

A US EXPERIENCE: CONSUMER RESPONSIVE QUALITY OF LIFE MEASUREMENT

MARION BECKER

University of South Florida, USA

Marion Becker is currently an Associate Professor at the University of South Florida's Department of Community Mental Health. Originally a psychiatric nurse by training, she has a graduate degree in gerontology from the University of Illinois and a PhD in social welfare from the University of Wisconsin. Dr. Becker is the principal investigator on the Wisconsin Quality of Life Project and the developer of the Wisconsin Quality of Life Index (W-QLI; Becker, Diamond, & Sainfort, 1993). Her research focuses on the practical problems of providing high quality, cost-effective health care for vulnerable populations, including the elderly, persons with AIDS, and persons with severe and persistent mental disorders. The common dependent variable cutting across her outcomes research is quality of life. Recently, she has been investigating the use of quality of life outcomes measurement to improve outcomes of care and the client-provider working alliance.

ABSTRACT

Objective: In the United States, interest in quality of life and social disabilities associated with mental illness intensified in the wake of the deinstitutionalization of the late '60s and '70s. Although mental health professionals in the United States have begun to recognize the importance of quality of life considerations to patient management and treatment outcomes, review of the literature shows there is minimal research in mental health on this important topic. As a result, little theoretical or methodological progress has been made. Quality of life has not been clearly conceptualized or defined and there are no agreed-upon standards or criteria for measurement. This presentation will: (a) review important conceptual issues in quality of life research, (b) discuss the benefits of and obstacles to incorporating consumer values in judgments of quality of life, and (c) present data from the Wisconsin Quality of Life Index (W-QLI; Becker et al., 1993) to illustrate the usefulness of a consumer responsive model of quality of life and the importance of incorporating consumer values in the assessment of quality of life of persons with schizophrenia.

Methods: The W-QLI was administered to a convenience sample of psychiatric outpatients with a DSM-IV diagnosis of schizophrenia. The W-QLI is a self-administered individually preference-weighted index that measures nine separate domains encompassing quality of life. The W-QLI scoring method results in separate scores for each domain and allows for the relationships among separate domains to be studied. The nine separate domains include: (a) satisfaction level for different objective quality of life indicators, (b) occupational activities, (c) psychological well-being, (d) physical health, (e) social relations, (f) economics, (g) activities of daily living, (h) symptoms, and (i) goal attainment.

Results: Study findings are consistent with previous theory and empirical research which supports the independence of component quality of life

domains. Results show that while consumers' and clinicians' judgments of outcome correlated, there were important differences. Clinicians systematically rated function higher and social relations lower than did consumers, and there were significant differences in consumer and provider goals for improvement with treatment. Overall ratings of quality of life and function are only weakly correlated with psychopathology. The findings support the importance and feasibility of incorporating consumer values and judgments of quality of life in outcome measurement.

INTRODUCTION

In the United States growing demand for health care reform and greater fiscal accountability has increased interest in monitoring the performance of mental health care. Cost constraints, concern over poor quality of life for psychiatric patients living in the community, and consumer dissatisfaction with services have focused attention on the need to improve quality of life and to develop better measures of the construct. Structural changes in the purchasing and delivery of health care and an increased emphasis on consumer participation have led to a recognition of the need to monitor outcomes from a variety of points of view, including that of the consumer. Because mental health professionals have identified quality of life as the major goal of treatment, they see the need to measure quality of life outcomes and to use the information to improve quality and outcomes of care. However, there are major conceptual and measurement barriers to the use of quality of life as an outcome measure. An important impediment is the absence of consensus about how to define and measure the construct. Lack of a common metric, national reference points, and standard criteria for measurement often render comparative studies meaningless. As we approach the 21st century, the question about how best to measure the quality of life of persons with mental illness remains unanswered.

Conceptual Issues and Measurement Barriers

Choice of definition and valid measurement are major issues facing researchers and clinicians wishing to evaluate quality of life outcomes. Conceptual issues which are related to definitions also represent important quality of life measurement challenges. Conceptual issues and critical questions for clinical work include: What is the meaning of quality of life and what is the best measurement approach? What does doing better mean? How can we consider the consumer's, clinician's and family's point of view about improvement over time? How can we use quality of life information to redesign practice and guide clinical work? What are the goals of treatment and how can we use quality of life data to measure the effectiveness of programs?

