MEASURING QUALITY OF LIFE IN A REFORMED HEALTH SYSTEM

by Anthony F. Lehman

Prologue: One of the most troubling aspects of managed care be it for mental or physical ailments, is the degree to which the outcomes of care can be assessed. Many hours of research and many millions of dollars have been devoted to the development of outcomes measures. For chronic mental illness, one of the most promising avenues in this regard is a measurement of quality of life that constitutes what Anthony Lehman refers to as “quality-of-life outcome assessment frameworks.” The main components of such a framework are a person’s ability to function, access to resources and opportunities in the community, and sense of well-being. Three types of frameworks exist: general quality of life, health-related quality of life, and disease-specific quality of life. Lehman notes a recent upsurge in interest in quality-of-life concerns; underlying this interest, he states, “is the fundamental question about what difference medical treatments really make in people’s lives, reflected by the well-known medical aphorism, ‘The surgery was a success, but the patient died.’” Looking at quality of life as it relates to mental health care serves as an example “within the broader context of any chronic and debilitating illness that persists over many years and that detracts from a person’s productivity and economic status.” Lehman is professor of psychiatry and director of the Center for Mental Health Services Research at the University of Maryland School of Medicine in Baltimore. He received his medical degree in psychiatry from the University of Rochester and also holds a public health degree from the University of California, Los Angeles. Lehman is principal investigator for the Schizophrenia Patient Outcomes Research Team (PORT), a five-year federal study to develop treatment recommendations for schizophrenia.
Abstract: “Quality of life” encompasses functional status, access to resources and opportunities, and sense of well-being. It offers a useful perspective on the value of health care, especially for chronically disabling conditions, including chronic mental illness. At least three major quality-of-life outcome assessment frameworks are available: general quality of life, health-related quality of life, and disease-specific quality of life. Choice of a framework must be driven by the intent of the services. For persons with chronic, disabling conditions, a general quality-of-life perspective is most appropriate, one that accounts not only for direct health outcomes but also for the potential social and economic effects of medical disability.

Chronic, disabling illnesses exert substantial and complex influences on people’s lives. The array of needs generated by such illnesses poses particular challenges for delivery of health care and for monitoring the effectiveness of services for chronically ill persons. Although chronic mental illnesses are the main focus here, these disorders can be viewed as examples within the broader context of any chronic and debilitating illness that persists over many years and that detracts from a person’s productivity and economic status. The disabling impact of these illnesses often blurs the boundaries between health care and social services. The outcomes that are relevant to evaluating services for persons with chronic mental illness reflect this blurring and include psychiatric status, general health status, functional status, access to community resources and opportunities, and sense of well-being. The latter three domains constitute the main components of “quality of life.” Additional outcomes of concern include burdens to families and to society.

How useful would a quality-of-life outcome assessment be in a reformed health care system for persons with chronic mental illness and other disabling medical disorders? In particular, as both private and public health care systems move to contain costs through managed care in its various forms, the selection of patient outcomes to monitor system performance becomes increasingly critical. These outcomes define accountability and provide a set of values that can both guide and monitor reform. For what patient outcomes, other than standard clinical outcomes, such as symptoms, should the health care system be held accountable in regard to persons with chronic, disabling illness? At stake are both fairness to patients and their families, who rely largely upon health care providers and affiliated social services to address their needs, and fairness to providers, who face an increasingly managed health care system that holds them accountable for outcomes and resources that are used.

This paper begins with a brief overview of the impact of chronic mental illnesses on quality of life and some trends in designing managed care systems to address the needs of persons with these disorders. This sets the stage to discuss the rationale for including quality-of-life outcomes in assessments of health care and to review alternative frameworks for conceptual-
izing and measuring quality of life. Finally, I explore the potential promise of quality-of-life assessment in the reform of health care for disabling mental illness.

**Overview Of Chronic Mental Illness And Service Needs**

Chronic mental illnesses are those psychiatric disorders that are persistently disabling. Standard definitions of chronic mental illness draw upon diagnosis, duration of illness, and level of disability. Although a wide variety of psychiatric disorders can meet this definition, by far the most common chronic mental illnesses are schizophrenia and the major mood disorders, including manic-depressive (bipolar) illness and chronic major depression.

