Quality of Life as an Outcome Measure in Pulmonary Diseases

Robert M. Kaplan, PhD; Andrew L. Ries, MD, MPH

Chronic obstructive pulmonary disease (COPD) is a disease state associated with airflow obstruction due to chronic bronchitis or emphysema. Patients with COPD experience significant limitations in daily activities. COPD has a profound effect upon functioning and everyday life. Current estimates suggest that COPD is diagnosed in approximately 11% of the adult population and the incidence is increasing. In addition, due to the large reserve in lung function and long preclinical phase of disease, patients are typically diagnosed late in the course of disease and many individuals with significant disease are unrecognized. Newer trends indicate that the rate of COPD among women is increasing to reflect the increase in tobacco use among women in the latter part of the 20th century. Reviews of the medical management of COPD justify the use of symptomatic measures including bronchodilators for stable patients and the addition of corticosteroids and antibiotic therapy for periodic exacerbations that characterize the course of disease. In addition, long-term oxygen therapy has been shown to be beneficial for patients with severe hypoxemia. Surgical interventions such as lung volume reduction surgery or lung transplantation may also be appropriate in selected patients. However, it is widely recognized that these measures cannot cure COPD. Pulmonary rehabilitation has been successful in improving symptoms, patient functioning, and quality of life (QOL).

The purpose of pulmonary rehabilitation is to improve outcomes for patients with chronic lung diseases including COPD, interstitial lung disease, and other lung diseases that cause activity limitations. Outcomes research brings a different perspective to the evaluation of rehabilitation programs that do not typically produce changes in traditional physiological measures of lung function or gas exchange.
A growing body of evidence suggests that patients who participate in rehabilitation programs experience reduced physical and psychological symptoms, have improved exercise tolerance, fewer hospitalizations and physician visits, and more gainful employment. Evidence-based reviews support the value of these programs. In this article, we emphasize outcomes as reported from the patient's perspective.

Methodologies to evaluate outcomes in chronic disease differ from those used for the assessment of acute disease. Treatments for acute disease often involve identification of the pathogen and eradication of problems leading to a complete cure. In contrast, chronic diseases are never cured; the goal is to reduce their impact. Different methodologies are required to evaluate interventions for chronic illnesses. Acute diseases are often identified through a biological test and patient reports about the experience are usually disregarded as unreliable. Most of the information required to diagnose and treat the condition can be identified in the laboratory. For chronic illnesses, patient interpretation of the condition and adaptation to the problem cannot be ignored. A different conceptual model is needed to measure consequences of chronic illness. We refer to this model as the Outcomes Model. In contrast to the Traditional Biomedical Model that requires identification of basic disease mechanism, the Outcomes Model emphasizes all medical and social factors that may affect the patient. Sometimes, the exact biological explanation for disability is unknown. For example, QOL outcomes in patients with pulmonary disease are not well predicted from measures of pulmonary function. The Outcomes Model accepts that biologic pathways may never be fully understood.

HEALTH-RELATED QUALITY OF LIFE

Chronic diseases and their consequent disabilities are important for 2 reasons. First, illness may cause a truncation of the life expectancy. In other words, those with specific diseases may die prematurely. Second, diseases may cause dysfunctions, as well as other symptoms, which lead to disabilities in an individual's performance of usual activities of daily living (ADLs). Biomedical studies typically refer to health outcomes in terms of mortality (death) and morbidity (disfunction) and sometimes to symptoms.

Over the last 30 years, medical and health services researchers have developed new quantitative methods to assess health status. These measures are often called quality-of-life measures. Because they are generally used exclusively to evaluate health status, we prefer the more descriptive term “health-related quality of life.”

MEASUREMENT OF HEALTH-RELATED QUALITY OF LIFE

Figure 1 summarizes the number of publications under the topic of quality of life identified in PubMed between 1972 and 2004. In 1972, PubMed does not identify any publications under the quality-of-life topic heading. However, over the next 30 years, the number of articles that use the “quality of life” keyword grew dramatically. In 2004, PubMed identified 5345 such articles. In one year from 2003 to 2004, the number of articles listed under the “quality of life” keyword grew by 10% (or nearly 500 articles). Quality of life is now a common outcome in studies of patients with chronic lung disease. A PubMed search crossing COPD with quality of life (in June 2005) yielded 1205 references. Adding the term rehabilitation still leaves 121 citations.