Significant differences exist among quality of life measurement approaches in the domains measured, respondents queried, subjectivity and objectivity of measurements, mode of administration, and method of aggregation. A number of validated quality of life measures have been accepted for use in mental health, making it unlikely that a single "gold standard" will be adopted in this century. The

variety of available instruments and measurement approaches has potential value in that it provides the user a choice based upon study goals and the need for information. However, there is a need for greater commonality in metric, language, definition, and measurement methods for quality of life. Because there is no agreed-upon definition or measurement method, there is an absence of comparability and compatibility across measures which complicates communication between investigators and often renders comparative studies meaningless. Establishing a consensus on definition and equivalence between scaled measures of quality of life would improve the future usefulness of data immensely.

Why Develop New Measures of Outcome?

Outcome measures used in mental health have come under scrutiny and attack for their lack of responsiveness to consumer values and for their cultural insensitivity. Standard measures of treatment outcome are not adequate for measuring quality of life. The two most commonly used outcome measures, rates of hospital recidivism and psychiatric symptomatology, are relatively easy to determine and seem to be reasonable markers of improvement, but are ultimately unsatisfactory. Psychiatric rehospitalization is too coarse an index for individual patients and is also affected as much by characteristics of the mental health system as by the clinical status of the patients. Psychiatric symptoms, even when improved, do not indicate how well patients can function or how they feel about their lives (Avison & Speechley, 1987; Baker & Intagliata, 1982; Tantam, 1988).

In addition to being a better and necessary measure of outcome, quality of life is the stated goal of most community-based treatment programs (Lehman, 1982; Rosenfield, 1992). Because elimination of disease is not a realistic goal for most persons with severe mental illness, treatment programs have begun to emphasize maintaining or improving clients' functioning and quality of life (Lehman, Ward, & Linn, 1982; Levitt, Hogan, & Bocosky, 1990; Maim, May, & Dencker, 1981). Quality of life has at least three other important attributes: (a) it can affect the client's compliance with treatment programs (Diamond, 1985), (b) it can be used predictively to estimate future levels of disability (Strauss & Carpenter, 1974), and (c) quality of life assessment has been mandated as a factor to be used by federal agencies in approving new medications and funding new programs (Jaeschke, Guyatt, & Cook, 1992).

Development of The W-QLI

The Wisconsin Quality of Life Index (Becker et al., 1993), originally named the Quality of Life Index for Mental Health, captures quality of life judgments from three different perspectives: client, provider, and family/caregiver. The W-QLI was developed for use in the reauthorization process for clozapine under the Wisconsin Medicaid Program. It was developed to provide an alternative to the more common reauthorization criteria of 20% improvement on the BPRS scale which was used in most states in the US. In developing the W-QLI we focused on (a) developing an easy to use, inexpensive, comprehensive index; (b) including measures used in previous studies to allow for comparison; (c) allowing for self-report and multiple respondents; (d) incorporating individualized preference weights; and (e) measuring whether individuals were helped with the specific goals

that brought them into treatment. The W-QLI is unusual in that each person individually weighs the relative importance of various components for him or herself, rather than merely responding to researcher-imposed a priori values for the different aspects of life quality assessed.

The W-QLI provides domain-specific and overall quality of life scores which can be used in cost-effectiveness analyses to relate cost to outcome. Information obtained with the index about clients' personal goals for improvement with treatment can also be used to guide interventions designed to improve the quality of life of persons with severe mental illness or to identify components of quality of life that are most important to clients and their families. The goal attainment domain was included to ensure that the unique characteristics and desired outcomes of consumers would be reflected in the outcome evaluation. Table 1 presents the kinds of information about mental health treatment that the goal domain is expected to capture. The categories of goals expressed by respondents are organized and presented in the accompanying Taxonomy of Treatment Goals (Table 2).