By definition, persons with chronic mental illness have impaired functional status that leads to an array of quality-of-life problems, including loss of family and social supports, unemployment, poverty, poor self-esteem, and, too often, substance abuse, homelessness, and victimization. These problems translate into a complex set of service needs: psychiatric treatment, social support and rehabilitation, vocational rehabilitation, income supports (for example, Supplemental Security Income or Social Security Disability Insurance), supportive and/or supervised housing, family services, general medical and dental care, and often also substance abuse treatment and legal services. The important point is that chronic mental illness generates not only medical but also social service needs that are related to impaired functional status and associated economic disadvantages. There is also good evidence that persons with chronic mental illness experience an impaired sense of well-being across many life domains, relative to the general population and even other economically disadvantaged groups.

**Models.** Although persons with chronic mental illness have traditionally been served by the public mental health system and are often excluded from private managed care groups by virtue of their unemployment or the “spending down” of available managed care benefits, for nearly two decades “models” of care for these persons have relied upon managed care concepts. This is exemplified by the principles of the National Institute of Mental Health (NIMH) Community Support Program (CSP) and the Wisconsin Program of Assertive Community Treatment (PACT) model.

The CSP concept asserts that an effective service system for persons with chronic mental illness must perform the following functions: (1) outreach to assure access; (2) assistance in meeting basic human needs (food, shelter, income supports, safety, and general medical and dental care); (3) mental health care; (4) twenty-four-hour crisis assistance; (5) psychosocial and vocational services; (6) rehabilitation and supportive housing; (7) consult-
ation and education; (8) support and assistance to patients’ natural support networks (families, friends, employers, landlords, and community agencies); (9) procedures to protect patients’ rights; and (10) ongoing case management. The CSP emphasizes comprehensive case management and ongoing accountability for the full range of service needs.

Similarly, the PACT model consists of an interdisciplinary treatment and case management team offering (1) assertive outreach; (2) availability twenty-four hours a day, seven days a week; (3) individualized psychiatric and general health care; (4) individualized social services, including access to entitlements and housing assistance; (5) rehabilitation services; (6) advocacy services; (7) an open-ended commitment to continuity of care; and (8) a high staff/patient ratio. PACT programs typically operate under a fixed per case budget, which is essentially a form of capitation.

Both of these models embrace the notion that appropriate care for persons with chronic mental illness must address their medical and psychiatric needs within the context of a comprehensive system of community-based support. The research on PACT suggests that this model is particularly effective at reducing unnecessary hospital admissions that stem from avoidable crises and at improving quality-of-life outcomes. These effects can be understood in the context of a “stress-vulnerability” model, which predicts that relapses arise when psychosocial stresses (often secondary to the disabling effects of the illness) interact with an underlying illness vulnerability to produce an acute illness relapse. For example, concerns about an impending eviction may produce sufficient stress to cause illness relapse and rehospitalization. From both cost and humanitarian perspectives, it makes sense to reduce the risk of relapse by addressing both health care and social support needs in a stable, continuous, and comprehensive service package. Appropriate care for persons with chronic mental illness therefore must address the social needs arising from disability in addition to providing appropriate medical care. Failure to assume this comprehensive care approach risks higher costs and poorer outcomes. This recognition has led several states to experiment with capitation approaches to managing the care of persons with chronic mental illness.

Why Measure Quality Of Life As An Outcome Of Health Care?

Quality-of-life concerns have gained considerable currency throughout the entire field of health care during the past decade. Several books have been published recently on the topic, entire issues of journals have been devoted to indexing quality-of-life measures, and new publications have been created to deal with the rapidly growing volume of research on the topic (such as Quality-of-Life Research and Quality-of-Life Newsletter).
Underlying this interest in quality of life is the fundamental question about what difference medical treatments really make in patients' lives, reflected by the well-known medical aphorism, “The surgery was a success, but the patient died.” Medical outcome assessments that focus strictly on the signs and symptoms of disease (for example, tumor size or survival time in cancer, range of motion or “joint counts” in arthritis, expiratory volume in lung disease, seizure frequency in epilepsy, or hallucinations in schizophrenia) are recognized as essential but not sufficient outcome monitors.

A humanitarian concern about the overall well-being of patients and concerns about costs are driving this movement toward quality-of-life research. For example, pharmaceutical companies now face U.S. Food and Drug Administration (FDA) expectations for evidence about the quality-of-life impact of new drugs. Such evidence may be used by hospital formulary committees in cost/benefit decisions to approve the use of new drugs in their facilities. Public policymakers and consumer groups raise the quality-of-life issue in discussions about what treatments are worthwhile.

