

# Using Health-related Quality-of-life Information:

## Clinical Encounters, Clinical Trials, and Health Policy

JOEL TSEVAT, MD, MPH, JANE C. WEEKS, MD, MS, EDWARD GUADAGNOLI, PhD,  
ANNA N. A. TOSTESON, ScD, CAROL M. MANGIONE, MD, MS,  
JOSEPH S. PLISKIN, PhD, MILTON C. WEINSTEIN, PhD, PAUL D. CLEARY, PhD

MANY HEALTH-RELATED DECISIONS faced by patients, physicians, researchers, and policymakers require information that goes beyond traditional biologic and physiologic outcomes. Information about purely physiologic outcomes is inadequate when a physician and a patient make decisions about treatment options that involve comparable survivals but markedly different impacts on the patient's health-related quality of life (HRQOL), because physiologic outcomes often do not correlate well with HRQOL.<sup>1-13</sup> Similarly, clinicians evaluating the effectiveness of new therapeutic interventions, such as antihypertensive agents, may want to review information about the impact of the drug on patients' HRQOL as well as on the biologic outcome, blood pressure.<sup>14, 15</sup> Finally, legislators faced with paying for health care within a constrained budget may find that data describing the biologic impact of various medical and surgical therapies are insufficient to make resource allocation decisions.

There is an emerging consensus that maximizing HRQOL is an important goal of medical care, particularly in the context of chronic diseases for which neither cure nor impending death is a likely outcome. There is less agreement, however, on how to measure HRQOL.<sup>16</sup> For many conditions, there exist a variety of reliable and

valid instruments.<sup>17, 18</sup> Yet disagreement over definitions and approaches to measuring HRQOL has inhibited the application of these measurement techniques in situations in which they probably could improve the decision making process. Much of this debate focuses, inappropriately, on the methodologic pros and cons of specific scales without adequately considering what they measure. The first step in integrating HRQOL information into medical practice, research, and health policy is to understand the appropriateness of the available instruments for particular purposes. In this article, we develop a framework of HRQOL measures, classifying them by underlying concepts,<sup>19-21</sup> measurement strategies, and scoring strategies. We then illustrate how HRQOL information from those measures should be used in making decisions among alternative treatments in each of three settings<sup>22-24</sup>: 1) the clinical encounter,<sup>25</sup> 2) clinical trials,<sup>14, 26-28</sup> and 3) health policy.<sup>19</sup>

## DEFINITIONS AND FRAMEWORK

Health-related quality of life can be defined as the "aspects of our lives that are dominated or significantly influenced by our mental or physical well-being."<sup>29</sup> The most fundamental distinction among HRQOL assessment techniques is whether they *describe* a person's state of health (health status measures) or ascertain a *value* for a state of health (measures of value, preference, or utility) (Fig. 1).

### Measurement Strategies

**Health status measures.** Health status measures describe states of health and their impact on function and disability. There are two general strategies for characterizing a person's state of health: objectively measuring it and asking the respondent about it. Examples of objective physical measures of health status include exercise tests, tests of visual acuity, and tests of grip strength [Fig. 1, (a)].

Most commonly, information about health status is obtained by eliciting reports and ratings from a patient or proxy. Such reports and ratings usually are descriptions of behavior or of symptoms and feelings.<sup>30</sup> For example, one way of assessing functional capacity is to ask a patient to rate or report his or her ability to climb stairs<sup>31, 32</sup> [Fig. 1, (b)]. Similarly, asking the patient to

