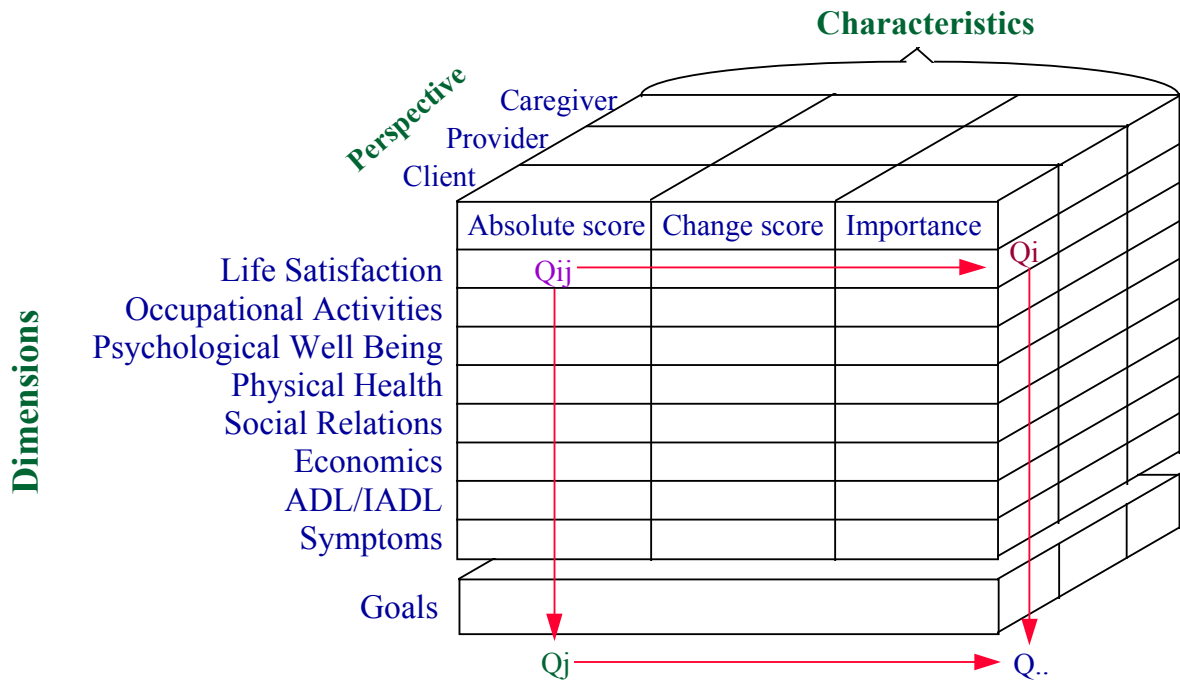
Whenever possible the questionnaire completion process should be supervised. Clients should be assisted to complete the self-report, self administered information requested and the questionnaires should be reviewed for completeness when they are returned. If the questionnaire has been administered as an interview, the client's choices and goals should be recorded verbatim and the interviewer should not influence the responders answer.

Performing Scoring Checks. Determine the completeness of the scale scoring. We have made decision rules regarding missing data for each domain based on the number of items in the domain. In general, scores are not calculated if half or more of the scale items are missing. Compute raw scale scores according to the calculations provided in the coding and scoring directions for the scale used. Coding books are available from the principle investigator upon request. Outcome scores and information can be used in a variety of ways. On the following pages, we provide examples of ways to display and use the data for individual and clinical use. We continue to work on the development of optimal ways to format the data.

In collaboration with Alvan R. Feinstein, MD, we have developed a taxonomy for evaluating the goals domain. This taxonomy which appears on page 9 is used to categorize the goals. The taxonomic number can be used to analyze goals by responder type (i.e. client, clinician or caregiver) and across clinical settings.

Wisconsin Quality of Life Index

Multi-Dimensional Conceptual Model for Evaluating Quality of Life



Q_{ij} = Evaluation of a particular dimension with respect to a particular characteristic.

Q_i = Evaluation of dimension across characteristics.

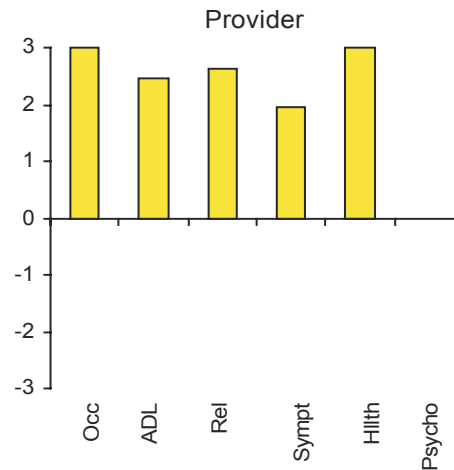
Q_j = Evaluation across dimensions.