Defining And Measuring Quality of Life

Although definitions vary, the quality-of-life concept encompasses what a person is capable of doing (functional status), access to resources and opportunities to use these abilities to pursue interests, and sense of well-being. The former two dimensions are often referred to as objective quality of life and the latter as subjective quality of life. Within these overarching dimensions, life domains have been identified (for example, health, family, social relations, work, financial status, and living situation). Quality of life thus is a complex notion. Three perspectives can be identified to frame core issues regarding quality-of-life assessment in health care: (1) the general quality-of-life framework; (2) the health-related quality-of-life framework; and (3) the disease-specific quality-of-life framework.

General quality-of-life framework. A considerable amount of research on broader issues of the quality of life of the general population has preceded the more recent development of quality-of-life research in the health care context. The intent of this research has been to derive a social perspective about how groups of people are doing and the value that they and their societies place upon various aspects of life experience. Such a perspective may provide insights into what people strive for, why they choose as they do, and how different societies and subgroups within a society fare in their life aspirations relative to others. These insights may guide decisions about how to improve quality of life. Measures based on this approach typically cover functional status, access to resources and opportunities, and sense of well-being across multiple life domains, some not
necessarily directly affected by health care (for example, housing).

An example of this type of quality-of-life measure is the Quality-of-Life Interview (QOLI), which was specifically developed to assess outcomes for persons with chronic mental illness. The QOLI assesses recent life experiences of the respondent in a variety of life domains, including living situation, family relations, social relations, daily activities, finances, safety and legal problems, work and school, and health (as well as religion and neighborhood in some versions). The sections on each life domain are organized such that information first is obtained about objective quality of life and then about life satisfaction in that domain. The variables generated by the QOLI include Objective Quality-of-Life Indicators: length of time at current residence, residential stability, homelessness, daily activities, frequency of family contacts, frequency of social contacts, total monthly spending money, adequacy of financial supports, current employment status, nights in jail, victimization, and general health status; and Subjective Quality-of-Life Indicators: satisfaction with living situation, daily activities, family relations, social relations, finances, work and school, legal issues and safety, and health.

Health-related quality-of-life framework. The notion of health-related quality of life emphasizes that of primary interest in the evaluation of health care are the specific impacts that disease, injury, and their prevention and treatment have on the value of survival. The concept of health-related quality of life acknowledges the limited but often vital influences that disease and health care have on quality of life, and holds health care accountable only for those aspects of quality of life that it may directly affect. The health-related quality-of-life framework focuses on functional status and sense of well-being, and within these dimensions covers only those aspects directly related to health (for example, functional role limitations stemming from emotional or physical illness as opposed to role limitations resulting from poverty or limited social opportunities).

The constructs measured by two well-known health-related quality-of-life measures illustrate this focus. The scales of the Duke Health Profile assess physical health, mental health, social health, perceived health, disability, and pain. The Medical Outcomes Study Health Status Form (MOS SF-36) measures physical functioning, role limitations stemming from physical problems, social functioning, physical pain, general mental health, role limitations stemming from emotional problems, vitality, and general health perceptions. Such measures offer generic, health-related quality-of-life assessments that can be used across most medical conditions.

Disease-specific quality-of-life framework. Marilyn Bergner presses for an even narrower definition of quality of life in health care evaluations: “Quality of life, just as health or illness, must be assessed specifically.
Although a few basic measurements might be applicable to everyone in every situation . . ., many more are relevant only to a particular patient. This raises the issue of disease-specific quality-of-life assessment, which is tailored to the potential quality-of-life impacts of a specific disorder and its treatment. This framework focuses entirely upon impairments that are due to a specific disorder and the effects and side effects of treatments for that disorder (such as an arthritis quality-of-life measure that assesses joint pain and mobility and the side effects of antiinflammatory agents, or a depression quality-of-life measure that assesses the symptoms of depression and such medication side effects as blurred vision, dry mouth, constipation, and impotence). As yet there are no disease-specific quality-of-life measures for chronic mental illnesses.

### Choosing A Quality-Of-Life Evaluation Framework

The choice of a quality-of-life outcome framework should be guided by the goals of the health care service being evaluated. The framework used conveys powerful messages regarding expectations and accountability to both the provider and the patient.