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Received from the Divisions of Clinical Epidemiology and General Medicine and Primary Care, Beth Israel Hospital, Harvard Medical School (JT), Boston, Massachusetts; the Section for Clinical Epidemiology, Division of General Medicine and Primary Care, Brigham and Women's Hospital, Harvard Medical School (JT, JCW, MCW), Boston, Massachusetts; the Department of Health Policy and Management, Harvard School of Public Health (JT, JSP, MCW), Boston, Massachusetts; the Division of Cancer Epidemiology and Control, Dana-Farber Cancer Institute, Harvard Medical School (JCW), Boston, Massachusetts; the Department of Health Care Policy, Harvard Medical School (EG, PDC), Boston, Massachusetts; the Departments of Medicine and Community and Family Medicine, Dartmouth Medical School (ANAT), Hanover, New Hampshire; the Division of General Internal Medicine and Health Services Research, Department of Medicine, UCLA Medical School (CMM), Los Angeles, California; and the Department of Industrial Engineering and Management, Ben-Gurion University of the Negev (JSP), Beer Sheva, Israel.

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Address correspondence to: Joel Tsevat, MD, MPH, Department of Medicine, Beth Israel Hospital, 330 Brookline Avenue, Boston, MA 02215.

Address reprint requests to: Paul D. Cleary, PhD, Department of Health Care Policy, Harvard Medical School, Parcel B, 1st Floor, 25 Shattuck Street, Boston, MA 02115.

assess the severity of his or her dyspnea would generate a report or rating of a symptom or feeling<sup>33</sup> [Fig. 1, (c)]. Ratings can also encompass such domains as functional status, role activities, social functioning, emotional well-being, cognitive functioning, sleep and rest, pain, energy and vitality, and general health perceptions.<sup>21, 34, 35</sup> Ratings and reports may also be global (discussed below in Scope of Measurement). Global scales ask the patient to synthesize aspects that he or she believes to be germane and generate one rating (e.g., "Overall, how would you rate your health: excellent, very good, good, fair, or poor?"<sup>35, 36</sup>).

Health status measures that provide descriptions of a patient's current state of health can be valuable for decision making in clinical encounters, for interpreting clinical trial results, and for formulating guidelines. Health status measures are also useful for health services research, describing the natural history of disease, monitoring populations, case finding, casemix adjustment, and quality assurance/continuous quality improvement.<sup>19, 37</sup>

*Measures of preference, value, and utility.* Value measures (preferences, values, and utilities) ask respondents to assign a value to a particular state of health.<sup>38, 39</sup> Whereas two patients with dyspnea may have the same limitations, as assessed by a health status measure, they might assign very different levels of importance to their limitations and would score differently on a value measure.<sup>40, 41</sup>

The simplest way of assessing the value of a health state<sup>42-45</sup> is to ask the subject to rate it (e.g., on a scale from 0 to 100, where 0 usually represents death and 100 perfect health) [Fig. 1, (d)]. Alternatively, one can

ask the respondent to compare a health state with an explicit metric: time, money, another health state, or willingness to take risk. We refer to such questions as equivalence measures [Fig. 1, (e, f, g, h)]. The time-tradeoff technique asks how many months or years of life one would be willing to give up in exchange for a better health state [Fig. 1, (e)]. Magnitude estimation ascertains how many times better or worse one health state is than another [Fig. 1, (f)], whereas willingness to pay asks the respondent how much he or she would be willing to pay for improving his or her health state [Fig. 1, (g)]. Finally, the standard gamble, the most orthodox utility measure, determines the risk of (usually) death that one would be willing to take to improve a state of health [Fig. 1, (h)]. Values assessed by the time-tradeoff and standard-gamble methods are scored on a scale on which 0 usually represents death and 1 represents perfect health.<sup>43</sup>

An advantage of value measures is that they usually provide a summary measure of HRQOL that can be used for evaluating the complex tradeoffs that are so common in medical decision making. Although health status measures can be global, the properties of preference scales allow their scores to be combined with survival data to yield a single measure called quality-adjusted life years (QALYs).<sup>46</sup> A disadvantage of equivalence measures is that since they rely on a comparison with a value that is not health-related, they are influenced by other values. For example, willingness-to-pay methods are influenced by the respondent's income and assets and the value he or she attaches to money, as well as his or her preferences for health states. Similarly, time tradeoffs assess preferences concerning time as well as preferences re-

