

# What are quality of life measurements measuring?

Matthew F Muldoon, Steven D Barger, Janine D Flory, Stephen B Manuck

Center for Clinical Pharmacology, University of Pittsburgh, Pittsburgh, PA 15260, USA  
Matthew F Muldoon, *assistant professor*

Department of Psychiatry, School of Medicine, University of Pittsburgh  
Steven D Barger, *postdoctoral fellow*

Department of Psychology, University of Pittsburgh  
Janine D Flory, *research assistant professor*

Stephen B Manuck, *professor*

Correspondence to: Dr Muldoon  
mfm10 + @pitt.edu

BMJ 1998;316:542-5

It is now widely acknowledged that the personal burden of illness cannot be described fully by measures of disease status such as size of infarction, tumour load, and forced expiratory volume. Psychosocial factors such as pain, apprehension, restricted mobility and other functional impairments, difficulty fulfilling personal and family responsibilities, financial burden, and diminished cognition must also be encompassed. The area of research that has resulted from this recognition is termed "health related quality of life." It moves beyond direct manifestations of illness to study the patient's personal morbidity—that is, the various effects that illnesses and treatments have on daily life and life satisfaction. Although quality of life assessment was almost unknown 15 years ago, it has rapidly become an integral variable of outcome in clinical research; over 1000 new articles each year are indexed under "quality of life."

Although the importance of quality of life is broadly acknowledged, scepticism and confusion remain about how quality of life should be measured and its usefulness in medical research. These responses may reflect important conceptual and methodological limitations of the current concept of quality of life. We offer a simple framework that describes the core elements of quality of life related to health and use this to evaluate quality of life measurement as it is currently conducted.

## A simple classification scheme for measuring quality of life

### Division into functional status and subjective wellbeing

While there is neither a precise nor agreed definition of quality of life, quality of life research seeks essentially two kinds of information, the functional status of the individual and the patient's appraisal of health as it affects his or her quality of life. In addition, current questionnaires used in quality of life assessments generally embody one or both of the following operational definitions—quality of life as an individual's behaviour or level of functioning or quality of life as an individual's perceived health status or wellbeing. Measuring someone's ability to perform common tasks or activities is putatively objective, while asking patients to rate the effects of health status on personal wellbeing is explicitly subjective. For example, the question "Are you able to carry two bags of groceries 20 yards?" seeks explicitly behavioural information, whereas "Does your health interfere with your enjoyment of life?" invites respondents to make subjective ratings.

Most early measures of health status,<sup>2</sup> as well as some contemporary quality of life instruments,<sup>3</sup> were designed to measure objectively the adequacy of individuals' functioning across life's various domains—physical, occupational, and interpersonal. Published reports describing these particular instruments often use the terms health status, functional status, and quality of life interchangeably. Other instruments define quality of life in an inherently subjective way;

### Summary points

Measures of disease status alone are insufficient to describe the burden of illness; quality of life factors such as pain, apprehension, depressed mood, and functional impairment must also be considered

Two operational definitions of quality of life are identified—objective functioning and subjective wellbeing

Assessments of objective functioning and subjective wellbeing convey different information, they also present different problems in relation to validation

Assessment of functioning derived from questionnaires must be validated against measures of directly observed behavioural performance

Subjective appraisal of wellbeing may be influenced substantially by psychological factors unrelated to health or to changes over time in patients' criteria for appraising wellbeing

Whether and how quality of life researchers respond to these obstacles and deficiencies will probably determine the quality of their work in the future

for example, they include questions that ask how disabled the patient feels.

### Division of health into physical and mental domains

Dividing health into physical and mental domains provides some further structure for understanding the effects of health status on quality of life.<sup>4</sup> The figure shows that assessing physical functioning (top left) involves measuring the ability to perform specific tasks (for example, activities of daily living or climbing stairs) as well as less easily defined concepts that are related to role (for example, the ability to continue employment as a carpenter).<sup>5</sup> In many respects, measurement of physical functioning is similar to assessment of physical disability. Mental functioning (figure, bottom left) is reflected in the patient's ability to rise to life's cognitive and social challenges, ranging from specific tasks (for example, balancing a cheque book) to complex social interactions (such as presenting a departmental productivity report at a business meeting).

