

# Quality of Life Issues and Assessment Among Persons with Schizophrenia

ANTHONY F. LEHMAN

Department of Psychiatry, University of Maryland, Center for Mental Health Services Research, Baltimore, Maryland, USA

## INTRODUCTION

Schizophrenic disorders afflict approximately 1% of the population during their lifetime. These disorders impose severe hardships on patients and their families and challenge society in the development of public policies that both preserve the public welfare and afford patients a decent quality of life. Among the various conceptual challenges inherent in evaluating services for persons with schizophrenia has been the development of appropriate outcome measures reflecting the broad range of problems faced by these patients (Schulberg & Bromet, 1981; Lehman *et al.*, 1982). Relevant outcome domains include psychiatric symptoms, functional status, access to resources and opportunities, subjective well-being, family burden, and community safety. Because of this broad array of relevant outcomes and because of a prevailing concern that outcome assessments should include the patient's perspective, there has been increased attention paid over the past decade to the development of measures of patient "quality of life" (Baker & Intagliata, 1982; Lehman, 1983a), and the new National Institute of Mental Health (NIMH) research plan on severe and persistent mental illnesses, *Caring for Persons with Severe Mental Illness*, identifies quality of life as one of the major outcome areas to be assessed in new research efforts (Attkisson *et al.*, 1992).

This chapter summarizes those measures of quality of life that have been developed specifically for persons with schizophrenia and other severe and persistent mental illnesses.

The measures reviewed emphasize the patient's "quality of life," that is, measures covering patient's perspectives on what they have, how they are doing, and how they feel about their life circumstances. At a minimum "quality of life" covers persons' *sense of well-being (subjective quality of life)*; often it also includes how they are doing (*functional status*) and what they have (*access to resources and opportunities*). The latter two dimensions constitute what is commonly referred to as *objective quality of life*. The measures selected for this review were identified from the literature on quality of life through October 1992. In order to be selected a measure had to at least assess the domain of subjective well-being; as will be seen most of these measures also cover the broad areas of functioning and resources.

## DESCRIPTION OF AVAILABLE MEASURES

The measures are presented in order of their chronological development. For each measure, the content and psychometric characteristics of the instrument are described. Also a listing of key references is provided and the seminal reference with regard to the instrument's development is marked with an asterisk (\*).

## Community Adjustment Form (CAF)

See (\*) Stein and Test (1980) and Hoult and Reynolds (1984).

This semi-structured self-report interview was developed to assess life satisfaction and other quality of life outcomes in a randomized study of an experimental system of community-based care for the severely mentally ill versus standard care in Dane County, Wisconsin. It consists of 140 items and requires approximately 45 minutes to complete.

The areas assessed include: Leisure activities; Quality of living situation; Employment history and status; Income sources and amounts; Free lodging and/or meals; Contact with friends; Family contact; Legal problems; Life satisfaction (21 items); Self-Utilization. No psychometric properties are reported.

The original patient sample studied included 130 patients seeking admission to a state hospital. Over half were men (55%) and their mean age was 31 years. Half carried a diagnosis of schizophrenia. They were treated both in the state hospital and in a community-based Assertive Community Treatment Program. The results of the original Wisconsin study were replicated in Australia using the same measures (Hoult and Reynolds, 1984).

## Quality of Life Checklist (QLC)

See (\*) Malm, May and Dencker (1981).

This checklist was developed to provide information about which aspects of quality of life are particularly important to patients and clinician raters to assist in therapeutic planning. This 93-item rating scale is completed by a trained interviewer after conducting a 1-hour semi-structured interview. Scoring for all areas assessed is dichotomized as “satisfactory” or “unsatisfactory.” The areas assessed include: Leisure activities, Work, Vocational rehabilitation, Economic dependency, Social relationships, Knowledge and education, Psychological dependency, Inner experience, Housing standard, Medical care (Psychiatric and General), and Religion.

No psychometric properties are reported. Data analyses report simple frequencies of “*satisfactory*” versus “*unsatisfactory*” by items.

The patients studied included 40 persons with chronic schizophrenia in a Swedish outpatient clinic. They ranged in age from 18 to 50 years and included 68% men.