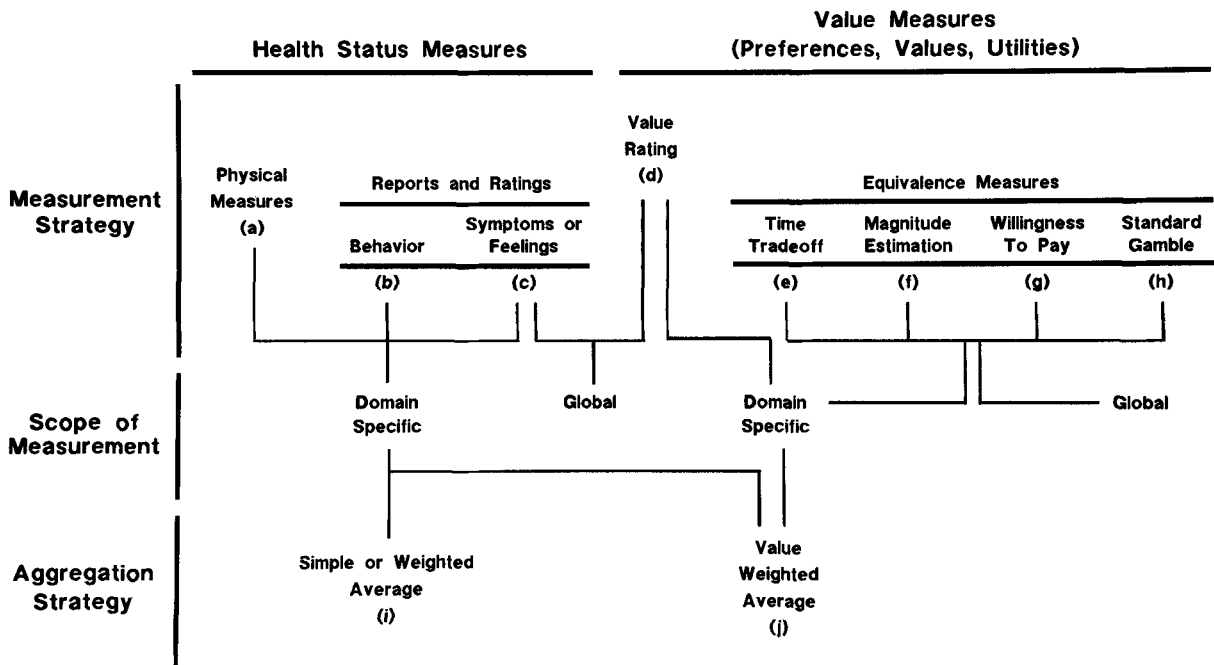


FIGURE 1. Taxonomy of health-related quality-of-life measures. Health status and value measures are categorized by measurement strategy, scope of measurement, and aggregation strategy. Different types of measures are identified by letters [(a)–(j)]. See text for details.

lated to health states. Standard gambles are influenced by how a respondent feels about risk; risk-averse individuals assign a higher utility to a given state of health than do risk-seeking individuals, all else being equal. Patients' feelings about the value of time and risk are certainly relevant to medical decision making, but it is important to be aware that the measures are not merely reflections of how they rate different health states.

### Scope of Measurement

Health status measures can be either domain-specific (referring to one attribute of health, such as physical functioning) or global (referring to overall health), whereas preference measures are usually global. An alternative (unrelated) classification of instruments is disease-specific vs generic. Disease-specific instruments are applicable to only one condition, such as arthritis, whereas generic instruments are applicable to any condition. Disease-specific measures may be more sensitive than generic health status instruments to clinically relevant changes in health over time,<sup>47, 48</sup> but generic measures afford comparison across diverse conditions.