### Importance of subjective appraisal of health

The alternative, or complementary, perspective on quality of life assigns central importance to an

individual's subjective appraisal of their state of health. This definition presumes that quality of life is at least partly independent of health status,<sup>6</sup> and "is a reflection of the way that patients perceive and react to their health status and to other non-medical aspects of their lives."<sup>7</sup> The subjective nature of this conceptualisation of quality of life is perhaps best understood as focusing on how ill or disabled patients say they feel in the context of their personal lives, as distinct from external attempts to quantify stage or degree of illness or disability. Physical wellbeing (figure, top right) concerns the sense of discomfort arising from a particular symptom (or freedom from such), and extends to vitality or general satisfaction with physical health. A patient's appraisal of his or her mental wellbeing (figure, bottom right) is usually interpreted as the absence of psychological distress (that is, anxiety, depression, anger, etc) and can also include emotional ties and social support.<sup>8</sup>

### Objective functioning should be distinguished from subjective wellbeing

All quality of life questionnaires purport to assess objective functioning, subjective wellbeing, or both. However, investigators have been reluctant to deal with the distinction between objective functioning and subjective wellbeing, partly because of controversy about the relative importance of these two ways of looking at quality of life. We believe that these approaches are both important, and that applying the classification scheme described above would make their definition clearer and more precise. Naturally, precision and clarity are also served by the investigators specifying the domains of quality of life that are of interest in each study.<sup>1</sup> Confusion also arises because many quality of life instruments produce composite indices. These combine information from numerous questionnaire items that span various domains (for example, working compared with home or family life) and include ratings of both functioning and subjective wellbeing. Composite indices have been criticised for failing to recognise that quality of life is inherently multidimensional.<sup>9</sup> Furthermore, some questionnaire items concern well defined behaviour or levels of functioning while others focus on subjective health appraisal, and we believe that aggregating these kinds of information is essentially illogical. By analogy, in the study of heart disease, measures of coronary stenosis and exercise tolerance are important and closely related to one another, yet actually combining these measures makes little sense.

### Questions of validity

#### Criterion validity

The value of quality of life questionnaires in medical research rests squarely upon their validity, and physicians cannot interpret quality of life measures until the instruments being assessed are adequately established. While validity can be examined in several ways, comparison with the best indicator available (criterion validity) is the preferred method. In evaluating quality of life measures of functioning, self reported physical abilities should correlate closely with behavioural performance that is defined objectively and measured directly. For example, in patients with

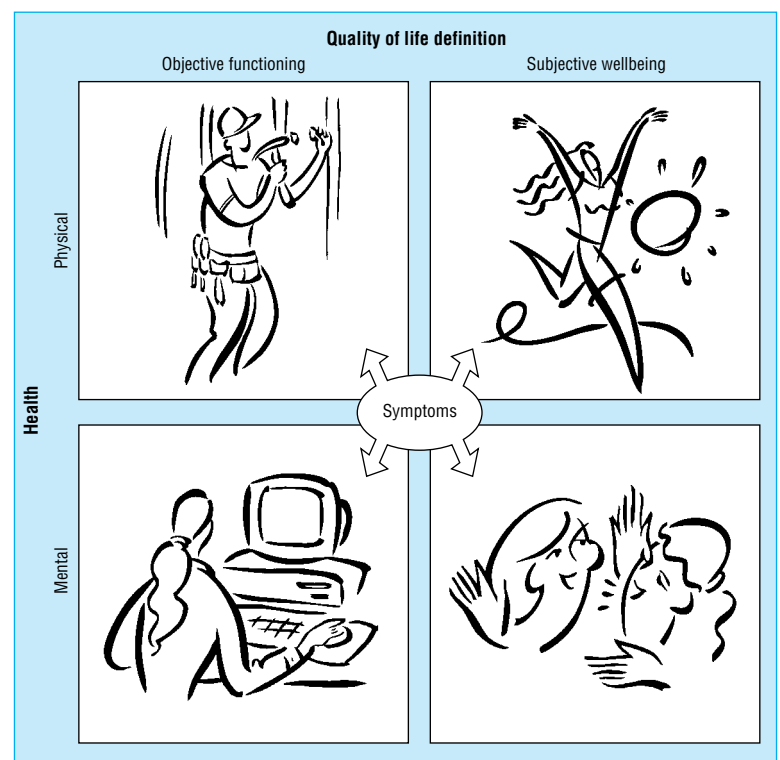
Parkinson's disease, self reported scores for mobility should be compared with objective testing of walking, turning, and rising from the seated position. With few exceptions, however, little or no such validation exists for most quality of life measures of physical functioning.<sup>10,11</sup>

#### Construct validity

Once we move beyond physical functioning (figure, top left), yardsticks are generally not available. However, we can, and should, examine the construct validity of quality of life questionnaires using two complementary evaluations.<sup>12</sup> The first of these is for convergent validity—the degree to which questionnaire scores correlate with self report data from established instruments measuring similar things and with the same construct assessed with different methods (for example, rated by a doctor or spouse). Low scores on a quality of life scale of psychological wellbeing, for example, should predict high scores on a standard structured interview for depressive symptoms. Conversely, a questionnaire to assess health related quality of life should not correlate with measures that are unrelated to health, such as height or personality. In other words, the quality of life measure should have discriminant validity.