Although many quality of life researchers stress the importance of the patient's perspective and values, most quality of life indexes are not weighted for individual preferences. Furthermore, few instruments allow patients to add their

TABLE 1
Information Available from the W-QLI Goal Attainment Domain

Desired Information	Goal Specifics	Measurement
1. What kinds of goals are set by consumers, providers, and caregivers?	1. Unique expectations	1. Taxonomic category
2. Do provider or consumer settings and characteristics influence types of goals set?	2. Comparability of desired goals	2. Correlation analysis
3. Were treatment goals achieved?	3. Explicit goal expectation	3. Goal achievement score

TABLE 2
Taxonomy of Treatment Goals

1. Control of Disease	3. Interpersonal Status
1.1 Manifestation of illness	3.1 Family relationships
1.2 Therapy	3.2 Nonfamily relationships
1.3 Side effects of therapy	3.3 Social functioning
1.4 Comorbidity	
2. Personal Status	4. Care Giver Relief
2.1 Self-care	4.1 Less dependent on parent
2.2 Independence	4.2 Less dependent on spouse
2.3 Sense of well-being	4.3 Less dependent on professional staff
	5. Other Treatment Goals
	5.1 Main hope for future

concerns or to introduce elements that might fit the respondent's own desires for a good quality of life (Avison & Speechley, 1987). This practice leads to three main problems: (a) clinicians and researchers do not have a satisfactory or standard way to measure quality of life, (b) clinicians treating patients with severe mental illness may aim at the wrong target or endpoint, and (c) mental health services personnel and program planners do not know how to optimize their limited resources or to choose services that would best help patients achieve a good quality of life. Despite a general belief that symptoms, such as positive and negative mood, strongly affect such features of personal life as functional status, occupational performance, and overall life satisfaction, this belief was not confirmed in the group of individuals we studied, and empirical support for this belief is not found in the literature.

REVIEW OF LITERATURE

A confluence of market forces and shifts in America's disability policy has increased interest in quality of life. Public policy has shifted from a focus on disability toward a participatory system of outcomes management designed to enhance consumer choice and responsibility. Challenges to a participatory system of outcome measurement are numerous and include political, methodological, educative, and other substantive obstacles.

Systematic research on quality of life in the United States began with the social indicators research that emerged after World War II and the work of Campbell and colleagues at the University of Michigan (Campbell, Converse, & Rogers, 1976). Using data from national surveys on the quality of American life, Campbell examined the components of quality of life in a sample taken from the US population (Campbell, 1981). In psychiatry attention to quality of life as an outcome measure in its own right emerged after large numbers of patients began moving out of psychiatric hospitals to community-based care. This national trend raised concerns about the quality of life of psychiatric patients living in the community in residential care facilities (Lamb, 1979) and nursing homes (Schmidt, Reinhardt, & Kane, 1977). Many people were moved from the state hospitals into nursing homes and residential care facilities. These facilities have been labelled the "new back wards" of the community, and critics have argued that quality of life for persons with serious mental illness in the community is worse than in long-stay hospitals (Bassuk & Lamb, 1986).

The quality of life of persons with serious mental illness is poor by any definition that one wishes to use. Recent reports suggest that psychiatric patients living in the community have the lowest overall life satisfaction scores in the general population (Lehman, Ward, & Linn, 1982). Persons with mental illness represent one third of the homeless population (Bachrach, 1987). Studies show they often live in substandard housing and are dissatisfied with their finances, level of employment, social relationships, and personal safety (Mechanic, 1986; Rossi & Wright, 1987; Stein & Test, 1976). To improve the quality of life of community-dwelling persons with severe mental illness, we must first determine what affects their quality of life and then determine which services can help achieve a good quality of life.

While there are associations between some quality of life indicators that might appear obvious (i.e., good quality housing leads to better quality of life than substandard or poor quality housing), the relationship of these "objective" indicators may be less important than commonly thought. Recent data indicate that demographic variables and objective life conditions are in fact only weakly correlated with individuals' subjective experiences and the quality of life evaluations of persons living under those conditions (Lehman, Ward, & Linn, 1982). As noted by Strain, "it may be that patients' perception (sic) of how they feel, function, or look, is more important than the actual reality." In fact, it is not only incongruity of the expected versus the actual, but the actual versus the perceived (Strain, 1990).

