9 Ministry of Agriculture, Fisheries and Food. *The dietary and nutritional survey of British adults—further analysis*. London: HMSO, 1994:72-5.
10 Viteri FE, de Tuna V, Guzman MA. Normal haematological values in the Central American population. *Br J Haematol* 1972;23:189-204.
11 Ji G, Su Z, Bo-ling S, Hui-min F, Li-hui H. Menstrual blood loss and hematologic indices in healthy Chinese women. *J Reprod Med* 1987;32:822-6.
12 Looker AC, Dallman PR, Carroll MD, Gunter EW, Johnson CL. Prevalence of iron deficiency in the United States. *JAMA* 1997;277:973-6.
13 Cook JD, Finch CA, Smith N. Evaluation of the iron status of a population. *Blood* 1976;48:449-55.
14 Cook JD, Skikne BS, Lynch SR, Reusser ME. Estimates of iron sufficiency in the US population. *Blood* 1986;68:726-31.
15 Hoffbrand AV, Pettit JE. *Essential haematology*, 3rd ed. Oxford: Blackwell Scientific, 1993;419.
16 Jain NC, Jain AH. *Essentials of veterinary hematology*. Philadelphia: Lea and Febiger, 1993.
17 Lynx. Haematological and biochemical data base. London: Zoological Society, Jan 2000.
18 Walker ML. Menopause in female rhesus monkeys. *Am J Primatol* 1995;35:59-71.
19 Hallberg L, Hultén L, Gramatkovski E. Iron absorption from the whole diet in men: how effective is the regulation of iron absoption? *J Clin Nutr* 1997;66:347-56.
20 Hallgren B, Sourander P. The effect of age on the non-haemin iron in the human brain. *J Neurochem* 1958;3:41-51.
21 Hallberg L, Sandström B, Aggett PJ. Iron, zinc and other trace elements. In: Garrow SJ, James WPT, eds. *Human nutrition and dietetics*, 9th ed. Edinburgh: Churchill Livingstone, 1993.
22 Dillmann E, Johnson DG, Martin J, Mackler B, Finch CA. Catecholamine elevation in iron deficiency. *Am J Physiol* 1979;237:337-81R.
23 Nelson M. Iron status and cognitive function in UK adolescent girls; an intervention study. *First report from the House of Commons Education and Employment Committee. School meals*. London: Stationery Office, 1999. (HC 96.)
24 Bruner AB, Joffe G, Duggan AK, Casella JF, Brandt J. Randomised study of cognitive effects of iron supplementation in non-anaemic iron deficient adolescent girls. *Lancet* 1996;348:992-6.
25 Srrimshaw NS. Functional consequences of iron deficiency in human populations [review]. *J Nutr Sci Vitamonol* 1984;30:47-83.
26 Hård S. Non-anemic iron deficiency as an etiological factor in diffuse loss of hair of the scalp in women. *Acta Derm Venereo*. 1963;43:562-9.
27 Rushton DH, Ramsay ID. The importance of adequate serum ferritin levels during oral cyproterone acetate and ethinyl oestradiol treatment of diffuse androgen-dependent alopecia in women. *Clin Endocrinol* 1992;36:421-7.
28 Andrews NC. Medical progress: disorders of iron metabolism. *N Engl J Med* 1999;341:1986-95.

(Accepted 20 February 2001)

Measuring quality of life

Are quality of life measures patient centred?

Alison J Carr, Irene J Higginson

Quality of life measures are increasingly used to supplement objective clinical or biological measures of disease to assess the quality of service, the need for health care, the effectiveness of interventions, and in cost utility analyses. Their use reflects a growing appreciation of the importance of how patients feel and how satisfied they are with treatment in addition to the traditional focus on disease outcomes. In this respect, quality of life measures capture patients' perspectives of their disease and treatment, their perceived need for health care, and their preferences for treatment and outcomes. They are hailed as being patient centred. But the challenge in measuring quality of life lies in its uniqueness to individuals. Many of the existing measures of quality of life fail to take account of this by imposing standardised models of quality of life and preselected domains; they are thus measures of general health status rather than quality of life.