## Satisfaction with Life Domains Scale (SDLS)

See (\*) Baker and Intagliata (1982) and Johnson (1991).

This instrument was developed to evaluate the impact of the Community Support Program (CSP) in New York State on the quality of life of chronically mentally ill patients. It is a self-report scale administered by a trained interviewer, consists of 15 items, and requires approximately 10 minutes to complete. Its individual items cover: Satisfaction with housing, neighborhood, food to eat, clothing, health, people lived with, friends, family, relations with other people, work/day programming, spare time, fun, services and facilities in area, economic situation, and place lived in now compared with state hospital. These can be summed into a total life satisfaction score.

The total life satisfaction score correlates at  $r = 0.64$  with the Bradburn Affect Balance Scale, at  $r = 0.29$  with the Global Assessment Scale. No other psychometric data are provided. The frequencies and means on these items can be compared with items scores in a national quality of life survey of the general population (Andrews & Withey, 1976).

The patients studied included 118 chronically mentally ill outpatients, age 18-86, in two community support programs. They had a mean age of 53.3 years, 61% were women, and 84% lived

in supervised residential settings. Diagnoses included 56% schizophrenia, 14% affective disorders, 5% substance use disorders, and 3% organic mental syndromes.

### Oregon Quality of Life Questionnaire (OQLQ) (1982, 1990)

See Bigelow *et al.* (1982), Bigelow, Gareau and Young (1990), (\*) Bigelow, McFarland and Olson (1991), Bigelow *et al.* (1991).

The OQLQ was originally developed based upon the Denver Community Mental Health Scale and has undergone a series of developments since 1981. The original purpose of the OQLQ was to assess quality of life outcomes among clients served by community mental health programs, especially those developed under the NIMH CSP initiative. Originally published in 1982, the OQLQ has recently been updated by its developer with more recent psychometric data, alternative versions, and further program applications.

The OQLQ exists in two versions: a structured self-report interview (263 items) and a semi-structured interviewer-rated interview (146 items). Both are administered by a trained (not necessarily clinical) interviewer. The theory underlying the OQLQ states QOL derives from the social contract between individual and society. Individuals' *needs* are met to the extent that persons fulfill the *demands* placed upon them by society. Most of the items use fixed, ordinal response categories, and the interview requires approximately 45 minutes to administer.

The OQLQ yields 14 scale scores: Psychological distress, Psychological well-being, Tolerance of stress, Total basic need satisfaction, Independence, Interpersonal Interactions, Spouse role, Social support, Work at home, Employability, Work on the job, Meaningful use of time, Negative consequences of alcohol use, and Negative consequences of drug use.

The psychometric properties of the OQLQ have been evaluated extensively. Cronbach's alpha for the 14 scales on the self-report interview versions range from 0.05 to 0.98 with a median of 0.84. Eight of the scales have excellent reliability (alpha > 0.8), 2 have intermediate reliability (alpha between 0.8 and 0.4) and 4 have poor reliability (<0.4). Test-retest reliabilities (interval not specified) ranged from 0.37 to 0.64 with a median of 0.50. The inter-rater reliability for the interviewer-rated version has been assessed in a small sample study ( $n=6$ ) and produced inter-rater agreement levels between 58 and 100% on the interviewer judgments. More than half of the items showed greater than 90% agreement, and Cronbach alpha ranged from 0.32 to over 0.80 (more than half over 0.80).

The predictive validity of the OQLQ has been evaluated by comparing: (i) clients in different types of community mental health programs (CSP, drug, alcohol, and general psychiatric clinics); (ii) general community respondents from economically distressed and non-distressed communities; and (iii) changes in community mental health clients over time. Results of these analyses support the overall predictive validity of the OQLQ.

The OQLQ has been applied to outpatients of mental health programs as well as to samples of the general population. The outpatient samples included patients at intake to community mental health programs in Oregon (includes chronically mentally ill, drug abusers, alcoholics, and general psychiatric patients). Their mean age was 33.8 years (range 18-85) and included 60% men and 96% "non-Hispanics." The community sample had 43% men, a mean age of 36.8, and was 92% non-Hispanic.