A review of outcome literature shows that different investigators have used very different definitions for quality of life (Mor & Guadagnoli, 1988). However, there is consensus on the core dimensions that make up quality of life. Quality of life is a construct that is commonly investigated either from a rating in a single global scale or from an aggregate of component ratings for multiple indicators of life quality. Unfortunately, when studying quality of life, researchers have often focused extensively on the statistical results and psychometric properties of their scales to the neglect of the content relevance of questions to patients. Investigators have rarely studied how the identified component domains of life quality affect one another or how they conjointly affect overall evaluations of quality of life. The standard practice of studying individual components of quality of life one at a time is particularly problematic in evaluating quality of life in psychiatrically impaired populations where there are hypothesized confounding effects of psychopathology on quality of life assessments (Warner & Huxley, 1993a). It is possible that individual quality of life domains have important but presently unstudied interactive characteristics that are important to patients' prognoses. For example, persons with inadequate amounts of money and low social support may be at higher risk for relapse than those with adequate money and social support.

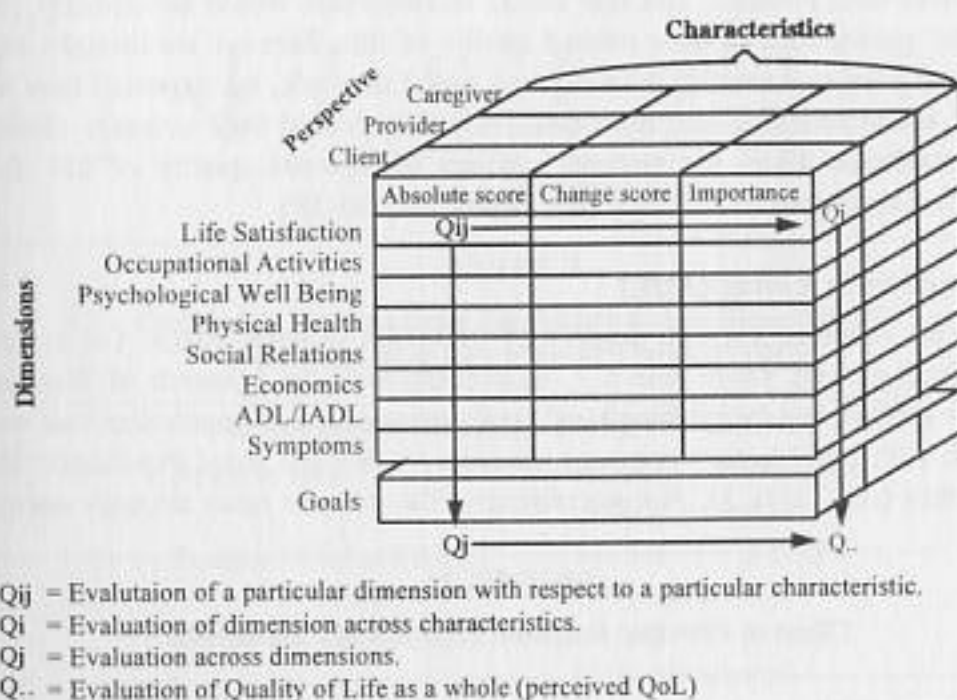
The limited data available regarding the effect of mood and psychopathology on perceived quality of life are inconclusive and difficult to interpret. One previous study by Lehman showed that psychiatric patients' ratings of life satisfaction may be influenced by their level of anxiety or depression (Lehman, 1992). However, other research concerned with feelings of general happiness and with negative and positive affect (Smith, Diener, & Wedell, 1989) shows there is no simple reciprocal relationship between affect states and assessments of general happiness or life satisfaction (Bradburn, 1965; Ryff, 1989). Additional research is needed to clarify the complex relationship between affect states and quality of life assessment.

Conceptual Framework

Along with Ferrans (Ferrans & Power, 1992), we define quality of life as a person's sense of well-being that stems from satisfaction or dissatisfaction with areas of life that are important to her/him. Here, quality of life reflects the distance between desired and achieved life circumstances. The greater the discrepancy between desired and achieved outcomes, the poorer the outcome. Quality of life is conceptualized as a multidimensional construct that includes both subjective (i.e., patient-rated perceptions) and objective (i.e., external observable components), domain-specific and global quality of life assessment. Objective indicators include

ratings of external circumstances such as income, housing, personal safety, social relationships, and functional status, while subjective indicators include perceptions of physical and psychological well-being, a sense of achievement, and satisfaction with personal goals. We believe an accurate quality of life assessment needs to incorporate both consumer and provider knowledge and perspective. In the few studies where quality of life has been studied in persons with severe mental illness, the questions used have not been designed to obtain the patient-centred information needed to understand quality of life from the consumer's point of view.