Questions arise as to whether such measures are truly patient centred and to what extent they actually represent the quality of life of individual patients or groups of patients. Do they simply describe a patient's health in terms of what health professionals or society believe constitutes quality of life for people who are ill, something that may include factors that have little relevance to or importance for patients?

This paper explores the extent to which standardised quality of life measures accurately quantify an individual patient's quality of life. It debates whether newer, individualised approaches, which allow patients to define their quality of life in relation to their goals and expectations, are more appropriate.

Summary points

Quality of life is an individual construct and measures should take account of this

Many widely used measures are not patient centred because of the ways in which items were generated, because a questionnaire may restrict a patient's choice, and because of the weighting system used

These limitations compromise their accuracy and usefulness because they do not measure what constitutes quality of life for all patients

It is possible to measure quality of life in a patient centred way using individualised measures

Some of the newer standardised measures may be more patient centred than their predecessors but further research is required

The individual nature of quality of life

Although there is no single agreed definition of health related quality of life, it is usually regarded as existing relative to individual or cultural expectations and goals (box). The first paper in this series proposed a model of quality of life that accounted for the interaction between expectations and experience.[1] While it seems reasonable to assume that there are some aspects of life that are of universal relevance to quality of life, the specific weights that individuals attach to these will differ between and in different cultures. Other aspects may be important only to the individual. For example, the first paper in this series considered how the variations in expectations of health that exist between groups and individuals will have an impact on measuring quality of life. The interactions between all these aspects (generic and individual) will also vary between individuals.[2] Moreover, these factors and their interrelationships are unlikely to remain static over time.[3] Values and priorities change in response to life circumstances, such as a life threatening illness, and experience, such as ageing or adapting to a chronic illness. Viewed in

This is the third in a series of five articles

Academic Rheumatology, University of Nottingham, Nottingham City Hospital, Nottingham NG3 5DE
Alison J Carr *ARC senior lecturer in epidemiology*
Department of Palliative Care and Policy, King's College London, New Medical School, London SE5 9PJ
Irene J Higginson *professor*
Correspondence to: A J Carr alison.carr@nottingham.ac.uk

Series editors: A J Carr, I J Higginson, P G Robinson

BMJ 2001;322:1357–60

Definitions of quality of life

Quality of life is determined by

- The extent to which hopes and ambitions are matched by experience[4]
- Individuals' perceptions of their position in life taken in the context of the culture and value systems where they live and in relation to their goals, expectations, standards, and concerns[5]
- Appraisal of one's current state against some ideal[6]
- The things people regard as important in their lives[7]

this way, both the determinants and evaluations of quality of life are highly specific to an individual.

Evidence for the individual nature of quality of life

Attempts to quantify and compare quality of life across different populations of patients using standardised generic measures have been confounded by the "disability paradox." Patients who clearly have significant health and functional problems or intrusive symptoms do not necessarily have quality of life scores that seem commensurate with their health. In one study more than half of patients with moderate to severe disabilities reported having an excellent or good quality of life despite experiencing severe difficulties performing daily tasks, being socially isolated, and having limited incomes and benefits.[8] Patients who have had transplants and patients having haemodialysis and peritoneal dialysis who reported a wide variety of health problems were more likely to rate themselves as "very happy" than the general population,[9] and patients with neoplasms rated their quality of life in the top quarter of the World Health Organization's quality of life questionnaire (WHOQOL) across all life domains: this was better than all other groups of patients including those attending a family planning clinic.[10]

These discrepancies are replicated for individual patients as well. Several studies have shown that there is a disparity between patients', doctors', and relatives' ratings of the patient's quality of life[11 12] or have suggested that doctors are unsuccessful in identifying aspects of disease and treatment that are important to patients.[13 14] The implications of these findings for the use of proxies to measure patients' quality of life will be discussed in the next paper in the series.[15]

These data provide evidence that generic factors are individually weighted and that there are other factors important in quality of life that are not included in standardised measures. They also suggest that quality of life is a dynamic construct that alters in response to illness.