### Lehman Quality of Life Interview (QOLI)

See Lehman, Ward and Linn (1982), Lehman (1983a), Lehman (1983b), Lehman, Possidente and Hawker (1986), Franklin *et al.* (1987), (\*) Lehman (1988), Simpson, Hyde and Faragher (1989), Levitt, Hogan and Bucosky (1990), Lehman, Slaughter and Myers (1991), Slaughter and Lehman (1991), Lehman, Slaughter and Myers (1992), Sullivan, Wells and Leake (1992), Huxley and Warner (1992), Rosenfield and Neese-Todd (1993) and Rosenfield (1992).

The overall purpose of the QOLI is to assess the life circumstances of persons with severe mental illnesses both in terms of what they actually do and experience (“objective” quality of life) and their feelings about these experiences (“subjective” quality of life). The Interview provides a broad-based assessment of the recent and current life experiences of the respondent in a wide variety of life areas of potential interest, including living situation, family relations, social relations, leisure activities, finances safety and legal problems, work and school, and health (as well as religion and neighborhood in some versions).

The QOLI is a structured self-report interview administered by trained lay interviewers. It consists of 143 items and requires approximately 45 minutes to administer. It has undergone a variety of revisions over the past 10 years, primarily to improve its psychometric properties and to shorten it. The Core Version contains a global measure of life satisfaction as well as measures of objective and subjective quality of life in eight life domains: living situation, daily activities and functioning, family relations, social relations, finances, work and school, legal and safety issues, and health. The sections *on each life domain* are organized such that information first is obtained about objective quality of life and then about level of life satisfaction in that life area. This pairing of objective and subjective quality of life indicators by domain is essential to the quality of life assessment model (Lehman, 1988).

All of the life satisfaction items in the interview utilize a fixed interval scale, which originally was developed in a national survey of the quality of American life (Andrews & Withey, 1976). The types of objective quality of life indicators utilized vary considerably across the domains. In general they can be viewed as of two types: measures of functioning (e.g., frequency of social contacts or daily activities) and measures of access to resources and opportunities (e.g., income support or housing type). The quality of life indicators include both individual items (e.g., monthly income support) and scales (e.g., frequency of social contacts).

The variables generated by the QOLI include:

**1** *Objective quality of life indicators:* Length of Time at Current Residence, Residential Stability, Homelessness, Quality of Living Circumstances, Leisure Activities, Frequency of Family Contacts, Frequency of Social Contacts, Total Monthly Spending Money, Adequacy of Financial Supports, Current Employment Status, Number of Nights in Jail During the Past Year, Victim of Violent Crime During Past Year, Victim of Non-Violent Crime During the Past Year.

**2** *Subjective quality of life indicators:* Satisfaction With: Living Situation, Leisure Activities, Family Relations, Social Relations, Finances, Work and School, Legal and Safety, Health (Religion and Neighborhood).

The psychometric properties of the QOLI have been extensively assessed. Internal consistency reliabilities range from 0.79 to 0.88 (median = 0.85) for the life satisfaction scales, and from 0.44 to 0.82 (median = 0.68) for the objective quality of life scales. These reliabilities have been replicated in two separate studies of persons with severe mental illnesses. Test-retest reliabilities (1 week) have also been assessed for the QOLI: life satisfaction scales: 0.41 0.95 (median=0.72); objective quality of life scales: 0.29 0.98 (median=0.65). Construct and predictive validity have been assessed as good by confirmatory factor analyses and multivariate predictive models. The QOLI also differentiates between patients living in hospitals and supervised community residential programs in the USA and Britain (Lehman *et al.*, 1986; Simpson *et al.*, 1989). Individual life satisfaction items clearly discriminate between persons with severe mental illness and the general population (Lehman *et al.*,

1982). Further construct validation has been assessed in studies of the predictors of quality of life among day treatment patients in Britain (Levitt *et al.*, 1990) and the relationship between quality of life and feelings of empowerment among persons with severe mental illnesses in the USA (Rosenfeld & Neese-Todd, 1993). A variety of methodologic papers have explored such other issues as the relationship between quality of life and clinical symptoms (Lehman, 1983b), gender and age (Lehman *et al.*, 1992), and housing type (Slaughter and Lehman, 1991; Lehman *et al.*, 1991).