FIGURE 1
Wisconsin Quality of Life Index
Multidimensional Conceptual Model for Evaluating Quality of Life



METHODS

Initial data were collected from a convenience sample of persons who met Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) criteria for schizophrenia (American Psychiatric Association, 1994). The study participants were recruited by mental health providers known to the authors. The responding clients were all outpatients receiving their care from the local county mental health centre. After informed consent was given, patients and clinicians completed the W-QLI questionnaires. Questionnaire completion took 10-20 minutes for providers and about 20-30 minutes for consumers.

RESULTS

Most (77 or 56%) of the patients were male, 117 (85%) were Caucasian, and 11 (8%) were black. Patients ranged in age from 22 to 73 years. The mean age of

patients was 42.3 years, and the modal education was 12 years within a range of 6 to 16 years. The average age at onset of illness was 21 years. Seven percent of respondents were married, 6% had common-law partners, 21% were divorced, and 67% had never married. To examine the associations between and among individual W-QLI domains, Pearson correlations were performed. Given that the W-QLI domains are all facets of a person's underlying quality of life, we expected moderate correlations between domains. However, the correlations are not so strong as to raise the problem of the separate domains not being empirically distinct from one another. Of the nine quality of life domains studied with the W-QLI index, the top two domains most strongly correlated with consumers' ratings of their overall quality of life were social relations and psychological well-being.

These data are consistent with the findings of others and with our initial hypotheses that psychiatric symptoms would be given higher ranks of importance by providers than patients, and that social relationships would be strongly related to patients' perceptions of their overall quality of life. Because we thought patients might be adapted to a smaller than average social network, we expected they would rate their social relationships more positively than would their primary clinicians. These hypotheses about the patients' ratings of separate quality of life domain scores were supported by the data (see Figure 2A and 2B).

Activities of Daily Living (ADL)

Patients reported varying degrees of limitation in basic ADLs. On a scale of 10, the average ADL score was 5.7. In keeping with the research of Strauss and Carpenter (1974), we found functional performance in our population was weakly correlated with psychiatric symptoms measured using the Brief Psychiatric Rating Scale (BPRS) (see Table 3). Not surprisingly, the domain most strongly correlated