IMAGES

Are existing measures patient centred?

Content

The lack of a widely agreed definition of health related quality of life means that many existing measures do not have any underlying theoretical conceptualisation of quality of life. Those few measures that are based on a theoretical model, such as the patient generated index,[16] the repertory grid,[17] and the World Health Organization's measures (the 100 item quality of life questionnaire (WHOQOL-100)[6] and the 26 item questionnaire (WHOQOL-BREF)), are not widely used. This has led those who develop questionnaires to use a variety of sources for content. Many earlier questionnaires were based on health professionals' definitions of what was relevant. Some were based on reviews or adaptations of existing scales (such as the European quality of life measure (EuroQol),[18] the McMaster health index,[19] and the medical outcomes study 36 item short form health survey (SF-36[20])). Few researchers directly asked patients about which factors they thought constituted quality of life. When they did involve patients, they asked about the impact of illness on people's lives or behaviour (for example, the Nottingham health profile[21] and the sickness impact profile[22]) but not about the important things in people's lives. There is a danger that the most widely used measures do not address what is important to patients in determining their quality of life. For example, the most important factor influencing the quality of life of patients with cancer attending one outpatient clinic was reported to be that they were unable to find a parking place each time they went to the clinic; this was not addressed by any of the measures used.[23] Further evidence for the limitations of measures in capturing what is important or relevant to patients comes from qualitative and survey research of the quality of life of different groups of patients.[7 24] When the domains identified from these studies are compared with the domains captured by some of the most widely used measures (table), it is clear that although there is some overlap in the generic factors included, there are factors that are important to patients that are not captured by these measures. Additionally some factors may be redundant or irrelevant to patients.

Weighting

Quality of life has many distinct but related determinants, some of which are captured by separate domains in measures. Scoring involves either recording the quality of life for each domain separately (profile measure) or combining the results from all domains to give a composite score (index measure). Meaningful interpretation of the results would be easier if there were some estimate of the relative importance of each of these domains. For example, pain is included in the physical domain of most measures but the importance attached to it varies across cultures.[25]

Quality of life measures have approached this problem in different ways. Some measures do not include any weighting assuming that patients find it impossible to put comparative values on important life domains, such as their family relationships and their ability to work. Other measures have used weights derived from the general population or from patients who have been asked to value the range of health states

Domains included in selected quality of life questionnaires or mentioned by patients as being important

	Questionnaires			Patients' responses		
Domain	SF-36[20]	EuroQol[18]	NHP[21]	OPCS omnibus patients[7]	Rheumatoid arthritis patients[24]	Neuromuscular disease patients*
Pain	Yes	Yes	Yes	Yes	Yes	Yes
Energy or tiredness	Yes	Not included	Yes	Yes	Not mentioned	Yes
Sleep	Not included	Not included	Yes	Not mentioned	Not mentioned	Not mentioned
Physical functioning or mobility	Yes	Yes	Yes	Yes	Yes	Yes
Daily living activities	Yes	Yes	Yes	Yes	Yes	Yes
Social interactions	Yes	Not included	Yes	Yes	Yes	Yes
Leisure activities	Yes	Yes	Not included	Not mentioned	Yes	Yes
Relationships	Not included	Not included	Not included	Yes	Yes	Yes
Sexual functioning	Not included	Not included	Not included	Yes	Yes	Not mentioned
Work	Yes	Not included	Not included	Yes	Yes	Yes
Emotional wellbeing	Yes	Yes	Yes	Yes	Yes	Yes
Dependence or independence	Not included	Not included	Yes	Not mentioned	Yes	Yes
Self perception or body image	Not included	Not included	Not included	Not mentioned	Yes	Yes
Perceptions of the future	Not included	Not included	Not included	Not mentioned	Yes	Yes