In developing an assessment of quality of life in a health care context, one must consider both the breadth and the specificity of the measures. No single quality-of-life measure will meet all needs. A general quality-of-life approach may raise issues that health care cannot reasonably be expected to address (such as decent and affordable housing or access to good jobs), and hence may be insensitive to the effects of health care on quality of life. A disease-specific approach, while sensitive to the issues that are of concern to patients with a specific diagnosis, lacks generalizability and comparability to other patient groups. General health-related quality-of-life measures, such as the Duke Health Profile and the MOS SF-36, permit fruitful comparisons across conditions but may lack sufficient specificity to guide improvements in care for persons with specific health problems. The information derived from health-related quality-of-life measures may be too narrow to adequately reflect the needs of persons who are chronically disabled and socially disadvantaged because of medical problems.

Quality-of-life assessments for persons with chronic mental illness have typically assumed a general quality-of-life perspective, assessing multiple life domains and including measures of functional status, access to resources and opportunities, and sense of well-being. The fact that quality-of-life assessments for chronic mental illnesses have taken this tack reflects the social and economic impacts of these disabling conditions on patients and the policy context in which they have evolved. Quality-of-life assessments for persons with chronic mental illness arose in the era of deinstitutionalization.
zation and the need to develop strategies (such as the CSP and PACT) to care for these persons in the community. In this regard, it was not only patients’ medical needs that were of concern (that is, proper pharmacotherapy, psychiatric care, and medical care) but also their social support needs (decent housing, income support, safety, and integration into families and communities). Therefore, a wider social perspective was chosen to assess these broader issues and to inform policymakers and service providers about how well comprehensive service programs, not just treatments, were addressing these needs.

Still, the choice of an appropriate quality-of-life assessment strategy for services for persons with chronic mental illness depends upon the context. Two examples illustrate this.

**Example one:** A managed care firm contracts with a medical provider for medical and psychiatric services for enrollees with schizophrenia. The contract includes a performance assessment of patient outcomes. Payment under the contract is on a fee-for-service basis with agreed-upon unit prices. What outcomes should be monitored? Keep in mind that the typical patient with schizophrenia will have many needs, including housing, rehabilitation, and other social supports. Should the managed care firm hold the medical provider accountable for such outcomes as episodes of homelessness, unemployment, and patients’ complaints about lack of opportunities to make friends? Since these outcomes are not directly related to adequate pharmacotherapy and other medical treatments, it would seem unreasonable to hold the medical provider accountable for these. In this case, a disease-specific or health-related quality-of-life framework would seem more reasonable—one that monitors psychiatric symptoms (hallucinations, delusions, suicidal behavior, depression), general health status, and side effects of antipsychotic medications.

**Example two:** A state mental health authority contracts with a managed care provider to deliver comprehensive services for chronically mentally ill patients using a capitation payment system. The capitation rate is set at $30,000 per year, which is 80 percent of the state’s estimate of its current costs for caring for these patients in its own hospitals and clinics. The authority’s goal is to reduce costs while maintaining or enhancing quality. What patient outcomes should be built into the performance contract? Under these circumstances, a broad quality-of-life outcome framework would be appropriate. Although the actual design of the service program is left to the managed care provider, the state wants to hold the provider accountable for the broad range of service needs previously met directly by the state. A broad quality-of-life outcome perspective coincides with this mandate and would include clinical outcomes (control of symptoms), functional status (involvement in rehabilitation, vocational activities, and
achievement), sense of well-being, and access to resources and opportunities (successful application for entitlements, reasonable housing, reduction of homelessness, and legal advocacy to eliminate unnecessary diversion to the criminal justice system). The managed care provider could decide how to best achieve these outcomes but would be held accountable for them. The provider may decide to directly operate PACT programs that deliver comprehensive treatment and support services or may contract out some of these services, such as for case management to help patients secure and maintain decent and affordable housing or for vocational rehabilitation services for those who need it.

Benefits And Risks

Quality-of-life assessments can prove useful in determining needs, developing intervention strategies, and evaluating the outcomes of interventions at both the system and the individual patient levels. At the system or policy level, the development of services and the deployment of resources must derive from a clear understanding of the needs of those being served and the priorities of these needs. Regarding system planning for persons with chronic mental illness, quality-of-life assessments provide important information about how patients are experiencing their current life circumstances (not just their health status) and permit some estimation of the priorities that they place upon these needs. Such information may be vital for allocating resources within service systems based on patients’ priorities. Although the ultimate allocation of resources must take into account the needs and perceptions of multiple constituencies (families, providers, and communities), a patient-based quality-of-life assessment provides the opportunity for systematic input from service recipients who often lack access to this decision-making process. Also at the system level, quality-of-life assessments can provide ongoing feedback from these recipients about the outcomes of services and thus influence the further development of service and resource allocation.