The QOLI has been used almost exclusively with persons with severe mental disorders. The samples in published studies have included approximately equal numbers of men and women, about 75% Caucasian, ranging in age from 18 to 65 years. The predominant diagnosis in these studies has been schizophrenia, ranging from 57 to 76% of patients. General population norms for individual life satisfaction items are available (Andrews & Withey, 1976).

### Quality of Life Scale (QLS)

See (\*) Heinrichs, Hanlon and Carpenter (1984) and Meltzer *et al.* (1990).

The QLS was developed to assess the deficit syndrome in patients with schizophrenia. It is a semi-structured interview rated by trained clinicians. Its 21 items are rated on fixed interval scales based upon the interviewer's judgment of the patient's functioning in each of the 21 areas. The interview requires approximately 45 minutes.

The 21 items of the QLS cover: Commonplace activities, Occupational role, Work functioning, Work level, Possession of commonplace objects, Interpersonal relations (household, friends, acquaintances, social activity, social network, social initiative, social withdrawal, sociosexual functioning), Sense of purpose, Aimless inactivity, Curiosity, Anhedonia, Motivation, Empathy, Emotional interaction, and Work satisfaction. These items reduce to four scales: Intrapsychic Foundations, Interpersonal Relations, Instrumental Role, and Total Score.

The interrater reliabilities on conjointly conducted interviews range from 0.84 to 0.97 on summary scales. Individual item intraclass correlations range from 0.5 to 0.9. Confirmatory factor analysis has been conducted.

This scale is widely used in the evaluation of psychopharmacologic treatments for schizophrenia, predominantly outpatients (e.g., see Meltzer *et al.*, 1990).

### Client Quality of Life Interview (CQLI)

See Goldstrom and Manderscheid (1986) and (\*) Mulkern *et al.* (1986).

The CQLI was developed as part of a battery of instruments to assess outcomes among persons with severe mental disorders who were served by the NIMH CSP. These instruments include the Uniform Client Data Instrument (UCDI), the UCDI-Short Form, the CSP Participant Follow-up Form, and the CQLI. The content of these instruments overlap to a considerable degree. All but the CQLI are completed by case managers or other professionals serving the clients and generally focus on functioning, services, and clinical outcomes. Only the CQLI asks clients directly about the quality of their lives and therefore only it is reviewed here. The conceptual model underlying the CQLI assumes that certain life essentials are necessary precursors to a quality life. One major purpose of the Community Support Program was to provide these essentials and thus to enhance quality of life.

CQLI is a structured self-report interview administered by a trained lay interviewer. It consists of 46 items rated by the respondent as well as 19 interviewer ratings. Ratings are done on fixed, ordinal scales. The content areas covered include Essentials of Life (food, clothing, shelter, health and hygiene, money, and safety), Job Training and Education, Daily Activities and Recreation, Privacy, Social Supports, Social Time, Self-Reliance, and Peace of Mind. In each area questions generally

cover both the quantity of resources or activity as well as the respondents' subjective feelings about these resources and activities. Many of the item sets lend themselves readily to composite scales, although the development or scoring of these scales is not available for the CQLI. Some of the scales parallel the UCDI for which scale computation guidelines as well as psychometric properties are available.

No formal psychometric analyses of the CQLI are available. Correlations of CQLI items rated by the clients with comparable items from the UCDI rated by the case manager were quite low. The CQLI ratings remained stable over a 14 month follow-up period.

The subsample in the CSP study who completed the CQLI were 109 severely mentally ill clients from six exemplary CSP programs. They included 51% men; 82% Caucasian, 11% Black, 6% Hispanic, and 1% other; and had a mean age of 41.5. No diagnoses are indicated, but all were severely mentally ill.

### California Well-Being Project Client Interview (CWBPCI)

See (\*) Campbell *et al.* (1989).