SF-36=Medical outcomes study 36 item short form health survey; EuroQol=European quality of life measure; NHP=Nottingham health profile; OPCS=Office of Population, Censuses, and Surveys.
*Information from personal communication from K Vincent and M Rose, 1999.

included in a questionnaire. Patients' responses to the questions are then valued according to these weights. However, these weights are unlikely to represent the values of individual patients. Different groups of patients attach a range of weights to the same domains (known as between patient variation),[26] and the weights patients attach to the same domains at different periods in their treatment and recovery also change (known as within patient variation).[27] In the same way that the determinants of quality of life are specific to individuals, the importance attached to those determinants will be influenced by an individual's expectations and aspirations as well as by their own belief system, their cultural belief system, and sociodemographic factors, such as age, sex, socioeconomic status, education, geographical location, and marital status. A true assessment of quality of life can only be achieved using weights for individual patients.

Does it matter if existing measures are not patient centred?

Using measures that are not patient centred can result in a number of problems. If they do not cover domains that are important to individual patients they may not be valid measures for those patients. Thus, standardised measures (in which the questions and range of answers are predetermined and the same for all patients) may measure something distinct from the quality of life of individual patients. In Bowling's study there were discrepancies between the free responses that patients made about the areas of their life that were most affected by disease and those elicited using "prompt cards"[7]; this suggests that results obtained using standardised measures may not capture a patient's quality of life.

If such measures do not capture the quality of life of individual patients they are unlikely to be responsive to change after treatment because they may not be measuring what is important to the patient and their scores may be difficult to interpret.

Measures that are not patient centred differ in content and the weights or importance they apply to different domains. Thus, significantly different scores may be obtained after the same intervention in the same patients. The SF-36 and the EuroQol measures, both of which are standardised measures, have produced contradictory results in the same patients when the effectiveness of cosmetic surgery has been assessed.[28] This clearly has implications for determining the effectiveness of interventions, the relative quality of services, and the allocation of resources.

Individualised measures

Quality of life can be measured in a patient centred way using individualised measures (box). Although less widely used than standardised measures, individualised measures are receiving increasing attention. However, they have their own problems. Firstly, some patients

Individualised measures of quality of life and health status

- The schedule for the evaluation of individualised quality of life (SEIQOL) is a questionnaire administered by an interviewer.[2] Patients are asked to specify the five areas of their life that are most important and then rate their current status in each of these areas using a visual analogue scale that ranges from 0 to 100. In the direct weighting version patients are then asked to rate the relative importance of each of the areas using a sectogram (a cardboard pie chart in which the size of the slices can be varied manually). Results can be presented as a profile of the five areas (in a bar chart) or as a global score
- The patient generated index (PGI)[10] is based on Calman's definition of quality of life as being the extent to which hopes and ambitions are matched by experience.[4] It can be administered by an interviewer or self administered, although some problems have occurred with the postal, self administered version. Patients specify the five areas of their life that are most affected by their condition. They then rate how badly affected they have been in these areas on a visual analogue scale that ranges from 0 to 100. Patients then weight the relative importance of these areas by allocating a total of 60 "spending points" between them: the most points are allocated to the area in which an improvement in health would be most important. The severity ratings are multiplied by the proportion of points allocated to an area and combined to give an index ranging between 0 and 100
- The disease repercussion profile (DRP) assesses the impact of disease, the personal consequences of that impact, and the importance of these consequences in each of six areas of life: functional activities, social activities and interactions, relationships, finance or work, emotional wellbeing, and body image and self esteem.[19] It produces a profile of the impact of the disease on quality of life. The profile is a self completed measure originally designed specifically for clinical practice but it has also been used successfully in clinical trials and cross sectional surveys

Standardised measures for capturing an individual's quality of life

- The subjective quality of life profile (SQLP) is a self administered, predefined checklist that covers a broad range of domains (functional, social, material, spiritual) and assesses an individual's goals including the importance attributed to the goal, tolerance of the distance between reality and the goal, and the ability to cope with this distance.[32] It produces a profile of quality of life
- The World Health Organization's quality of life profile (WHOQOL-100) was developed by the WHO as a multilingual, multidimensional profile of quality of life for cross cultural use.[10] The UK version is self administered and covers 25 facets of quality of life within six broad domains. It assesses domains of satisfaction with life as well as the impact of disease or illness, and it captures positive and negative aspects of quality of life