#### Accuracy of reporting

Quality of life assessments of mental functioning generally include questions on memory, job performance, sexual activity, and family role functioning. Self reported information in this area raises particular concern because neurological or psychological dysfunction can limit a patient's ability to report accurately.<sup>13</sup> In other words, we seek accurate information on cognitive



A classification scheme of quality of life measures (daily functioning and sense of wellbeing) related to health (mental and physical)

abilities when dysfunction in this area might make the patient's judgments unreliable. Alcoholism and other forms of psychopathology, for example, would present a problem in this regard.<sup>14</sup> Here, evaluating the convergent validity of a quality of life measure should be based upon agreement between the questionnaire scores and other measures of cognitive abilities, social behaviour, and job performance. However, this type of validation is virtually absent in published reports. Comparing how patients rate their driving abilities with performance during a driving test or in a driving simulator is an example of how self completed questionnaires could be validated (or found wanting).

#### **Should perceived wellbeing and not functional assessment be used?**

Much recent comment has maintained that quality of life is inherently subjective and that only perceived wellbeing, not functional assessment, should be used to determine quality of life.<sup>7 15</sup> This approach posits that the patient has privileged access to the quality of life outcomes of disease and treatment and that his or her assessment of wellbeing is of central importance. Subjective indices of quality of life correlate reliably with standard measures of psychiatric symptoms such as depression or anxiety, suggesting that in this sense they do measure subjective wellbeing (that is, have convergent validity).<sup>9</sup>

#### **Effect on scores of extraneous factors**

Ideally, subjective quality of life indices ideally should not be influenced by patient characteristics that are outside of the domain of disease and health care. These tests of discriminant validity are typically ignored or mischaracterised in quality of life validation. Patterns of response in questionnaires do vary with marital status, education, income, race, and geography, and, furthermore, are influenced by a variety of extraneous psychological factors.<sup>16-19</sup> For example, some people have response biases that lead them to give the answers they think are most socially acceptable or cast them in a favourable light.<sup>20</sup>

#### **Influence of personality characteristics**

Subjective quality of life scores can also be influenced by personality factors. Scores are therefore affected by enduring dispositional characteristics that predate the illness and treatment.<sup>21 22</sup> For example, a single item rating recommended as a suitable expression of quality of life—"Rate your overall quality of life as poor, fair, good or excellent"<sup>27</sup>—inadvertently measures personality characteristics such as the propensity to report negative affect, as well as hypochondriasis and somatisation.<sup>23 24</sup> The 36 item health survey of the medical outcomes study is a popular quality of life instrument that includes several subscales related to functioning as well as perceived wellbeing.<sup>25</sup> In a community sample of 348 generally healthy volunteers, we found that eight of the nine medical outcome study subscales correlated significantly with neuroticism, as measured by the NEO personality inventory (Muldoon MF et al, unpublished data). Other similar studies suggest that most subscales of the medical outcome study instrument vary with neuroticism and other dimensions of personality.<sup>19 26</sup> As the medical outcome study is a "mixed" instrument, this overlap suggests that self

reported measures of functioning and perceived wellbeing lack optimal discriminant validity.

#### **Confounding requires statistical adjustment**

To protect against this confounding, investigators should report correlations between quality of life indices and characteristics that are unrelated to illness, and conduct statistical adjustments as indicated. For example, patients with mood or psychosomatic disorders in a primary care sample gave a lower rating for their general health than did patients with diabetes or pulmonary disorders.<sup>27</sup> On the surface, these findings indicate that mood or psychosomatic disorders reduce perceived health more than medical disorders do, but further analysis might suggest that personality factors lead to different response predispositions in various diagnostic groups.

#### **Changes over time**

How patients evaluate their quality of life may also change over time. For example, many cancer patients report benefits from their illness, ranging from an increased ability to appreciate each day to greater feelings of personal strength, self assurance, and compassion, such that they are sometimes more satisfied with their global quality of life than healthy comparison groups.<sup>24 28-30</sup> We might conclude that cancer improves quality of life. In fact, this paradox is now understood to reflect a psychological adaptation (a "response shift") that occurs in cancer patients as well as in patients with other chronic diseases such as diabetes, renal disease, and dermatological disorders.<sup>31 32</sup> The internal standard by which patients appraise their current state shifts and the same questionnaire items on wellbeing can elicit fundamentally different answers over time. To the extent that subjective wellbeing reflects psychological adaptation, the connection between subjective quality of life and disease course (or treatment response) weakens. Therefore, reported changes in quality of life over time<sup>33</sup> need not necessarily derive from actual changes in health or symptoms.