At the individual patient level, quality-of-life assessments can be used similarly to determine needs and to monitor the impact of treatment interventions and services. Ulf Malm and colleagues used a quality-of-life assessment to guide treatment planning in a mental health clinic. Ronald Diamond and George Awad have discussed the use of quality-of-life assessments in the context of psychopharmacology for patients with chronic mental illness, in particular, to enhance comfort and compliance. Robert Liberman has proposed that in a rehabilitation context, quality-of-life assessments can be used to identify those life areas with which a patient is most dissatisfied and which therefore may be most fruitful to address in a
behavioral treatment program. \(^\text{21}\) And Joseph Oliver and colleagues in Great Britain have used quality-of-life assessments in developing and evaluating a reformed national health policy mandating case management services. \(^\text{22}\)

As with any assessment endeavor, one must consider the costs as well as the benefits of collecting quality-of-life data. It is difficult to argue against assessment in principle or to identify ways in which improving the health care system’s knowledge about patients’ quality of life can do any harm. However, collecting meaningful and sound quality-of-life information is not a trivial task, and therefore it must be efficient and goal-directed.

There are at least three important potential risks or costs of quality-of-life assessment. First are the monetary costs of collecting the data and the burden placed on respondents. This is an obvious concern, and the point simply needs to be made that the most efficient means of assessment should be used. Assessment costs and burden on respondents will be affected by the length of the quality-of-life measures (determined in turn by both their psychometric efficiency and their scope), mode of administration (for example, interview versus questionnaire), and frequency of administration. A brief quality-of-life assessment administered relatively infrequently (such as one to three times a year) with a high response rate will be far more valuable than a more burdensome, frequent assessment that burns out respondents and agencies and yields highly incomplete data. Excessively costly assessment procedures will be rejected as not being cost-effective.

A second risk of collecting quality-of-life data is a mismatch between the quality-of-life domains assessed and the mission of the treatment or service provider. As already mentioned, measurement of an outcome implies accountability. Thus, only those aspects of quality of life for which a health care provider will be held accountable should be measured. This seems obvious, but it actually requires careful forethought. Typically, when a health care provider develops an interest in assessing or a need to assess quality of life, this should precipitate considerable reflection and debate about its mission in order to decide what to measure.

A third risk, related to the first two, is information overload. Quality-of-life assessment can easily generate more data than an agency can process or interpret. Focusing on the top quality-of-life priorities relevant to the agency’s mission and use of brief, efficient measures will keep the information relevant and reduce the risk of assessment burnout.

Conclusions

Quality-of-life impacts are becoming a standard aspect of outcome assessments in health care. This focus on functional status, access to resources and opportunities, and sense of well-being broadens the accountability of
the health care system in meeting the needs of patients. The value of health care will be judged more and more by balancing costs and impacts on quality of life. At least three major quality-of-life assessment frameworks are available, and the choice of a framework must be driven by the context of the services being evaluated. The benefits and costs of using quality-of-life assessments also must be weighed. From an individual provider’s standpoint, only those aspects of quality of life that reasonably can be expected to respond to the service mission should be assessed. Health-related and disease-specific quality-of-life frameworks are most appropriate for time-limited (for example, acute inpatient episodes) or narrow service programs (for example, medication clinics) for persons with chronic mental illness. Broader, more general quality-of-life assessments are needed for evaluating ongoing comprehensive service systems. At present, these are primarily in the public sector but, with the changing health care environment, may soon include systems of care that are funded by public dollars and managed privately, integrating networks of public and private providers.

Given the ongoing risks of fragmentation of services for persons with chronic mental illness, from a health care policy standpoint society must take a broad quality-of-life perspective. This will enable us to assess whether needed medical and supportive social services are being delivered and to detect inappropriate cost shifting to publicly supported nonhealth care sectors (such as the criminal justice system), which is always a risk with this vulnerable patient population.

NOTES

2. Attkisson et al., “Clinical Services Research.”
3. Ibid.
6. Stein and Test, “Alternative to Mental Hospital Treatment.”
8. B. Spilker, ed., Quality of Life Assessments in Clinical Trials (New York: Plenum Press, 1990); D. Patrick and P. Erickson, Health Status and Health Policy: Allocating Resources

9. Schulberg and Bromet, “Strategies for Evaluating the Outcome of Community Services;” Mechanic and Aiken, Paying for Services; and Patrick and Erickson, Health Status and Health Policy.


18. Schulberg and Bromet, “Strategies for Evaluating the Outcome of Community Services.”


