Quality of life measurements in patients with malignant disease: a review

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Introduction

It is common to read 'assessment of quality of life' listed at the end of many clinical research proposals, particularly those involving the treatment of cancer. This lowly rank in the hierarchy of research aims is both odd and iniquitous, given the aggressive nature of many cancer therapies and their consequent impact on the quality of life. The marginal benefits in survival that accrue from quite drastic treatment regimens receive widespread publicity, whilst the social and financial costs are often not mentioned or even ignored. A review of 16 studies which assessed different forms of cancer surgery revealed that the authors only report end results in terms of survival and recurrence[1]. Very different treatment regimens often failed to show significant differences using these criteria, although the effects of radical surgery would have profound effects on patients' quality of life. Similarly, cytotoxic therapies that could produce tumour shrinkage and some prolongation of life might not be considered as beneficial to the patient if those precious extra months are spent with the miseries of alopecia, nausea, vomiting and mouth soreness.

The arguments for pursuing aggressive therapies despite their toxicity are persuasive when considering potentially curative treatment for diseases such as childhood leukaemia, but in less curable disease where palliation is the primary goal, the psychosocial burden upon the patient might be too heavy.

From their conversations it is clear that most doctors are concerned about the quality of their patients' lives, although they do not routinely make formal assessments of it. Many rely on a short 'doctor-directed' clinical consultation, despite the fact that the failure of both surgeons and general practitioners to determine psychosocial problems amongst their patients is well documented[2,3]. This oversight is hardly surprising, as few clinicians have received anything more than very basic training in communication skills and have experienced little, if any, exposure to the psychometric techniques that do exist.

The purpose of this short paper is to encourage the interested and concerned clinician or research worker, who may not have the time or expertise to plough through the literature, to find an appropriate test for his or her needs. This is by no means meant to be a comprehensive view, but merely represents a cross-section of different methods currently available, with comments on validity, ease of administration and scoring (Table 1).

Karnofsky performance status scale (KPS)[4]

When assessment of quality of life is actually made at all by clinicians, it is almost invariably by the Karnofsky scale[4]. Frequency of usage is no indication of appropriateness and this scale, whilst useful as a measure of health performance status, is not a satisfactory estimation of quality of life. Ratings from 0–100 are made by the clinician, 100 being normal with no evidence of disease, and 0 being the terminal point of the scale, i.e. dead. There are several problems with this method, in particular the

Table 1. Some currently available methods for assessing quality of life

Test	*Administrator*	*No. of categories*	*No. of questions*	*Average time to complete*	*Approximate time to score*	*Reliability*	*Validity*
Karnofsky performance Status Scale (KPS)[4]	Clinician	1	10	1 min	30 sec	Poor	Good
Linear Analogue Self-Assessment (LASA)[10]	Patient	4	25	2 min	Lengthy	Very good	Good
QL-Index[14]	Clinician or patient	5	15	1 min	30 sec	Good	Good
Cancer Inventory of Problem Situations (CIPS)[18,19]	Patient	21	131	18 min	10 min	Very good	Good
Psychological Adjustment to Illness Scale (PAIS)[20]	Clinician or patient	7	45	20–30 min 15–20 min	10 min	Very good	Good
Hospital Anxiety and Depression Scale (HAD)[21]	Patient	2	14	2 min	2 min	Good	Good

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assumption that a patient with a lowish score due to immobility necessarily has a poorer quality of life than a patient with a higher score and vice versa. To give an example, an incontinent paraplegic or wheelchair-bound multiple sclerosis victim might well achieve only 40 on the scale, despite the fact that these patients might have good social supports and experience rich and happy relationships. A breast cancer patient with a score of possibly 80 might, on the other hand, be emotionally crippled by depression, which the scale does not attempt to assess. Yet the concomitant loss of libido and self esteem would give her an extremely poor quality of life. Another major criticism is that the scale takes no account of previous pretreatment levels of activity. This is potentially serious when comparing the effects of similar biological disease burdens in active, working extroverts with more passive, housebound patients. An important deficiency of this rating system is common to all observation scales: assessment is an entirely subjective evaluation by the doctor, thus open to bias and potentially wide variability between raters. Several workers have found very low reliability coefficients[5,6]. Despite these criticisms, a literature review[7] examining the frequency of measuring quality of life in clinical trials in six international cancer journals showed that only 6% even bothered to attempt to measure it, and the overwhelming majority of that 6% used the original performance criteria of Karnofsky and Burchenal.