There are at least 3 reasons for measuring QOL in clinical studies. First, QOL measures are used to quantify the impact of a condition and to compare the effects of lung diseases with the consequences of other chronic medical problems. Second, QOL measures can be used to evaluate changes resulting from clinical intervention or the course of disease. Third, QOL measures are necessary as a central component of cost-effectiveness analysis. We will address each of these issues in the following sections.

A wide variety of measures has been used to quantify health-related QOL. These measures are similar in that each expresses the effects of medical care in terms that can be reported directly by a patient. However, the rationales for the methods differ considerably.

Distinctions Between Measures

Table 1 lists some of the many methods for evaluating QOL outcomes in studies of patients with lung diseases. The table makes several distinctions between measures. There are 2 major approaches to QOL assessment: psychometric and decision theory. The psychometric approach is used to offer a profile summarizing different dimensions of QOL. The best known example of the psychometric tradition is the Medical Outcomes Study 36-Item Short Form (SF-36). The decision theory approach attempts to weight the different dimensions of health in order to provide a single expression of health status. Supporters of this approach argue that psychometric methods fail to consider that different health problems are not of equal concern. A minor itch is a symptom and coughing up blood is also a symptom. However, the importance of a minor itch and coughing blood are not equal. Simple symptom counts may miss the severity or impact of more serious complaints.

In an experimental trial using the psychometric approach, some aspects of QOL may improve while
others get worse. For example, a medication might reduce coughing, but increase skin problems or reduce energy. When components of outcome change in different directions, an overall subjective evaluation is often used to integrate the components and offer a summary of whether the patient is better or worse off. The decision theory approach attempts to provide an overall measure of QOL that integrates subjective function states, preferences for these states, morbidity, and mortality.

In addition to the distinction between psychometric and decision theory approaches, measures can be classified as either generic (top of Table 1) or disease targeted (bottom of Table 1). Generic measures can be used with any population, whereas disease-targeted measures are used for patients with a particular diagnosis. Finally, measures can be divided by their probable uses. Most measures can used to characterize populations and to study clinical changes. However, only generic, decision theory–based measures can be used to evaluate cost-effectiveness.

The measures will be reviewed in the following sections. We begin with the disease-targeted approaches and then cover the generic methods. Although our review touches on different methods, we devote greater attention to generic, decision theory–based methods because they have received less attention in previous reviews.

DISEASE-TARGETED METHODS

This section reviews measures of health-related QOL that have been designed specifically for patients with lung diseases. All measures cannot be covered in the limited space allowed, so we will concentrate on a few

Table 1 • SUMMARY OF QUALITY-OF-LIFE MEASURES USED TO EVALUATE OUTCOMES IN ADULTS WITH CHRONIC LUNG DISEASES

<table>
<thead>
<tr>
<th>Measure</th>
<th>Type</th>
<th>Purposes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disease-Targeted Measures</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chronic Respiratory Questionnaire</td>
<td>Profile</td>
<td>Descriptive studies, clinical change</td>
</tr>
<tr>
<td>UCSD Shortness of Breath</td>
<td>Profile/Symptom-specific</td>
<td>Descriptive studies, clinical change</td>
</tr>
<tr>
<td>St George’s Respiratory Questionnaire (SGRQ)</td>
<td>Profile</td>
<td>Descriptive studies, clinical change</td>
</tr>
<tr>
<td>Generic Measures</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SF-36</td>
<td>Profile</td>
<td>Descriptive studies, clinical change</td>
</tr>
<tr>
<td>Sickness Impact Profile (SIP)</td>
<td>Profile</td>
<td>Descriptive studies, clinical change</td>
</tr>
<tr>
<td>Nottingham Health Profile (NHP)</td>
<td>Profile</td>
<td>Descriptive studies, clinical change</td>
</tr>
<tr>
<td>Health Utilities Index (HUI)</td>
<td>Decision Theory</td>
<td>Descriptive studies, clinical change, cost-effectiveness</td>
</tr>
<tr>
<td>EuroQol (EQ-5D)</td>
<td>Decision Theory</td>
<td>Descriptive studies, clinical change, cost-effectiveness</td>
</tr>
<tr>
<td>Quality of Well-being Scale (QWB)</td>
<td>Decision Theory</td>
<td>Descriptive studies, clinical change, cost-effectiveness</td>
</tr>
<tr>
<td>Health and Activities Limitations Index (HALex)</td>
<td>Decision Theory</td>
<td>Descriptive studies, clinical change, cost-effectiveness</td>
</tr>
</tbody>
</table>
Chronic Respiratory Questionnaire