### Aggregation Strategies

Many HRQOL instruments are designed so that an overall assessment of HRQOL can be obtained by combining domain-specific scores rather than by asking the respondent directly about global HRQOL. Several strategies have been used to determine how much importance or weight to assign to each part of an instrument in arriving at an overall score. The simplest approach is to average all items or subscales (Fig. 1, (i)). A more sophisticated approach is to weight each domain using empiric data on the importance of that domain [Fig. 1, (j)]. For example, one health status instrument weights each item using judges' ratings of the dysfunction associated with the given problem.<sup>49</sup>

## APPLICATIONS OF HEALTH STATUS AND HEALTH VALUE INFORMATION

### The Clinical Encounter

In some clinical situations, one treatment is so obviously preferable to the alternatives that HRQOL data are superfluous. For instance, if a patient has bacterial meningitis, there is no need (or time) to discuss the outcomes of antibiotic treatment or the patient's preferences regarding whether to administer them. Similarly, abrupt closure of a major coronary artery during percutaneous transluminal coronary angioplasty that is unresponsive to standard reversal procedures is a surgical emergency; information about HRQOL is not necessary for the immediate decisions required.

In many clinical situations, though, there are several possible treatments, with comparable survivals, for which

death is not a likely outcome or for which potential changes in survival must be balanced against potential changes in HRQOL. In such cases, the relevant information includes the effect of the therapy on HRQOL. In the following sections, we discuss several common clinical situations that help elucidate the types of information that—if available—would most facilitate clinical decision making.

### *The patient who wants to be involved actively in decision making.*

A 55-year-old woman with recently diagnosed localized breast cancer understands that mastectomy and lumpectomy plus radiation therapy will offer her similar chances of survival. Knowing what she values, she reviews with her physician information about the short- and long-term effects of each form of treatment on other aspects of health so that she can make her decision.

To make an informed choice, a patient who wishes to be involved actively in decision making should have information about the main outcomes of each reasonable treatment strategy,<sup>50</sup> including the impact on HRQOL. If alternative treatments offer similar life expectancies and differ only with respect to their impacts on certain aspects of health, then such information is paramount.

With information about the likelihoods of different outcomes, the patient can decide, using his or her own "internal" values, which set of outcomes he or she prefers; visual aids and written material may help patients assimilate information regarding treatment options, probabilities of outcomes, and anticipated health status.<sup>51</sup> Patients may differ in the weights they apply to different outcomes in making decisions involving such tradeoffs. For example, in the case described above, the patient is offered two equally efficacious forms of treatment. If she is presented with the outcomes experienced by women who have undergone those treatments, then she can weigh those outcomes and decide for herself which course of treatment she prefers. Her decision will reflect the relative importance she places on treatment duration, cosmetic results, arm function, and worry over recurrence of malignancy in her breast. If she wants to participate actively in decisions about health care and is able to assimilate the information presented, then there is no need to elicit her values for different states.

In general, there usually is little reason to provide the self-assured, actively involved patient with data describing other patients' preferences because those will reflect their values, which may differ from those of the patient. Yet competent patients may make decisions that seem to be unconventional and/or unreasonable; the basis of such choices may involve the complexity of the decision process, inordinate fear of pain or medical procedures, or deeply held beliefs or values.<sup>52, 53</sup> It is the patient's prerogative to incorporate his or her own values, but it is the physician's responsibility to attempt to

help patients avoid making decisions that are harmful to themselves. In such circumstances, a formal analysis of the potential risks and benefits of a procedure (i.e., decision analysis) could help patients to make a choice that is consistent with their best interests and ensure that the decision be driven by the patient's values rather than by a misunderstanding of the probabilities of the various outcomes.<sup>54</sup>

#### *The unsure patient who wants guidance.*

A previously healthy 55-year-old man has just had an acute myocardial infarction. His cardiologist has recommended and performed coronary angiography, which showed stenosis of two coronary arteries. The cardiologist explains the findings to the patient and informs him that possible treatment options include medication and/or percutaneous transluminal coronary angioplasty. The cardiologist explains the risks of the procedure, including the risk of restenosis after angioplasty. Overwhelmed by the recent events and unable to process all the information, the patient asks the physician, "What would you do if you were I?"