The California Well-Being Project was a 3-year initiative funded by the California Department of Mental Health to develop a better understanding of the health and well-being concerns of persons who have been treated for mental illness, the so-called "psychiatrically labeled." The most unique aspect of this initiative is that it was designed and conducted entirely by mental health care consumers. The Project consisted of three components: (i) research and analysis of well-being factors for individuals assessed through a structured survey of consumers, family members, and professionals; (ii) production of educational materials based upon this survey; and (iii) dissemination of these educational materials to consumers, family members, and mental health providers.

Three versions of the survey questionnaire on well-being were developed for consumers (151 items), family members (76 items), and mental health professionals (77 items). Time required for administration is not indicated. The questionnaires consist predominantly of Likert scale questions, but with some open-ended questions interspersed. The questionnaires are designed to be administered either in face-to-face interviews (conducted by trained consumers), self-administered by mail, or group self administration with an interviewer available to answer questions. The instrument is thus designed for flexibility in administration to provide the multiple perspectives of consumers, family members, and professionals.

In the California survey the CWBPCI was administered to 331 persons who were "psychiatrically labeled" and living in various settings, including psychiatric hospitals (non-state), skilled nursing facilities, board-and-care homes, satellite houses, single occupancy hotels, community residential treatment centers, drop-in centers, client self-help groups, organizations serving people identified as "homeless mentally ill," and on the streets. The final sample consisted of 61 randomly selected members of the California Network of Mental Health Consumers (surveyed by mail), 249 volunteer respondents from various facilities in California (face-to-face interviews, not randomly selected), and 21 randomly selected Project Return clients. The sample was 52% men, 67.5% Caucasian, 14.7% Black, and 4.6% Hispanic. They were predominantly young with 41% below the age of 35 and 75% below age 45, and the authors describe them as predominantly chronically mentally ill, but no further clinical details are given.

No information is provided on the instrument's psychometric properties, and for the most part data from individual items are reported as frequencies (or percentages) in a narrative section that discusses the many concerns of the respondents. Topics covered in this narrative include: Adequate Resources, Age, Alternatives to Psychiatric Hospitalization, Aspirations, Benefit Agencies, Board and Care Residents, Boredom, Causes of Psychological and Emotional Problems, Children, Client/Consumer,

Conservatorship, Control of Emotional Problems, Creativity, Stereotype of Dangerousness, Discrimination, Electroconvulsive Therapy, Empowerment, Ethnic/Cultural Group, Family Relationships, Freedom, Friends, Gender, General population, Hallucinations and/or Voices, Happiness, Health, Homelessness, Hospitalization, Income, Informed Consent, Internalized Stigma, Involuntary Treatment/Hospitalization, Labeling, Loneliness/Isolation, Mass Media, Meaningful Work and Achievement/Activity, Medications, Misdiagnosis, Neighborhood Resistance, “Normal” People, Patients’ Rights, Personhood, Poverty, Privacy, Pro-choice, Professional/Client Relationship, Public Policy, Quality of Life, Seclusion and Restraint, Self-esteem, Self-help, Sexual Life, Side-effects, Social Life, Spiritual Life, Stigma, Stress, Tolerance, Stereotype of Unpredictability, Validation, Vocational Rehabilitation, Warmth and Intimacy, Well-being, and Young Adult Chronic Mentally Ill. A key measure derived from the interview is the Well-being Quotient. This measure is derived from two questions providing information about the relative importance assigned to various factors that may affect well-being and whether the respondent currently lacks these factors. The questions read:

- 1 “Below is a list of things that some people have said are essential for their well-being. Please mark all of those things that you believe are *essential* for your well-being.”
- 2 “Of the things that people have mentioned that are essential for well-being which of the following, if any, do you lack in your everyday life?”

The response factors include happiness, health, adequate income, meaningful work or achievement, comfort, satisfying social life, satisfying spiritual life, adequate resources, good food and a decent place to live, satisfying sexual life, creativity, basic human freedoms, warmth and intimacy, safety, and other. Besides simply rank-ordering these factors according to the percentages of respondents who identify each factor in each of the question, four well-being profiles are computed: (i) for each factor, the proportion of respondents who indicate that they lack a well-being factor that they consider essential; (ii) the proportion of respondents who do not lack a factor they consider essential; (iii) proportion of clients who consider a factor essential regardless of whether they have it; and (iv) the proportion of respondents who lack a given factor regardless of its essentialness.