The Chronic Respiratory Questionnaire (CRQ) is a disease-specific QOL instrument that evaluates 4 domains: dyspnea, fatigue, emotional function, and mastery. It should be noted that for the dyspnea measure, patients are asked to rate breathlessness on 5 most important ADLs that they choose from a standard list. Therefore, this measure is unique to each individual and cannot be compared between subjects. The 20-item questionnaire can be administered in about 15 to 25 minutes. In one study, it was demonstrated that the questionnaire was responsive to change for 13 patients participating in a drug treatment protocol and 28 patients participating in a respiratory rehabilitation program. Changes on the questionnaire correlated with changes in spirometric values, exercise performance, and subjective ratings of improvement by both the patients and the physicians. In another study, the questionnaire was demonstrated to be sensitive to bronchodilator treatment. Guyatt et al also administered the CRQ in a pretest-posttest study on the effects of bronchodilators. At the posttest, half of the patients were shown their previous responses. When patients were given information about their previous responses, changes in CRQ scores for dyspnea and fatigue were more strongly correlated with changes in spirometry, exercise performance, and subjective ratings of improvement than they were for patients who had not been given the information. Guyatt et al believe this finding supports giving patients feedback on their previous responses. In a fourth study, Jaeschke et al evaluated changes in CRQ scores against changes in global ratings of change. Using global change rating as the criterion, they argued that the CRQ captured clinically important differences. The CRQ has been used in several trials of rehabilitation.

St. George’s Respiratory Questionnaire

The St. George’s Respiratory Questionnaire (SGRQ) is a self-administered standardized 50-item instrument with 3 separate scales (symptoms, activity, and impacts on daily life). A total score can also be calculated from the 3 component scores. Specific questions carry varying weights. The questionnaire has been evaluated for reliability and validity in several studies of patients with chronic lung disease of varying severity, particularly COPD and asthma.

Despite the advantages of general and disease-specific QOL measures, lung disease specialists have been concerned that global approaches may miss some of the most important outcomes in their patients. For example, several studies have observed low correlations between general QOL measures and measures of lung functioning. However, the correlation between QOL and dyspnea was substantial. Schrier et al found no correlation between lung function tests and SIP scores. However, they did observe substantial correlations between symptoms of wheezing and dyspnea and SIP scores. Yet, the general measures miss many of the subtle characteristics or subtle aspects of the clinically important symptoms. These findings suggest that measures of shortness of breath may be of central importance for evaluating outcomes in COPD. In the next sections the construct of shortness of breath is explored in more detail. One of these measures relates shortness of breath during daily activities, while the others measure dyspnea.

UCSD Shortness of Breath Questionnaire

The Shortness of Breath Questionnaire is self-administered and asks subjects to rate their breathlessness for 21 various daily activities (plus 3 overall items) on a 6-point scale from none at all (0) to severe (4) to maximal or unable to do because of breathlessness (5). For activities that they do not typically perform, respondents are expected to estimate their breathlessness for that activity. The 21 ADLs are grouped according to factor analysis into 4 categories of ADLs: rest and light ADLs (Factor 1), 8 questions; moderate ADLs (Factor 2), 5 questions; walking (Factor 3), 4 questions; and strenuous ADLs (Factor 4), 4 questions. The score on each of the 24 items is summed to produce a total score (range of 0 to 120).

DYSPNEA

Dyspnea, the clinical term for shortness of breath, is defined as the subjective sensation of difficult or labored breathing. Dyspnea is one of the most common and disabling symptoms of people with COPD. Therefore, measures of dyspnea are used commonly in evaluating outcomes in chronic lung disease. The sensation of labored breathing can be extremely distressing and may be perceived as life threatening, in addition to limiting the function and QOL of people with COPD. Although this review focuses on the measurement of dyspnea in COPD, it should be noted that dyspnea is a common symptom of other medical conditions as well (eg, cardiac disease, obesity, neuromuscular disorders affecting the respiratory system). The sensation of dyspnea is often accompanied by fear and anxiety. Several authors have described a dyspnea-panic cycle in which the experience of breathlessness leads to anxiety, which creates muscle tension,
The distress caused by dyspnea can become part of a vicious cycle leading to fear of future attacks of shortness of breath. This may cause patients with COPD to slowly decrease their activity level, resulting in greatly limited independent functioning and QOL, and furthering the course of deterioration in COPD.