FIGURE 2A
Client vs Provider Response Over a 1-Month Interval

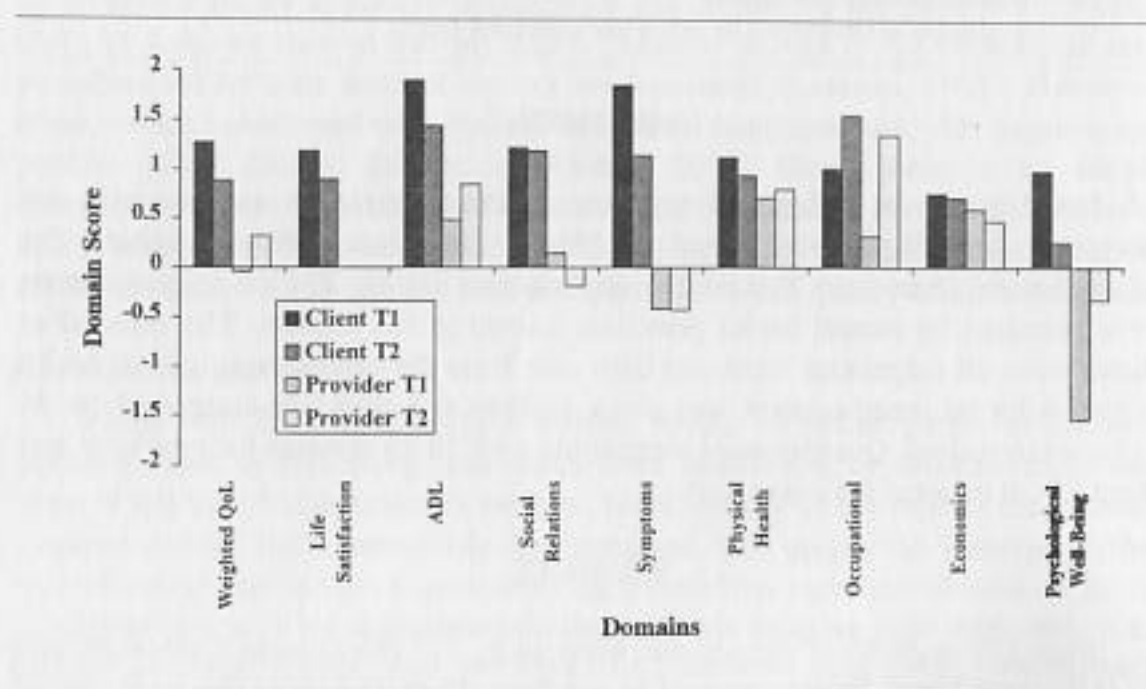


FIGURE 2B
Client vs Provider Change Score Over a 4-Month Interval

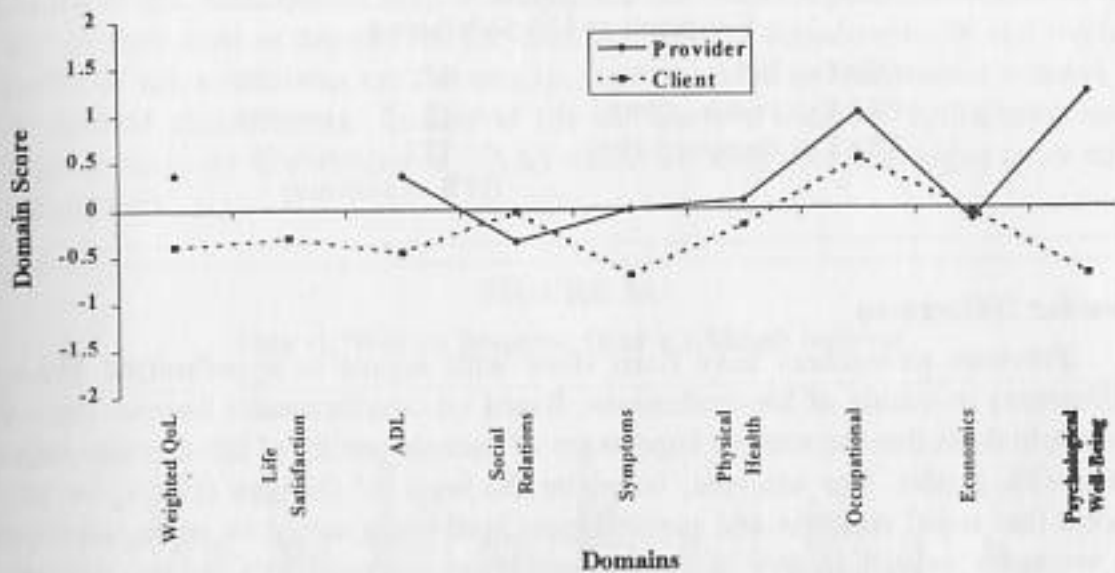


TABLE 3
Correlation between Brief Psychiatric Rating Scale (BPRS) and Patient Activities of Daily Living (PADL)

Symptoms vs Clinician's Rating of Function		
BPRS vs PADL	$r = .582$	$p < .001$ (34% of variance)
Positive BPRS vs PADL	$r = .380$	$p < .05$ (14% of variance)
Negative BPRS vs PADL	$r = .385$	$p < .05$ (15% of variance)

with ADL functioning was occupation. People who have poor ADL ability are understandably going to have difficulty holding down a job.

Psychopathology and Overall Quality of Life Assessment

Because of a common and untested assumption that the credibility of psychiatric patients' responses is impaired, patients with severe mental illness have seldom been asked to rate the importance of different personal phenomena or to express their perceptions of their quality of life. The observations of the primary clinicians in our study indicate that most patients had little difficulty completing the W-QLI. Previous researchers have expressed concerns that psychopathology, mood, and cyclical nature of disease might affect the self-reporting of quality of life (Moum, 1988; Van Dam, Sommers, & Van Beek-Couzin, 1981). In the current study, overall ratings of life satisfaction (CSAT) were not well predicted by clients' levels of psychopathology or mood measured using the Brief Psychiatric Rating Scale (BPRS) (Table 4). Symptoms account for only a scant 12% of the variance.