$Q_{..}$ = Evaluation of Quality of Life as a whole (perceived QoL)

Example of Individual Level Data Presentation
Looking at Client's Quality of Life from Client and Provider Perspectives

Client ID: FL 010101 Client Date: 01/01/01 Client location: Outpatient Substance Abuse
 Provider Date: 01/01/01 Provider location: Outpatient Substance Abuse

| | Client | Provider |
|----------------------------|---------------|-----------------|
| Occupational Activities | 2.33 | 3.00 |
| Activities of Daily Living | 3.00 | 2.45 |
| Relationships | 1.50 | 2.63 |
| Symptoms | 1.88 | 1.95 |
| Physical Health | -0.50 | 3.00 |
| Money | -0.33 | 0.00 |
| Psychological Health | 1.35 | 0.00 |
| Quality of Life | 1.37 | 1.86 |
| W - Quality of Life | 1.39 | 1.89 |



| Client Goals | Importance | Achieved | Provider Goals | Importance | Achieved |
|--------------------------------------|-------------------|-----------------|-----------------------------------|-------------------|-----------------|
| 1. Stable life | 10 | 7 | 1. Attend school/college | 10 | 1 |
| 2. Take better care of myself - body | 10 | 7 | 2. Maintain substance free living | 10 | 4 |
| 3. Going to school | 10 | 1 | 3. Improve personal health | 10 | 4 |

| Agreed Upon Goals | Importance | Achieved | Agreed Upon Goals | Importance | Achieved |
|-----------------------------------|-------------------|-----------------|--------------------------|-------------------|-----------------|
| 1. Maintain substance free living | 10 | 4 | 3. Attend school/college | 10 | 1 |
| 2. Improve personal health | 10 | 4 | | | |

**Examples of Client Questionnaire Aggregate Data Presentation
for Use in Clinical and Program Evaluation**

| Aggregate Data for Assertive Community Treatment Program | | | | | |
|---|------|-----------|---------|---------|----|
| | Mean | Std. Dev. | Minimum | Maximum | N |
| General Satisfaction | 1.00 | 1.12 | -1.78 | 2.89 | 59 |
| Occupational Activities | .76 | 1.66 | -3.00 | 3.00 | 58 |
| Activities of Daily Living | 1.84 | 1.03 | -1.67 | 3.00 | 57 |
| Psychological Well-Being | .38 | 1.45 | -2.70 | 3.00 | 59 |
| Symptoms/Outlook | 1.45 | 1.11 | -1.50 | 3.00 | 51 |
| Physical Health | .38 | 1.45 | -2.70 | 3.00 | 59 |
| Social Relations / Support | 1.15 | 1.26 | -2.60 | 3.00 | 58 |
| Money | .10 | 1.68 | -3.00 | 3.00 | 57 |
| Quality of Life Score | .75 | .96 | -1.28 | 2.33 | 47 |
| Weighted Quality of Life Score | .70 | .98 | -1.31 | 2.41 | 43 |

| Aggregate Data for Self-Help Day Program | | | | | |
|---|------|-----------|---------|---------|----|
| | Mean | Std. Dev. | Minimum | Maximum | N |
| General Satisfaction | .78 | 1.19 | -2.00 | 3.00 | 48 |
| Occupational Activities | .66 | 1.47 | -1.67 | 3.00 | 45 |
| Activities of Daily Living | 2.12 | .78 | .00 | 3.00 | 43 |
| Psychological Well-Being | .47 | 1.30 | -1.95 | 3.00 | 46 |
| Symptoms/Outlook | 1.55 | .97 | -.30 | 3.00 | 46 |
| Physical Health | -.14 | 1.59 | -3.00 | 3.00 | 46 |
| Social Relations / Support | .84 | 1.44 | -2.17 | 3.00 | 49 |
| Money | -.14 | 1.69 | -3.00 | 3.00 | 39 |
| Quality of Life Score | .80 | .85 | -.71 | 2.33 | 29 |
| Weighted Quality of Life Score | .77 | .84 | -.71 | 2.33 | 28 |

Data can also be presented in aggregate form and used to compare the outcome of clients in different programs or to compare outcomes of different populations. For example, the above data provides a basis of comparison for outcomes between two programs. The top table contains data from a Program for Assertive Community Treatment (PACT) and the bottom table contains data from a self-help day program. The W-QLI project team has begun to investigate a number of questions using the W-QLI to examine outcomes for different populations including persons with and without co-occurring serious substance abuse problems and persons with and without hope for the future.

**Outline of Categories: Taxonomy of Treatment
Goals for Improvement of Persons with Schizophrenia
Proposed by Clients, Clinicians, and Families**

1. Control of Disease

1.1 Manifestation of Illness

- 1.1.1. Cardinal Manifestations of Schizophrenia
 - 1.1.1.1 Thought Disorders
 - 1.1.1.2 Auditory Hallucinations
- 1.1.2. Mental Stability
 - 1.1.2.1. Achieve Mental Stability
 - 1.1.2.2. Maintain Stability
- 1.1.3. General Manifestations
 - 1.1.3.1. Aggression & Anxiety
 - 1.1.3.2. General Mental Health
 - 1.1.3.3. “Be on Level Keel”
- 1.1.4. Co-morbidity
 - 1.1.4.1. Alcoholism
 - 1.1.4.2. Substance Abuse