Despite its importance, dyspnea is not well understood. Dyspnea represents a complex interplay of physiologic and psychological mechanisms. Dyspnea correlates only modestly with measures of lung function, and although many theories of physiologic mechanisms have been proposed, none has received consistent support. It is not uncommon to encounter patients with mild impairment in lung function who report extreme breathlessness and, on the other hand, patients with severe impairment who report little breathlessness. Although it is agreed that dyspnea is an important clinical symptom, the measurement of dyspnea presents several methodological and technical challenges. A number of instruments are available to assess dyspnea, including structured interviews and self-report questionnaires that evaluate a patient’s historical recall of breathlessness associated with daily activities and measures of perceived breathlessness that can be administered during an exercise or physical stimulus to report symptoms occurring at that specific point in time. Dyspnea may be measured in a variety of clinical and research settings. Some of these measures are summarized in Table 2. The table lists 7 methods and offers some evidence for the validity of each. The center column of the table offers a brief description and makes the distinction between measures that ask for recall of dyspnea associated with activities and measures that ask subjects to rate perceived symptoms during exercise or some other physical stimulus. A review of dyspnea measures by Eakin et al offers more details about the measures and their properties.

The literature on dyspnea measurement reflects a lack of consensus and standardization. It is difficult to determine which are the most reliable and valid measures for a given setting. And there are few standards for the administration of measures or the induction of dyspnea.

### Table 2 - SUMMARY OF DYSPNEA MEASURES

<table>
<thead>
<tr>
<th>Measure</th>
<th>Description</th>
<th>Validity Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>British Medical Research Council (MRC)</td>
<td>5 yes-no questions about shortness of breath. Requires recall.</td>
<td>$r = -0.53$ with other dyspnea measures, $r = -0.42$ with FEV$_{1.0}$</td>
</tr>
<tr>
<td>American Thoracic Society Respirator Questionnaire</td>
<td>5 yes-no items. Similar to MRC, but asks about magnitude of effort and impairment. Requires recall.</td>
<td>$r = 0.50$ with MRC questionnaire</td>
</tr>
<tr>
<td>Baseline and Transition Dyspnea Indexes (BDI-TDI)</td>
<td>Single ratings in 3 categories. Ratings of transition require recall of baseline dyspnea.</td>
<td>$r = 0.53$ with other dyspnea indexes, $r = 0.60$ with 6 minute walk</td>
</tr>
<tr>
<td>Modified Dyspnea Index</td>
<td>Ratings for impairment at work and impairment at home. Similar to BDI. Requires recall.</td>
<td>$r = 0.71$ with FEV$_{1.0}$</td>
</tr>
<tr>
<td>Oxygen Cost Diagram (OCD)</td>
<td>Ratings of breathlessness with different activities on 10-cm line associated with ADLs. Requires recall.</td>
<td>$r = 0.68$ with 6 min walk, $r = -0.53$ to $-0.79$ with other dyspnea measures</td>
</tr>
<tr>
<td>Visual Analogue Scale (VAS)</td>
<td>10-cm line to rate perceived symptom associated with exercise or physical stimulus. This measure does not require recall—ratings are taken during activity.</td>
<td>$r = -0.85$ with peak expiratory flow rate.</td>
</tr>
<tr>
<td>Borg Scale</td>
<td>0 to 10 rating scale for rating intensity of breathlessness on 1-10 log scale. This measure does not require recall—ratings are taken during activity.</td>
<td>$r$ with FEV$_{1.0} = 0.88$</td>
</tr>
</tbody>
</table>

Note: More detailed descriptions of the measures and validity studies are summarized by Eakin et al.22