Patients may not always want or be able to use health status data to make decisions. Like the hypothetical patient with two-vessel coronary artery disease, they may be too distressed to evaluate clinical alternatives, may be overwhelmed by the complexity of the task, may not know what they value or how to compare values, or may simply prefer to defer the decision.<sup>39, 50</sup> What sort of information is most useful when a patient asks a clinician "What would you do if you were I?"

To the extent that the decision involves a tradeoff among HRQOL outcomes, the relative importances of those outcomes should be evaluated. If patients can provide any information at all about how they value those outcomes, then those preferences should be used. A generic decision analysis also can be very helpful in combining information about different health-related outcomes and in determining which patient values matter most for a given clinical decision.<sup>55</sup> For example, in helping a woman with recently diagnosed node-negative breast cancer to decide whether to undergo adjuvant chemotherapy, the decision analysis published by Hillner and Smith<sup>56</sup> could be very helpful. That analysis demonstrated that the best treatment plan for an individual patient depends on that patient's feelings about undergoing chemotherapy and her concerns about the recurrence of cancer. The analysis suggested that the preferred choice for a woman at low risk of recurrence, who is as frightened of chemotherapy as she is of cancer, is to forgo chemotherapy. In contrast, a woman with the same risk profile who would "do anything to prolong [her] life and avoid the return of cancer" would maximize her quality-adjusted life expectancy by choosing to have chemotherapy.

For patients participating in decisions regarding their care, preferences for outcomes can usually be ascer-

tained without resorting to formal measurements. In certain circumstances, however, formal preference assessment can be beneficial. For example, Pauker and Pauker<sup>57</sup> have used formal preference assessment to help couples decide whether they want a diagnostic amniocentesis.

#### *The patient who cannot participate in decision making.*

Over the past four months, a 35-year-old man with AIDS has developed manifestations of HIV-associated dementia, including memory loss and confusion. He is now admitted to the hospital with abdominal pain, diarrhea, and dehydration. During his hospitalization, questions arise regarding the performance of invasive diagnostic tests and the institution of therapies with potential benefits but toxic side effects. The patient cannot participate in the decision making process and had not signed any advance directive. His providers call for a family meeting to decide how to proceed.

In the case of the patient who cannot supply any information about his or her preferences, someone else must make the decision. To the extent that physicians consider outcomes besides mortality, they probably would incorporate their own preferences or the preferences of other health care professionals. Because those preferences are often incongruent with those of patients,<sup>58-60</sup> perhaps a preferable alternative would be to use the preferences of previous similar patients, if such data are available. Those preferences could have been obtained formally, or indirectly by observing choices made by patients who had been fully informed of the relevant survival and health status data.

### Clinical Trials

A randomized controlled trial of a new nonsteroidal anti-inflammatory drug in patients with osteoarthritis shows improvements in pain relief and joint mobility but a higher rate of peptic ulcer disease and renal insufficiency than does a second, commonly used agent. The costs of the two agents are comparable. Which of the two should be judged superior based on the clinical trial?

Increasingly, clinicians, researchers, and policy-makers agree that HRQOL information is usually useful and often essential in evaluating the results of clinical trials, especially when the interventions being evaluated have comparable impacts on survival, as in the case of nonsteroidal anti-inflammatory drugs.

Both health status data and preference data can be helpful in interpreting clinical trials.<sup>14, 15, 28, 40, 61-63</sup> For example, health status was a major endpoint in a study by Coates and coworkers<sup>61</sup> of two strategies for treating women with metastatic breast cancer: continuous and intermittent chemotherapies. They found that survivals in the two groups were not significantly different, but that patients in the continuous treatment group scored

higher on serial health status measures of overall HRQOL and on all attribute-specific measures except nausea. The authors reasonably concluded that continuous chemotherapy was a better strategy. Had they found that patients receiving continuous therapy lived slightly longer but experienced worse HRQOL than did patients receiving intermittent therapy, or that survivals were equivalent but patients in the continuous therapy arm reported more nausea, depression, and anxiety but better functional status, then identifying the “better” strategy would have been problematic. In such a case, global health status or preference measures might have helped resolve the issue.