There have been two variations of this clinical observation instrument in recent years[8,9], but neither appears to be any more effective as a quality of life assessment than the original KPS.

Linear analogue self-assessment (LASA)

Visual analogue scales (VAS), such as the LASA[10], provide a much more satisfactory method of measuring quality of life. These tests employ lines, the length of which are taken to denote the continuum of some emotional or physical experience such as pain or anxiety. The line in any VAS is usually 10 cm long with stops at right angles to the line at its extremes, representing the limits of the experience being measured; for example:

Have you had pain today?

Not at all |__________| *severe pain*

The patient is instructed to mark along the line a point that corresponds to his or her perception of the experience. The distance from the 'not at all' stop to the patient's mark provides us with a numerical score for pain.

The LASA questionnaire has 25 items, 10 of which probe the symptoms and effects of the disease and treatment (e.g. pain and nausea); 5 examine psychological consequences (e.g. anxiety and depression); 5 measure other physical indices (e.g. level of activity, ability to perform housework); and another 5 items are concerned with personal relationships. The LASA has been used successfully to evaluate quality of life of patients receiving cytotoxic therapy for advanced breast cancer[10].

The advantages of tests like these are that they are simple, reasonably sensitive and – more importantly – reproducible (test–retest correlations of the LASA were 0.73). Consequently, they are useful tools to employ in clinical trials and clinical practice. There are disadvantages, however, not least of which is that though theoretically simple to score, they are time-consuming unless the research worker has a research assistant or some sophisticated electronic measuring aid. Some patients need a fair amount of time to grasp the concept, although it is a technique that has been used successfully with 5-year-olds[11]. Adequate explanation is vitally important: patients should initially be encouraged to use the whole of the line for each experience being investigated, and to avoid bipolar responses at each extreme of the dimension or marking the line at its midpoint for everything.

The most worrying criticism of any VAS is the very real doubt some workers have that the measurement may not relate well to the experience under consideration. There are many references in the literature to its validity and usefulness in measuring pain (*see* Melzack[12] for a really good up-to-date review of the subject), but other work shows that patients complaining of extreme weakness using VAS actually had good grip strength (the physician's objective assessment of the patients' grip strength did not correlate either!)[13]. The final difficulty shared with all types of assessment scales with fixed end points is the 'ceiling effect'. For example, when examining the efficacy of a new drug regimen, a patient who starts the trial by responding 'not at all' along the pain dimension can only get worse, whilst one who starts with a mark at severe pain will never be measurably worse although in reality he or she sadly might well be.

QL-Index

The QL-Index[14] is an interesting test developed specifically for use by physicians to measure the quality of life of cancer patients. Its originators established clearly defined criteria for their test, which were basically that it had to be quick to complete (one minute on average); simple to score, administer and analyse; and able to address a comprehensive range of quality of life dimensions. The assessment items were chosen after a considerable amount of field-work by cancer patients, lay people, doctors, nurses and other health-care professionals. Five items – (1) activity; (2) living; (3) health; (4) support; (5) outlook on life – are rated on a 3-point scale 0–2, giving a maximum possible score of 10 (rather like a neonatal APGAR scoring system). The test has high inter-rater correlations between physicians and, what is more, good correlations between the self-ratings of patients and their doctors. In contrast, studies have shown the Karnofsky scale to have poor correlation between patients' and doctors' scores[5,15]. As the QL-Index produces reliable ratings whether used by professional or non-professional raters, the test lends itself very well to use in clinical trials or follow-up clinics, where a variety of personnel might be involved in assessments. The QL-Index has been validated in Australia and Canada on patient populations with various types and stages of chronic disease, and correlates extremely well with the LASA[16]. Like all quality of life scales it has some limitations, for example it gives equal weighting to all items contained in the index, which might not be realistic. (This criticism is an interesting and perhaps insoluble methodological problem.) Furthermore, it does not allow the item specificity contained in some of the lengthier questionnaires such as the

PAIS[17]. This could lead to difficulty in rating; e.g. in the daily living section, self-reliance in eating, washing, toiletting, dressing, using public transport or driving own car are all put together. It is quite possible that the personal care items could be achieved with the patient housebound and unable to use transport.

This rating scale takes on average one minute of a doctor's or nurse's time and could have far-reaching implications for the course of treatment chosen for an individual. That extra workload seems a very small price to pay for potentially better patient care.

Cancer inventory of problem situations (CIPS)[18]

A promising new test recently developed is the CIPS. It is self-administered, requiring approximately 20 minutes to complete, and consists of 141 problem statements grouped into 21 categories. These categories are then subdivided under 4 main headings: (1) personal care; (2) medical situations; (3) interpersonal interactions; (4) miscellaneous. All the problem items used in the CIPS resulted from a review of the cancer literature, extensive interviews with health-care professionals and patients and their families.