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Profile Methods

**SF-36**

Perhaps the most commonly used outcome measure in the world today is the Medical Outcome Study Short Form-36 (SF-36). The SF-36 grew out of work by the RAND Corporation and the Medical Outcomes Study (MOS). Originally, it was based on the measurement strategy from the RAND Health Insurance Study. The MOS attempted to develop a very short, 20-item instrument known as the Short Form-20 or SF-20. However, the SF-20 did not have appropriate reliability for some dimensions. The SF-36 includes 8 health concepts: physical functioning, role-physical, bodily pain, general health perceptions, vitality, social functioning, role-emotional, and mental health. The SF-36 can be either administered by a trained interviewer or self-administered. It has many advantages. For example, it is brief, and there is substantial evidence for its reliability and validity. The SF-36 can be machine scored and has been evaluated in large population studies. The reliability and validity of the SF-36 are well documented.

Despite its many advantages, the SF-36 also presents some disadvantages. For example, it does not have age-specific questions and one cannot clearly determine whether it is equally appropriate at each level of the age continuum. The items for older retired individuals are the same as those for children. The SF-36 has become the most commonly used outcome measure in contemporary medicine.


**Nottingham Health Profile**

The Nottingham Health Profile (NHP) is a profile measure that has been particularly influential in the European community. The NHP has 2 parts. The first includes 38 items divided into 6 categories: sleep, physical mobility, energy, pain, emotional reactions, and social isolation. Items within each of these sections are rated in terms of relative importance. Items are rescaled in order to allow them to vary between 0 and 100 within each section.

The second part of the NHP includes 7 statements related to the areas of life most affected by health: employment, household activities, social life, home life, sex life, hobbies and interests, and holidays. The respondent indicates whether or not a health condition has affected his or her life in these areas. Used in a substantial number of studies, the NHP has considerable evidence for its reliability and validity.

The NHP is consumer based and arises from definitions of health offered by individuals in the community. Furthermore, this scale uses language easily interpreted by people in the community and conforms to minimum reading requirements. Substantial testing has been performed on the NHP. However, the NHP does not provide relative-importance weightings across dimensions. As a result, it is difficult to compare the dimensions directly with one another.

**DECISION THEORY APPROACHES**

Some approaches to the measurement of health-related QOL combine measures of morbidity and mortality to express health outcomes in units analogous to years of life. The years of life measure can be adjusted for diminished QOL associated with diseases or disabilities.

Modern measures of health outcome consider future as well as current health status. Lung cancer, for example, may have very little impact on current functioning but may have a substantial impact on life expectancy and functioning in the future. Today, a person with a malignant tumor in a lung may be functioning very much like a person with a chest cold. However, the cancer patient is more likely to remain dysfunctional or to die in the future. Comprehensive expressions of health status need to incorporate estimates of future outcomes as well as to measure current status.

Quality-of-life data can be used to help evaluate the cost-utility or cost-effectiveness of healthcare programs. Cost studies have gained in popularity because healthcare costs have grown so rapidly in recent years. Not all healthcare interventions equally return benefit for the expended dollar. Objective cost studies might guide policymakers toward an optimal and equitable distribution of scarce resources. Cost-effectiveness analysis typically quantifies the benefits of a healthcare intervention in terms of years of life, or quality-adjusted life years (QALYs). Cost-utility is a special use of cost-effectiveness that weights observable health states by preferences or utility judgments of quality. In cost-utility analysis, the benefits of medical care, surgical interventions, or preventive programs are expressed in terms of common QALYs.

If a man dies of COPD at age 60 and we expected him to live to age 80, we might conclude that the disease precipitated 20 lost life-years. If 100 men died at age 60 (and also had a life expectancy of 80 years), we might conclude that 2000 (100 men × 20 years) life-years had been lost. Yet death is not the only relevant outcome of lung disease. COPD might also cause long time and diminished QOL. QALYs take into consideration such consequences. For example, a disease that reduces QOL by one-half will take away 0.5 QALY over the course of each year. If the disease affects 2 people, it will take away 1 year (2 × 0.5) over each year. A medical treatment that improves QOL by 0.2 for each of 5 individuals will result in the equivalent of 1 QALY if the benefit persists for 1 year. This system has the
advantage of considering both benefits and side effects of programs in terms of the common QALY units.

Of the several different approaches for obtaining QALYs, most are similar. The most commonly used methods are the EQ-5D, the Health Utilities Index (HUI) and the Quality of Well-Being Scale (QWB), and the Health Activities Limitations Index (HALex).