TABLE 4
Correlation between Client Satisfaction with Life Scores
and Brief Psychiatric Symptom Scores

Symptoms vs Life Satisfaction		
CSAT vs BPRS	$r = .272$	$p = .104$
CSAT vs Positive BPRS	$r = .157$	$p = .354$
CSAT vs Negative BPRS	$r = .353$	$p < .05$
	(12% of variance)	

Gender Differences

Previous researchers have been silent with regard to hypothesized gender differences in quality of life evaluations. Based on developmental theories there is reason to think that the relative importance of various quality of life domains might vary with gender. For example, based on the work of Gilligan (1982), we predicted that social relations and psychological well-being would be more important to women's overall quality of life ratings when compared to ratings by men. Further, we predicted that occupation and economics would be more strongly correlated with men's quality of life assessment than women's. Study results supported these working hypotheses (see Figures 3A and 3B).

DISCUSSION

This presentation reviewed the state of quality of life research in the US and a new consumer responsive approach to quality of life measurement for mental health. It contributes to a further understanding of factors that affect quality of life among community-dwelling citizens with schizophrenia in the state of Wisconsin. New information about the correlations between gender, mood, functional status, psychiatric symptoms, and other factors that contribute to psychiatric patients' quality of life was presented. Findings are compatible with and extend previous theory and empirical research. Data show that while there are slight to moderate correlations between separate W-QLI domain scores, the underlying domains are independent and represent distinct aspects of quality of life. The study has implications for mental health service provision for persons with schizophrenia. For example, given the identified importance of social relations to consumers' quality of life, service providers might productively emphasize interventions that enhance patients' social skills and work to support psychiatric outpatients' full integration into the community.

In light of the poor outcomes and low quality of life experienced by community-dwelling persons with schizophrenia, a reorganization of psychiatric rehabilitation philosophy and procedures may be warranted. As part of such a reorganization, attitudes and expectations of mental health clinicians should be evaluated. It is possible that clinicians are overly focused on psychiatric symptoms to the neglect of key quality of life considerations that are of importance to patients' adaptation and survival in the community, to patient compliance, and to

improved outcomes of care. If clinicians have low expectations for patients' recovery or their achievable quality of life, a "vicious cycle" may be set up whereby clinicians' low expectations influence patients' expectations, which in turn influence outcomes negatively. Although previous investigators have suggested that quality of life assessments may be simply a reflection of a person's "mood of the day" or their level of depression, our data indicate that domain-specific and overall quality of life evaluations are not simply a reflection of the respondent's mood at the time of measurement. Quality of life is clearly a complex multidimensional outcome made up of a number of factors which we have only just begun to identify and research.