The most noteworthy aspect of this instrument is that it was entirely consumer-generated. The fact that it is consumer-generated enhances its face validity even though no formal psychometric analyses were conducted. The researchers consider this instrument in a developmental stage.

#### Lancaster Quality of Life Profile (LQOLP)

See (\*) Oliver (1991-92) and Oliver and Mohamad (1992).

The LQOLP was developed in the UK during the late 1980s by Oliver and colleagues in response to a mandate by the British government that all community care programs serving persons with severe mental disorders assess the impact of their service on patients’ quality of life. The LQOLP is based upon the Lehman QOLI, but modified to reflect cultural variations and the broader survey intent of the government mandate for service-based evaluation of quality of life. The theory underlying the LQOLP is essentially the same as that described under the Lehman QOLI above.

The LQOLP is a structured self-report patient interview designed for administration by clinical staff in community settings. It consists of 100 items and requires approximately 1 hour to administer. It assesses objective quality of life and life satisfaction in nine life domains: Work/Education, Leisure/Participation, Religion, Finances, Living Situation, Legal and Safety, Family Relations, Social Relations, and Health. In addition it includes a measure of General Well-being and Self-concept. Objective quality of life information is collected by means of categorical or continuous measures depending upon the content area. Life satisfaction ratings are on a seven-point Likert scale.

Psychometric properties of the life satisfaction have been evaluated in a series of pilot studies (Oliver, 1991-92). Test-retest reliabilities for life satisfaction scores range from 0.49 to 0.78, depending upon the patient sample. Internal consistency reliabilities (Cronbach's alpha) of these scales range from 0.84 to 0.86. Content, construct, and criterion validities were also assessed using a variety of techniques and judged to be adequate.

The LQOLP has been used with chronically mentally ill patients in a variety of community care in settings in the UK and in Colorado. Details of sample characteristics are not available. A briefer version of the LQOLP is currently being piloted in 12 European countries and is being considered by the World Health Organization in conjunction with their broader studies of quality of life.

## DISCUSSION

### Selecting a Quality of Life Measure

The choice of a measure must rest with the investigator's particular purpose and needs. The most comprehensive and best characterized scales from a psychometric standpoint are the Oregon Quality of Life Questionnaire, the Lehman Quality of Life Interview, the Lancaster Quality of Life Profile, and the Heinrichs-Carpenter Quality of Life Scale. The first three cover similar domains of objective and subjective quality of life, are based upon comprehensive quality of life models, and have acceptable psychometric properties. They have been used with typical samples of severely mentally ill patients in the USA, which included high percentages of patients with schizophrenia. The Heinrichs-Carpenter Quality of Life Scale is also a comprehensive and well characterized instrument. However, it was developed for the more focal purpose of assessing the deficit functional symptoms of schizophrenia and requires administration by a trained clinician. As such it does not fit readily into the mainstream of quality of life assessment measures and must be viewed as more disease-specific than the others. All of these instruments require approximately 45 minutes to administer.

The remaining instruments have had much more limited usage and are less comprehensive. The Satisfaction with Life Domains Scale is a reasonably well-characterized and brief measure of life satisfaction that has been used with severely mentally ill populations. As it only measures life satisfaction, measures of quality of life functioning and resources would have to be added to provide a comprehensive quality of life assessment. The QLC was developed specifically for use in a clinic setting and seems particularly adapted to help clinicians assess the various areas of quality of life functioning. However it has no known psychometric properties and apparently has only been used in one small study. The Community Adjustment Form has demonstrated sensitivity to changes over time among patients assigned to alternative community treatment programs, but lacks adequate psychometric analysis. The WBPCI has not undergone any psychometric evaluation and has been used in only one study, but it has the important distinction of being the only instrument developed primarily by service consumers. Finally, the CQLI has been used as a companion to the UCIDI in the major evaluation of the NIMH CSP. Its major shortcoming also is that it has not been characterized adequately from a psychometric perspective.