Future research and education

Research into quality of life measures should focus on

- Developing and refining individualised measures
- Testing ways of combining in a short interview individualised measures and key disease and treatment outcomes
- Simplifying weighting systems and analysing data from individualised measures
- Establishing the extent to which new standardised measures (such as WHOQOL-100) are patient centred

have difficulty understanding the system of direct weighting; this limits their use as self completed questionnaires[29] among patients who are very sick or among those who have compromised concentration spans. Secondly, patients may not readily volunteer some factors that are important to them, particularly those related to mood,[30] and the information that an individual is willing to volunteer may change over time.[31] Finally, because of its individualised nature, the interpretation and analysis of some of the data are complex. This can make the comparison of groups of patients, or change within individuals over time, difficult, although many of the measures take account of this by using specific questions about change. Further work is needed to refine and evaluate these individualised measures.

Implications for the future

Many of the most widely used measures of quality of life are limited in their ability to capture the quality of life of individual patients. These limitations result from the structure and content of the measures, the ways in which they were developed, and their systems of weighting. Some of these problems can be overcome by using individualised measures but these have their own problems which need further attention. A compromise may be to use recently developed standardised measures, which not only are sufficiently broad to include most facets of life important to any patient but which also use direct weighting systems; this should result in an individualised assessment of a patient's quality of life (box). The extent to which such measures reflect an individual's quality of life requires further assessment, and the clinical utility and interpretability of these measures also need to be established.

The articles in this series are from *Quality of Life*, which will be published by BMJ Books next year

We thank our colleagues in the Interdisciplinary Research Group in Palliative and Person Centred Care at King's College London, in particular Peter Robinson, Barry Gibson, Stanley Gelbier, Robert Dunlop, Julia Addington-Hall, Lalit Kalra, Alan Turner-Smith, who have participated in discussions and commented on an earlier draft of this work.

Funding: AJC's post is funded by the Arthritis Research Campaign.

Competing interests: None declared.