1.2 Therapy

- 1.2.1 Regulation of Medication
- 1.2.2. Compliance
- 1.2.3. Other (e.g. day treatment)

1.3 Side Effects of Therapy

- 1.3.1. Tardive Dyskinesia
- 1.3.2. Parkinsonism

2. Personal Status

2.1 Self Care

- 2.1.1. ADL
- 2.1.2. Other (e.g. coping skills)
- 2.1.3. Gain or lose weight

2.2 Independence

- 2.2.1. Domiciliary Issues
 - 2.2.1.1. Deinstitutionalization
 - 2.2.1.1. Domiciliary Independence
- 2.2.2. Finances
- 2.2.3. Occupation
- 2.2.4. Education
- 2.2.5. General Function

2.3 Sense of Well Being

- 2.3.1. “Improve Self-Esteem”
- 2.3.2. “Be Happier”

3. Interpersonal Status

- 3.1 Family Relationships
 - 3.1.1. Parent(s)
 - 3.1.2. Spouse
 - 3.1.2. Child(ren)
- 3.2 Non-Family Relationships
 - 3.2.1. Personal Relationships and Friends
 - 3.2.2. Relationships at Work
- 3.3. Social Functioning
 - 3.3.1. Social Interaction
 - 3.3.2. Social Independence

4. Caregiver Relief

- 4.1 Less Dependence on Parent(s)
- 4.2 Less Dependence on Spouse/Partner
- 4.3 Less Dependence on Paid Providers

5. Other Treatment Goals

- 5.1 “A Place of Healing”
- 5.2 “Maintaining Hope for Future”

WISCONSIN QUALITY OF LIFE INDEX (W-QLI): FREQUENTLY ASKED QUESTIONS

Who developed the W-QLI?

The W-QLI was developed by a team of clinicians, consumers, and researchers at the University of Wisconsin in Madison and by the University of South Florida.

What is the W-QLI?

The W-QLI is an easy-to-use self-report and self-administered instrument used to assess and monitor consumer's quality of life (QoL). It is designed to document consumer goals for improvement with treatment and to aid consumers and staff in their work together to achieve desired goals and improved quality of life for consumers. The W-QLI provides

- ✓ Information
- ✓ Goals for improvement with treatment
- ✓ Decision support
- ✓ Monitoring and outcome data

What are the goals of using the W-QLI?

- ✓ Consumers and providers will increase their understanding of the current consumer QoL status;
- ✓ Consumers will take a more active role in their treatment;
- ✓ Communication between consumers and providers will be improved;
- ✓ Clinician's role as consumer educator will be enhanced;
- ✓ Consumers will increase their QoL and goal achievement; leading to increased empowerment.

How do service providers and consumers work together with the W-QLI?

Consumer feedback is a crucial part of assuring the best outcomes of care. The W-QLI provides information about consumer's values and goals for improvement with treatment. The W-QLI is also repeated to insure that progress is ongoing, goals are still active, and information is up-to-date. Used in conjunction with the *Workbook for Success*, consumers are empowered to meet their individual needs and achieve their desired goals.

How should consumers and providers go about completing the W-QLI?

For more information about the W-QLI and directions for completing the forms, consult the W-QLI manual or visit our website at <http://wqli.fmhi.usf.edu> .

What does the W-QLI score tell me?

The W-QLI scores range from -3 (the worst things could be) to +3 (the best things could be). A score of 0 on the W-QLI is a middle range score which is close to the average or normative value for the target population. When W-QLI scores are computer-scored, a one-page report is produced documenting the score for each domain. Client goals for improvement with treatment are presented verbatim, allowing the consumers and service providers to discuss discrepancies and come to agreement on goals to be pursued.

What happens when provider and consumer scores/goals are different?

Provider and consumer scores are often slightly different. As long as provider and consumer scores are within a half a point (.5) of each other then they may be considered to be in reasonable agreement. Differences over .5 indicate the need for discussion between the provider and consumer to understand the reason for the differences in assessment. However, review of the W-QLI scores should be looked at as an opportunity and a crucial step in the process of enhancing the working alliance between consumers and providers as they work to explore consumer goals and values. Using the *Workbook for Success* in conjunction with the W-QLI allows additional opportunities for providers and consumers to collaborate to achieve consumer goals and illuminates factors that may impede or facilitate the consumer's progress toward their stated goals.

Is there a way to involve other consumer/survivor/recovering persons (CSR's) in this process?

The *Workbook for Success* is a useful tool that consumers trained as peer coaches can use to facilitate goal achievement with other consumers. Peer coaches can also provide invaluable support and encouragement to others, which will sustain morale and hope for a better future for consumers on the road toward recovery.

Who do I contact if I have questions or feedback about the W-QLI or the *Workbook for Success*?

For general information about the W-QLI please visit the W-QLI website at <http://wqli.fmhi.usf.edu>. You can also email the developers of the instruments at the following address: becker@fmhi.usf.edu.