Interventions sometimes involve tradeoffs between survival and HRQOL. Here, preference measures can be used to determine which (if any) therapy produces the best quality-adjusted survival. For example, Feeny and colleagues<sup>64</sup> have developed an instrument that could be used in clinical trials to assess quality-adjusted survival of children with cancer, where improved survival often comes at the expense of treatment-related morbidity.

As discussed above, health status and preference data from clinical trials have several uses beyond interpreting the results of clinical trials per se. For researchers, it would often be advantageous to ascertain both health status and health values in clinical trials.<sup>26, 65</sup> Because health value measures tend to be less responsive to clinical change than health status measures,<sup>66–72</sup> trials that plan to use health values as major endpoints may need large sample sizes. Health values may thus be more useful for weighting conflicting health outcomes than for detecting experimental effects.

### Resource Allocation

Facing increasing budget constraints, your legislature is trying to ensure universal coverage, but it knows that some services will have to be cut. It wishes to obtain the maximum benefit—in terms of reducing mortality and morbidity—given its health care budget, but finds the available data describing health services inadequate.

Perhaps the most vexing decisions facing health policymakers in the future will involve allocating resources among different treatments. One approach is to decide which therapies are the most “effective” and fund them preferentially. This usually is done by analyzing mortality data, but such an approach ignores both HRQOL and cost considerations.

When one wishes to compare the impacts on HRQOL of multiple approaches to one clinical problem, domain-specific health status data may suffice. But in order to combine information about different outcomes for different conditions, it is useful to have global measures of the outcomes. As mentioned previously, global equivalence measures can be used to create a combined score in common units—QALYs—representing the net im-

pact of treatment on both life expectancy and HRQOL. Many analysts,<sup>73–75</sup> although certainly not all,<sup>75–79</sup> have advocated using QALYs for just such purposes. If the net costs of treatment are also determined, then QALYs can be used in determining the relative cost–effectiveness of therapies for diverse diseases.

Using health status and value information to develop measures of the relative value of different treatments is complicated and the data necessary for such calculations are often not available. The issue of whose values to use is unresolved.<sup>58, 80–85</sup> Furthermore, concerns of particularly needy population subgroups or inclinations to fund heroic life-saving procedures (the “rule of rescue”) may play as great a role as information about the impact of HRQOL when making allocation decisions.<sup>79, 86</sup> Nevertheless, routine use of data describing both the health status outcomes of different medical treatments and preferences for different health states would focus attention on these issues and would help policymakers explicate the rationale behind policies affecting the allocation of scarce resources.

### CONCLUSION

A major step in reducing confusion and facilitating the use of information about health status and preferences is to clarify the situations in which the information should be used. The information needed for different types of decisions may be quite different. In some situations, such as decision making involving self-assured, actively participating patients, information about the changes in health that are likely to result from treatment may be adequate and probably is the most appropriate information to provide. For other patients and for resource allocation, information about both health status and health values is desirable. Clinical trials can provide a rich source of both health status data and preference data, useful for interpreting the trials themselves and for each of the decision making paradigms described.

Once a determination is made regarding the type of information needed, selecting the correct instrument is a much simpler task.<sup>19</sup> Considerations such as ease of administration, length, salience to the population being studied, and psychometric properties of the instrument can be used to select the best measure.<sup>87</sup> The first task in selecting an instrument, however, is knowing what the question is.

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## REFLECTIONS

Medicine is a strange mixture of speculation and action. We have to cultivate a science and to exercise an art. The calls of science are upon our leisure and our choice; the calls of practice are of daily emergence and necessity.—PETER MERE LATHAM