**EQ-5D**

The approach most commonly used in the European community is the EQ-5D. This method, developed by Paul Kind and associates, has been advanced by a collaborative group from Western Europe known as the EuroQol group. The group, originally formed in 1987, comprises a network of international, multicenter, multidisciplinary researchers, originally from 7 centers in England, Finland, the Netherlands, Norway, and Sweden. More recently, researchers from Spain as well as researchers from Germany, Greece, Canada, the US, and Japan have joined the group. The intention of this effort was to develop a generic currency for health that could be used commonly across Europe. The original version of the EuroQol had 14 health states in 6 different domains. In addition, respondents placed their health on a continuum ranging from death (0.0) to perfect health (1.0). The method was validated in postal surveys in England, Sweden, and the Netherlands. More recent versions of the EuroQol, known as the EQ-5D, are now in use in a substantial number of clinical and population studies. Although the EQ-5D is easy to use and comprehensive, there have been some concerns about ceiling effects. Substantial numbers of people obtain the highest possible score.

General information on the EQ-5D can be located at: http://www.euroqol.org.

**Health Utilities Index**

The HUI is a family of health status and preference-based health-related QOL measures suitable for use in clinical and population studies. Each member of the family includes a health status classification system, a preference-based multi-attribute utility function, data collection questionnaires, and algorithms for deriving HUI variables from questionnaire responses. The Health Utilities Index Mark 2 (HUI2) consists of 7 dimensions of health status: sensation (vision, hearing, speech), mobility, emotion, cognition, self-care, pain and fertility. There are 5 to 6 levels per attribute. HUI2 focuses on capacity rather than on performance. Multiplicative multi-attribute utility functions based on community preferences have been estimated for HUI2 and HUI3. This form of function can represent a simple type of preference interaction among the attributes.

Evidence on test-retest reliability in the 1991 Statistics Canada General Social Survey has been reported. Agreement (kappa statistics) was high for most attributes. For the overall score, the intraclass correlation was 0.77. Evidence on agreement among assessors (self and proxy assessment) is provided by Glaser et al. Results indicate that self and proxy assessments should not be viewed as interchangeable, agreement varies by attribute, and that, in general, agreement was moderate to high. Evidence on responsiveness and construct validity has been published. Evidence of construct validity in the 1990 Ontario Health Survey is provided in Grootendorst. HUI3 described the burden of morbidity for both stroke and arthritis, showing disease impacts in the attributes that had been expected to be affected by these health conditions.


**Self-Administered Quality of Well-being Scale**

The QWB combines preference-weighted values for symptoms and functioning. The preference weights were obtained by ratings of 856 people from the general population. These judges rated the desirability of health conditions in order to place each on the continuum between death (0.00) and optimum health (1.00). Symptoms are assessed by questions that ask about the presence or absence of different symptoms complexes. Functioning is assessed by a series of questions designed to record functional limitations over the previous 3 days, within 3 separate domains (mobility, physical activity, and social activity). The 4 domain scores are combined into a total score that provides a numerical point-in-time expression of well-being that ranges from zero (0) for death to one (1.0) for asymptomatic optimum functioning.

The QWB has been used in numerous clinical trials and studies to evaluate medical and surgical therapies in conditions such as COPD, HIV, cystic fibrosis, diabetes mellitus, atrial fibrillation, lung transplantation, arthritis, end-stage renal disease, cancer, depression, and several other conditions. Further, the method has been used for health resource allocation modeling and has served as the basis for an innovative experiment on rationing of healthcare by the state of Oregon. Studies have also demonstrated that the QWB is responsive to clinical change derived from surgery or medical conditions such as rheumatoid arthritis, AIDS, and cystic fibrosis. The self-administered form of the QWB (QWB-SA) was developed more recently. It has been shown to be highly correlated with the interviewer-administered QWB and to retain the psychometric properties.

General information about the QWB can be found at: http://orpheus.ucsd.edu/famed/hoap/MEASURE.html.
Health and Activities Limitation Index

Where European investigators have invested in a standardized health-related QOL instrument, the EQ-5D, and the Canadians have de facto adopted the HUI3 as a national survey instrument, the United States has no one standardized instrument used broadly in national data sets. We have several national surveys of health: the National Longitudinal Study of Aging (LSOA), the Health and Retirement Study (HRS), the National Health and Nutrition Examination Study (NHANES), the National Health Interview Survey (NHIS), and the Medical Expenditure Panel Survey (MEPS).