## **Conclusion**

Assessment of the patient's experience of disease and treatment is now acknowledged as a central component of health care and healthcare research. Self reported information obtained from quality of life questionnaires is and will continue to be essential in this endeavour. However, conceptual and methodological issues that underlie this research—matters of definition, measurement objectives, and instrument validity—have received insufficient attention and thereby constrain permissible interpretation of the current medical literature.<sup>33</sup> In turn, implicit recognition of these deficiencies may partly account for the reluctance of many doctors to accept the legitimacy of quality of life research. Whether and how the quality of life "industry" responds to these obstacles and deficiencies will probably determine the future quality of research on quality of life.

Funding: This work was supported in part by National Institutes of Health grants HL46328, HL07560, and HL40962.

Conflict of interest: None.

1 Leplège A, Hunt S. The problem of quality of life in medicine. *JAMA* 1997;278:47-50.

- 2 Bergner M, Bobbitt RA, Carter WB, Gibson BS. The sickness impact profile: development and final revision of a health status measure. *Med Care* 1981;19:787-804.
- 3 Kaplan RM, Anderson JP, Patterson TL, McCutchan JA, Weinrich JD, Heaton RK, et al. Validity of the quality of well-being scale for persons with human immunodeficiency virus. *Psychosom Med* 1995;57:138-47.
- 4 Hays RD, Stewart AL. The structure of self-reported health in chronic disease patients. *Psychol Assess* 1990;2:22-30.
- 5 Katz S, Downs TD, Cash HR, Grotz RC. Progress in development of the index of ADL. *Gerontologist* 1970;10:20-30.
- 6 Guyatt GH, Feeny DH, Patrick DL. Measuring health-related quality of life. *Ann Intern Med* 1993;118:622-9.
- 7 Gill TM, Feinstein AR. A critical appraisal of the quality of quality-of-life measurements. *JAMA* 1994;272:619-26.
- 8 Veit CT, Ware JE. The structure of psychological distress and well-being in general populations. *J Consult Clin Psychol* 1983;51:730-42.
- 9 McHorney CA, Ware JE, Raczek AE. The MOS 36-item short-form health survey (SF-36). II. Psychometric and clinical tests of validity in measuring physical and mental health constructs. *Med Care* 1993;31:247-63.
- 10 Hlatky HA, Boineau RE, Higginbotham MB, Lee KL, Mark DB, Califf RM, et al. A brief self-administered questionnaire to determine functional capacity (the Duke activity status index). *Am J Cardiol* 1989;64:651-4.
- 11 Kempen GI, Steverink N, Ormel J, Deeg DJ. The assessment of ADL among frail elderly in an interview survey: self-report versus performance-based tests and determinants of discrepancies. *J Geront Psychol Sci* 1996;51B:P254-60.
- 12 Campbell DT, Fiske DW. Convergent and discriminant validation by the multitrait-multimethod matrix. *Psychol Bull* 1959;56:81-105.
- 13 Lopez OL, Becker JT, Somsak D, Dew MA, DeKosky ST. Awareness of cognitive deficits and anosognosia in probable Alzheimer's disease. *Eur Neurol* 1994;34:277-82.
- 14 Shedler J, Mayman M, Manis M. The illusion of mental health. *Am Psychol* 1993;48:1117-31.
- 15 Quality of life and clinical trials [editorial]. *Lancet* 1995;346:1-2.
- 16 Bucquet D, Condon S, Ritchie K. The French version of the Nottingham health profile: a comparison of item weights with those of the source version. *Soc Sci Med* 1990;30:829-35.
- 17 Hüry C, Bernhard J, Gelber RD, Coates A, Castiglione M, Isley M, et al for the International Breast Cancer Study Group. Quality of life measures for patients receiving adjuvant therapy for breast cancer: an international trial. *Eur J Cancer* 1992;28:118-24.
- 18 Centres for Disease Control. Quality of life as a new public health measure-behavioural risk factor surveillance system, 1993. *MMWR* 1994;43:375-80.
- 19 VanderZee KI, Sanderman R, Heyink JW, de Haes H. Psychometric qualities of the RAND 36-item health survey 1.0: a multidimensional measure of general health status. *Int J Behav Med* 1996;3:104-22.
- 20 Brooks WB, Jordan JS, Divine GW, Smith KS, Neelon FA. The impact of psychological factors on measurement of functional status. *Med Care* 1990;28:793-804.
- 21 Watson D, Pennebaker JW. Health complaints, stress, and distress: exploring the central role of negative affectivity. *Psychol Rev* 1989;96:234-54.
- 22 Duits AA, Boeke S, Taams MA, Passchier J, Erdman RA. Prediction of quality of life after coronary artery bypass graft surgery: a review and evaluation of multiple, recent studies. *Psychosom Med* 1997;59:257-68.
- 23 Barsky AJ, Cleary PD, Klerman GL. Determinants of perceived health status of medical outpatients. *Soc Sci Med* 1992;34:1147-54.
- 24 Tempelaar R, de Haes J, de Ruiter JH, Bakker D, van den Heubel WJA, van Nieuwenhuijzen MG. The social experiences of cancer patients under treatment: a comparative study. *Soc Sci Med* 1989;29:635-42.
- 25 Stewart AL, Hays RD, Ware JE. The MOS short-form general health survey: reliability and validity in a patient population. *Med Care* 1988;26:724-35.
- 26 Kempen GI, Jellic M, Ormel J. Personality, chronic medical morbidity, and health-related quality of life among older persons. *Health Psychol* 1997;16:539-46.
- 27 Spitzer RL, Kroenke K, Linzer M, Hahn SR, Williams JB, deGruy III FV, et al. Health-related quality of life in primary care patients with mental disorders. *JAMA* 1995;274:1511-7.
- 28 Fromm K, Andrykowski MA, Hunt J. Positive and negative psychosocial sequelae of bone marrow transplantation: implications for quality of life assessment. *J Behav Med* 1996;19:221-40.
- 29 Taylor SE, Lichtman RR, Wood JW. Attributions, beliefs about control, and adjustment to breast cancer. *J Personal Soc Psychol* 1984;46:489-502.
- 30 Danoff B, Kramer S, Irwin P, Gottlieb A. Assessment of the quality of life in long-term survivors after definitive radiotherapy. *Am J Clin Oncol* 1983;6:339-45.
- 31 Cassileth BR, Lusk EJ, Strouse TB, Miller DS, Brown LL, Cross PA, Tenaglia AN. Psychosocial status in chronic illness. *N Engl J Med* 1984;311:506-11.
- 32 Breetvelt IS, van Dam FS. Underreporting by cancer patients: the case of response-shift. *Soc Sci Med* 1991;32:981-7.
- 33 Hemingway H, Stafford M, Stansfeld S, Shipley M, Marmot M. Is the SF-36 a valid measure of change in population health? Results from the Whitehall II study. *BMJ* 1997;315:1273-9.