1 Carr AJ, Gibson BA, Robinson PG. Is quality of life determined by expectations or experience? *BMJ* 2001;322:1240-3.
2 Bernheim JL. How to get serious answers to the serious question: 'How have you been?' Subjective quality of life (QOL) as an individual experiential emergent construct. *Bioethics* 1999;13:272-87.
3 O'Boyle CA, McGee H, Hickey A, O'Malley K, Joyce CRB. Individual quality of life in patients undergoing hip replacement. *Lancet* 1992;339:1088-91.
4 Calman KC. Quality of life in cancer patients—an hypothesis. *J Med Ethics* 1984;10:124-7.
5 WHOQOL Group. The development of the WHO quality of life assessment instruments (the WHOQOL). In : Orley J, Kuyken W, eds. *Quality of life assessment: international perspectives*. Berlin: Springer-Verlag, 1994: 41-57.
6 Cella DF, Tulsky DS. Measuring quality of life today: methodological aspects. *Oncology* 1990;4:29-38.
7 Bowling A. What things are important in people's lives? A survey of the public's judgements to inform scales of health related quality of life. *Soc Sci Med* 1995;41:1447-62.
8 Albrecht GL, Devlieger PJ. The disability paradox: high quality of life against all odds. *Soc Sci Med* 1999;48:977-88.
9 Quality of life. *Lancet* 1991;338:350-1.
10 Skevington S. Measuring quality of life in Britain. Introducing the WHOQOL-100. *J Psychosom Res* 1999;47:449-59.
11 Slevin ML, Plant H, Lynch D, Drinkwater J, Gregory WM. Who should measure quality of life, the doctor or the patient? *Br J Cancer* 1988;57:109-12.
12 Pearlman RA, Uhlmann RF. Quality of life in chronic diseases: perceptions of elderly patients. *J Gerontol* 1988;43(suppl):M25-30.
13 Donovan J. Patient education and the consultation: the importance of lay beliefs. *Ann Rheum Dis* 1991;50:418-21.
14 Kwoh CK, O'Connor GT, Regan-Smith MG, Olmstead EM, Brown LA, Burnett JB, et al. Concordance between clinician and patient assessment of physical and mental health status. *J Rheumatol* 1992;19:1031-7.
15 Addington-Hall J, Kalra L. Who should measure quality of life? *BMJ* 2001 (in press).
16 Ruta DA, Garratt AM, Leng M, Russell IT, MacDonald LM. A new approach to the measurement of quality of life. The patient-generated index. *Med Care* 1994;32:1109-26.
17 Thunedborg K, Allerup P, Bech P, Joyce CRB. Development of the repertory grid for measurement of individual quality of life in clinical trials. *Int J Methods Psychiatr Res* 1993;3:45-56.
18 EuroQol Group. *EuroQol EQ-5D user guide*. Rotterdam: Rotterdam Centre for Health Policy and Law, Erasmus University, 1996.
19 Chambers LW. *The McMaster health index questionnaire (MHIQ): methodologic documentation and report of second generation of investigators*. Hamilton, Ontario: McMaster University, Department of Clinical Epidemiology and Biostatistics, 1982.
20 Ware JE, Sherbourne CD. The MOS 36-item short-form health survey (SF-36) I. Conceptual framework and item selection. *Med Care* 1992;30:473-83.
21 Hunt SM, McEwan J, McKenna SP. *Measuring health status*. Beckenham: Croom Helm, 1986.
22 Bergner M, Bobbitt RA, Carter WB, Gilson BS. The sickness impact profile: development and final revision of a health status measure. *Med Care* 1981;19:787-805.
23 Coates AS, Kaye SB, Sowerbutts T, Frewin C, Fox RN, Tattersall MHN. On the receiving end. Patient perceptions of side-effects of cancer chemotherapy. *Eur J Clin Oncol* 1983;13:203-8.
24 Carr AJ. A patient-centred approach to evaluation and treatment in rheumatoid arthritis: the development of a clinical tool to measure patient-perceived handicap. *Br J Rheumatol* 1996;35:921-32.
25 Skevington SM. Investigating the relationship between pain and discomfort and quality of life, using the WHOQOL. *Pain* 1998;76:395-406.
26 Rose M, Scholler G, Klapp BP, Bernheim JL. Weighting dimensions in generic QOL questionnaires by anamnestic comparative self-assessment: different weights in different diseases [Abstract]. *Qual Life Res* 1998;7:655.
27 Hickey AM, Bury G, O'Boyle CA, O'Kelly F, Shannon W. A new short form individual quality of life measure (SEIQOL-DW): application in a cohort of individuals with HIV/AIDS. *BMJ* 1996;313:29-33.
28 Klassen A, Fitzpatrick R, Jenkinson C, Goodacre T. Contrasting evidence for the effectiveness of cosmetic surgery from two health related quality of life measures. *J Epidemiol Commun Health* 1999;53:440-1.
29 Macduff C, Russell E. The problem of measuring change in individual health-related quality of life by postal questionnaire: use of the patient-generated index in a disabled population. *Qual Life Res* 1998;7:761-9.
30 Vachon ML, Kristjanson L, Higginson I. Psychosocial issues in palliative care: the patient, the family, and the process and outcome of care. *J Pain Symptom Manage* 1995;10:142-50.
31 Higginson I, Priest P, McCarthy M. Are bereaved families a valid proxy of a patient's assessment of dying? *Soc Sci Med* 1994;38:553-7.
32 Dazord A, Leizorovicz A, Gerin P, Boissel JP. Quality of life of patients during treatment of type I diabetes. Importance of a questionaire focused on the subjective quality of life. *Diabete et Metabolisme* 1994;20:465-72.