FIGURE 3A
Men vs. Women Response Over a 1-Month Interval

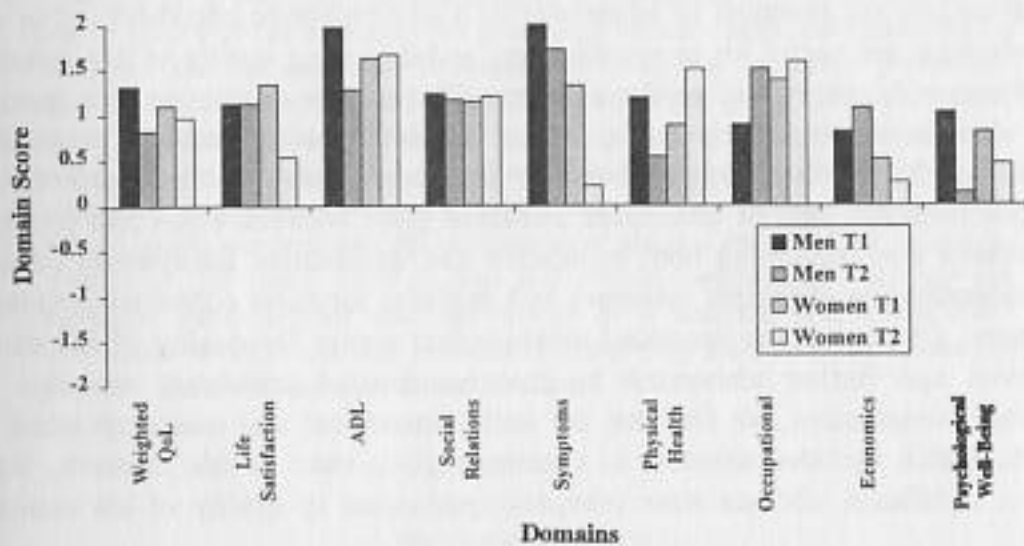


FIGURE 3B
Men vs. Women Change Score over a 4-Month Interval

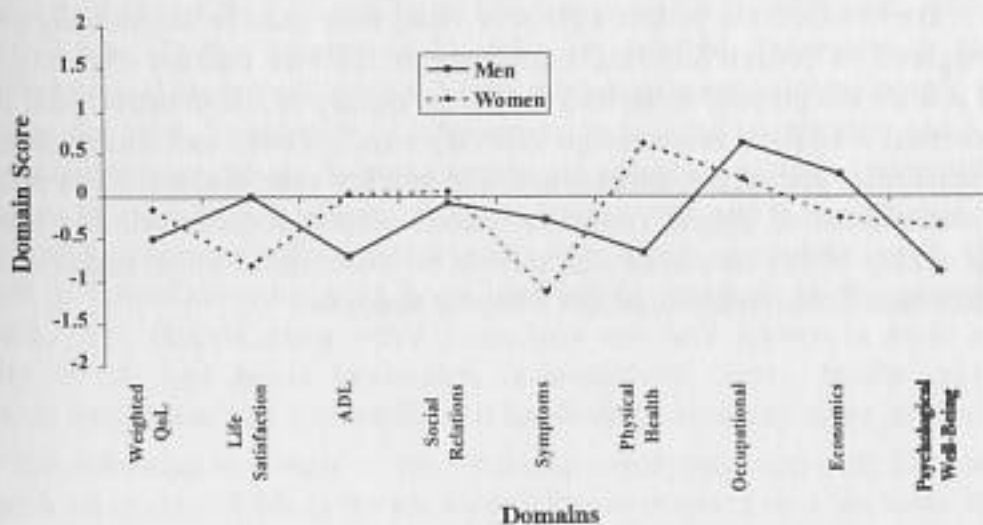


TABLE 5
Mental Health Treatment Goals from Client and Provider

Client	Provider
To be able to control my own money	Will actively work on dealing with Benadryl addiction
Make new friends	Will refocus therapy to work with a CSP staff person
To join a support group with others like me	Will use crisis homes instead of hospital at least once in next 6-12 months

Experience over the last 3 years indicates that paper and pencil quality of life questionnaires are practical to administer in a schizophrenic population. The data thus obtained are useful for monitoring and understanding quality of life outcomes in persons with severe and persistent mental illness. The qualitative data from the goals domain is particularly useful in that it allows both client and provider to examine possible discrepancies between treatment goals. Table 5 provides an example from our data of discrepant treatment goals between client and provider. We believe that combining both qualitative and quantitative information enriches our understanding of patient outcomes and provides for more consumer-responsive treatment. Of course, the proposed measurement model for quality of life can be improved and further elaborated by the inclusion of additional variables and domains. Nonetheless, we feel that the multidimensional and multirespondent approach, which includes attention to consumer goals used in this research, represents a significant advance over previous approaches to quality of life measurement.

This approach represents a significant advance over previous approaches to quality of life measurement. Because quality of life is not separable from individual preferences, we believe adequate measurement should reflect personal preferences and individual goals for improvement with treatment. Therefore, if quality of life measures are to reflect the patient's point of view, they must be individually preference weighted to reflect differing individual values and cultural diversity. Additional studies are planned to further define the quality of life construct and to explore potential reciprocal relationships that may exist between and among domains. Longitudinal data and larger samples are required for such analyses. The possibility of simultaneous or lagged reciprocal effects among domains and the linkages between quality of life outcomes and service provision need to be explored if we are to understand the dynamics of this complex construct.