For some of the measures described above, there are published norms for different samples of patients, thus allowing some comparisons of new patient samples with these samples. For the life satisfaction measures in the QOLI and SLDS, there are also national normative data because these measures were based heavily upon prior work assessing general quality of life in the USA (Andrews & Withey, 1976).

Beyond these instrument-specific comments, some general comments and caveats are warranted for the investigator or program evaluator seeking a quality of life measure for persons with

schizophrenia, whether one of those described above or some other. First, a major concern with using normative quality of life measures in this population is that floor effects are frequently encountered, especially in role functioning domains (e.g., spouse, parent, employment roles). Therefore special attention must be paid to instrument sensitivity. Such floor effects are typically not a problem in the domains of life satisfaction and resources. Second, significant numbers of these patients have problems with task perseverance and comprehension; therefore, pencil-and-paper questionnaires are ill-advised. Note that nearly all of the instruments discussed here are interviews.

## INTERPRETING QUALITY OF LIFE INFORMATION

Because of the newness of this field in psychiatric research, it is not possible to make specific recommendations about the interpretation of quality of life data. Conceptually, quality of life is generally seen as related to, but distinct from such clinical syndromes as depression and anxiety. Perhaps the most “important point about interpretation that can be made at present is the need to distinguish psychological quality of life, for example, life satisfaction or morale, from clinical symptomatology, particularly depression. We know that measures of subjective quality of life are clearly affected by clinical symptomatology (Lehman, 1983). However, at least conceptually, subjective quality of life equivalents are viewed as distinct from clinical syndromes. This distinction has particular relevance with regard to implications for interventions. That is, one might attempt to effect various changes in a patient’s environment to improve housing, financial or work dissatisfaction, whereas one might prescribe a clinical intervention, such as an antidepressant, to alleviate symptoms of depression. Certainly we can foresee the development of an interactive model between quality of life and clinical symptomatology, but at the very least we can say that to interpret adequately quality of life data from psychiatrically impaired populations one needs to assess both quality of life and clinical symptoms.

A common dilemma encountered in the assessment of quality of life among persons with schizophrenia is that at times their perceived quality of life differs from what social norms would predict. Such counterintuitive quality of life results frequently raise concerns about the reliability or validity of their quality of life assessments. While such basic psychometric concerns may be reasonable, the fact is that the psychometric properties of the better quality of life measures for persons with schizophrenia are comparable with those in the general population. Rather than reflecting measurement limitations, such intuitively inconsistent quality of life findings may offer valuable information for clinical interventions and service planning.

Counterintuitive quality of life results may reflect idiosyncratic views and values of persons experiencing schizophrenia and should affect the clinician’s approach to service planning. Patients are unlikely to be motivated to change circumstances with which they are content even if the clinician and family feel otherwise. Conversely, failure to address an area of life with which a patient is dissatisfied, even though the clinician and family view the patient’s circumstances as satisfactory, can adversely affect the treatment alliance with the patient. Such disagreements about quality of life may signal the need for a period of negotiation regarding treatment and service goals.

Counterintuitive quality of life findings also may represent patients’ accommodation to adverse circumstances. Patients who have lived with adversity for extended periods of time may report relative positive life satisfaction. Their satisfaction reflects an accommodation to their circumstances and does not necessarily mean that they would not seek changes in their lives if offered the hope and opportunity for such changes. Conversely, interventions that promote positive change, for example, vocational rehabilitation or a novel antipsychotic medication (e.g. clozapine), may produce transient decreases in life satisfaction in response to change and the renewed awareness that their lives could be

better. Such possibilities form the basis for caution and more thoughtful consideration about how we expect interventions to affect quality of life.

## RESEARCH NEEDS

In order to advance quality of life assessment for persons with schizophrenia to the point that more scientifically and clinically meaningful applications can be achieved, there are several areas of needed work. First, we need a clearer definition of what quality of life is and what it is not. The existing literature is characterized by conceptually clear but disparate models of quality of life as well as overly broad and vague definitions of the phrase “quality of life.” Definitions include life satisfaction, illness-related “deficit states,” very comprehensive multi-dimensional models of well-being, and ill-defined, although appealing humanistic notions. Second, with the adoption of a common definition, there needs to be some agreement about how to measure quality of life. This will allow us to begin to accumulate comparable data across studies and populations.