There has, however, been an effort to develop an ad hoc measure in association with one of our largest national data sets, the NHIS. This measure is now called the Health and Activities Limitation Index, or HALex.77 This index grew out of a desire to have a single summary index of health for the NHIS data to compute a health-weighted summary of life expectancy measuring achievement on the Healthy People 2000 goals. This summary was called “Years of Healthy Life” and was developed by the National Center for Health Statistics retrospectively to use the NHIS data.78 The HALex has 2 dimensions, a 7-level classification of activities and function limitations ranging from “no limitations” to “limited in instrumental activities of daily living (IADLs)” and “limited in activities of daily living (ADLs)”, and self-rated overall health using the 5-level, “excellent, very good, good, fair, poor” classification. The resulting classification scheme has $7 \times 5 = 35$ health states. Building on prior attempts to develop a national composite index for health states,79 through a process using correspondence analysis, these states were weighted retrospectively to correspond to roughly what the investigators presumed they would be weighted by the HUI Mark I.77

Although its retrospective development may bring into question its validity, comparison to other indexes collected in different studies has shown favorable performance at a population level.80 This measure has 2 other attractive properties. First, it is computable in one of the major national data sets for health in the United States, the NHIS, so any study that collects data on activity and function limitations and self-rated health sufficient to score the HALex can compare results to this large national survey in the United States. Second, collecting sufficient data to score the measure does not seem onerous.

INTEGRATING COST OUTCOME WITH DATA

Although treatment programs provide health benefits, they also have costs. Resources are limited, and good policy requires that they be used wisely. Methodologies for estimating costs have now become standardized.83 From an administrative perspective, cost estimates include all costs of treatment and any costs associated with caring for side effects of treatment. Typically, economic discounting is applied to adjust for using current assets to achieve a future benefit. From a social perspective, costs are broader and may include costs of family members staying off work to provide care. Comparing treatment programs for a given population with a given medical condition, cost-effectiveness is measured as the change in costs of care for the program compared to the existing therapy or program, relative to the change in health measured in a standardized unit such as the QALY. The difference in costs over the difference in effectiveness is the incremental cost-effectiveness and is usually expressed as the cost/QALY. Because the objective of all programs is to produce QALYs, the cost/QALY ratio can be used to show the relative health benefits from investing in different programs.84

Rehabilitation service providers must compete with other healthcare providers for limited resources. In order to compete successfully, it will be necessary to document that rehabilitation services provide a benefit to the consumer. One of the advantages of using QALY outcomes is that the common metric allows for comparisons among very different types of services. All providers in the healthcare system have the common objectives of increasing length of life and improving QOL. General QOL outcomes, such as QALYs, allow evaluations of the relative value of investing in each of these specialties in comparison to the resources that they use. Several different governments have proposed allocating resources based on systematic data.84 For example, the Australian government now requires evidence of effectiveness, as do a variety of European governments. In Ontario, Canada, QALY has been considered as a basis for formulary decisions.83 Similar proposals have been considered in the United Kingdom.82

The American Thoracic Society maintains a Web site that summarizes QOL measures that can be used in outcomes research for lung disease. The site lists measures by disease and offers references on their use. You can access the site at: http://www.atsqol.org/.

SUMMARY

Current healthcare is built on an acute disease model. However, most resources are used for chronic illnesses. Measurement of outcomes for chronic pulmonary illnesses requires a different conceptualization of health. The Outcomes Model is an alternative perspective that focuses of life duration and life quality. From the outcomes perspective, QOL measures are essential to the assessment of treatment effectiveness.
Quality-of-life measures evolve from 2 different measurement traditions: psychometric theory and decision theory. Psychometric methods, such as the SF-36, typically create a profile of outcomes, whereas decision theory methods attempt to portray an integrative summary judgment of health. Decision theory methods are better suited for cost-effectiveness studies.

A review of current outcomes research for chronic pulmonary disease shows that QOL measures are now commonly used. There is substantial evidence for the validity of these measures in many chronic illnesses. QOL data are now commonly used in major clinical trials and in public policy analysis.

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