(Accepted 5 August 1997)

## Continuing medical education Recertification and the maintenance of competence

Philip G Bashook, John Parboosingh

Completion of postgraduate specialist training is a landmark event for most doctors. The award of a certificate is acknowledgment that a doctor has undergone a recognised training programme and been assessed as competent to practise as a specialist in his or her field. Specialists begin practice with a common knowledge base and similar clinical skills but go on to develop different areas of expertise in response to patients' needs. In time, the knowledge and skills of doctors within a specialty will vary appreciably.

### Recertification in the United States

Recognition of the disparity in doctors' skills and the need to maintain common core standards have been a key factor behind the "recertification" movement in the United States.<sup>1</sup> The movement became established in 1969 when the American Board of Family Practice began issuing time limited certificates. Although recertification is nominally a voluntary process, doctors must get recertified every seven years if they want to retain the status of being "board certified."<sup>2</sup> The United States is currently the only country in which most trained specialists are expected to obtain recertification certificates at set intervals throughout

### Summary points

Recertification should assess real performance in practice and competence to continue to learn

Recertification programmes in the United States use examinations and performance assessments as "snapshots" of competence taken every 7-10 years

In other countries most programmes evaluate documented participation in continuing education as evidence of continuing competence as a specialist

The proposed continuous recertification programme uses computer technology to document self directed learning from practice and to monitor performance

Poor performers could be recognised early, given focused assistance and additional periodic examinations at testing centres, and if necessary their certificates could be rescinded

**This is the fourth in a series of seven articles looking at international trends and forces in doctors' continuing professional development**

American Board of Medical Specialties, Evanston, IL 60201-5913, USA  
Philip G Bashook, director of evaluation and education

continued over

*BMJ* 1998;316:545-8