Third, we need to compare quality of life data from psychiatrically impaired populations with those from other non-psychiatric groups, particularly the physically disabled, the general population, and other economically disadvantaged groups to establish some normative perspective. Fourth, we need a better understanding about how quality of life varies naturally over time in psychiatric populations, the predictive validity of quality of life measures for subsequent illness course and outcome, and the sensitivity of quality of life measures for detecting treatment effects among these patients, who may at best experience very modest improvements.

Finally, there is a need for better and more specific conceptual models for integrating quality of life data into the evaluation of interventions for persons with schizophrenia. No matter how well measured, “quality of life” remains a complex, multi-dimensional outcome that can be unwieldy unless careful consideration is given to the hypotheses that underlie any particular application. Different types of interventions are likely to affect different dimensions of quality of life and to do so over different times frames for different persons. A time-limited efficacy trial for a new antipsychotic medication is likely to need a different type of quality of life impact assessment than a multi-year follow-up assessment of an assertive case management program. For the successful use of quality of life assessment, future research must be driven by more precise theories about how interventions may impact on quality of life.

## IMPORTANCE OF QUALITY OF LIFE ASSESSMENT IN ECONOMIC EVALUATIONS

A well known truism asserts, “You can’t buy happiness.” Nonetheless, it is also true that achievement of well-being can cost money, and it is therefore relevant to consider the relationship between quality of life outcomes and costs. The linkage of quality of life outcomes to costs is relatively virgin territory in mental health services research. Therefore, it is possible to offer only a theoretical rather than an empirical discussion of this topic. It seems useful to consider the issue from two perspectives, cost-effectiveness and cost-benefit.

The cost-effectiveness view is the more straightforward. All of the quality of life measures reviewed in this chapter generate a variety of quality of life indicators that could be used as effectiveness indicators in a cost-effectiveness evaluation. The major methodologic issues are which indicators of effectiveness to choose for a particular study and how to prioritize them. The choice of appropriate quality of life effectiveness indicators, as already discussed, must be governed by the nature of the intervention and the areas of expected or desired impact. More difficult are establishing the priorities among these indicators. For example, appropriate quality of life outcome indicators for a program for homeless persons with severe mental illness may include number of days housed, housing

satisfaction, victimization, satisfaction with personal safety, days in jail, amount of income supports, satisfaction with finances, contact with family, and satisfaction with family relations. For each of these quality of the outcomes, a cost-effectiveness ratio could be computed: e.g., the cost of achieving  $x$  number of days in stable housing or  $y$  units increase in housing satisfaction. It becomes a judgment call, however, to decide which among the various relevant quality of life outcomes are the most important. This is especially critical when a study does not yield consistent effectiveness across multiple indicators. For example, a program for the homeless may reduce days homeless and housing satisfaction, but not improve family relations. In such instances, short of some empirically derived valuation schema, cost-effectiveness ratios for the various outcomes can be reported and their relative significance interpreted within the overall context and goals of the intervention. The issue of the value of quality of life outcomes brings us to the more difficult cost-benefit perspective. Efforts can be made to estimate the actual monetary value of quality of life outcomes. This seems more feasible for some objective quality of life indicators, such as housing, victimization, arrests, and employment. However, it is quite problematic for other objective quality of life indicators, such as the frequency of contacts with friends and family, and for subjective quality of life indicators. What is the value of life satisfaction or the sense of well-being? It is, of course, possible to imagine procedures for estimating the utilities of alternative levels of these outcomes and relative trade-offs for other outcomes. Hence it may be possible to estimate the value of these for a cost-benefit analysis. These empirical approaches still beg the question, "At what price happiness?"

Given the current emphasis on the costs of outcomes, it is important to develop useful strategies that relate quality of life impacts to costs. The most fruitful avenue would seem to be through the cost-effectiveness perspective with an eye toward the relative priorities for various domains of quality of life outcomes. These priorities must take into consideration both the nature of the intervention and the values of the relevant stakeholders, including providers, payers, patients, families, and communities.

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