The patient indicates on a 5-point scale, ranging from 'not at all' to 'very much', how much of a problem each statement has been in the preceding month. The problem statements within each category are quite specific; for example, in the eating category there are three probes concerned with (1) the patient's perception of how appetizing food is now; (2) how it tastes; and (3) how well the patient can swallow. The specificity highlights areas of psychosocial functioning of concern to individual patients and its main value, therefore, would be to alert the clinician to aspects of the patient's world in need of intervention (assuming resources such as counselling are available for this). Following each response box on the questionnaire, the patient is invited to indicate in another box if help with the problem is required; for example:

	Want help?
'I do not know what to say to my	( )
relatives and friends about my cancer'	( )

The CIPS has excellent test–retest reliability coefficients ($r = 0.89$). The instrument also appears to be more sensitive than a semistructured interview with a trained rater at picking up certain difficulties that patients are experiencing. Many clinicians worry that psychiatrically orientated tests will offend their patients, but the authors make the important observation that their patients responded well to the CIPS[19].

There are two main criticisms of the test – namely that the authors have yet to provide any normative data and that it has only been validated on a small (306) heterogeneous sample of cancer patients[19].

This might well be a useful test for the clinician interested in assessing the psychosocial and physical impact of treatment programmes, with a view to tailoring therapy to cause minimal distress to the patient by providing ancillary backup wherever possible for problem areas.

Psychological adjustment to illness scale (PAIS)[20]

One of the most comprehensive tests developed in recent years is the PAIS. It was originally a semistructured interview administered by a trained health professional (doctor, nurse, psychologist, social worker, etc.), but the authors have now developed a comparable self-report version[17]. The test examines a patient's global adjustment to illness, with 45 questions in 7 principal psychosocial domains: (1) health care orientation (attitudes to physicians and treatment, expectations, etc.); (2) vocational environment (job performance, satisfaction and adjustment); (3) domestic environment (impact on finances, communication within family); (4) sexual relationships (changes in frequency, pleasure or satisfaction of sexual activity since illness); (5) extended family relationships (difficulties in relation to extended family since illness); (6) social environment (maintenance of interest in social activities); (7) psychological distress (anxiety/depression, etc.).

Ratings for each question within each domain are made on a 4-point (0–3) scale and after conversion to standardized T-scores, provided in tables in the accompanying handbook, these generate a PAIS total score. This score is then compared with published norms. The authors have researched their instrument well over the past 8 years and, unlike many other available tests, provide norms for different patient groups. To date norms have been published for lung cancer, renal dialysis, cardiac, and mixed cancer patients[17].

This instrument is not, strictly speaking, concerned with an attempt to both define and then measure quality of life. It could reasonably be assumed that a patient who is well adjusted and accepting of his or her illness and treatment will be more likely to experience a reasonable quality of life than a patient with poor adjustment.

Either version of the test takes about 30 minutes to complete and both have good reliability coefficients and correlations with other psychological tests.

Hospital anxiety and depression scale (HAD)[21]

Few of the available psychometric tools purporting to measure quality of life make more than a cursory assessment of the impact of illness on a patient's psychological functioning. Patients with depression and anxiety are just as likely to show a decline in their enjoyment of life, a disruption of social contacts and diminution of leisure activities as patients suffering severe physical distress. Studies have shown that clinicians often fail to discern psychiatric morbidity amongst their patients[22,23]. Maguire, for example, claims that as many as 80% of clinically depressed or anxious patients post-mastectomy are unrecognized as such by their surgeons. There are also reports in the literature that when such women volunteer the information that they have felt anxious or depressed, their problems are sometimes dismissed as understandable, normal reactions to having cancer or losing a breast and therefore do not merit treatment[23,24]. The tragedy of this is that antidepressant and anxiolytic drugs are effective; even young children receiving chemotherapy can be helped enormously by the recognition and treatment of depression and anxiety[25].

The HAD[21] is a brief but useful assessment of anxiety and depression. The test consists of 14 items divided into 2 subscales for anxiety and depression. The patient rates items on a 4-point scale; for example:

'I get sudden feelings of panic'	*'I look forward with enjoyment to things'*
Very often	As much as I ever did
Quite often	Rather less than I used to
Not very often	Definitely less than I used to
Not at all	Hardly at all

The HAD's advantage over many other similar self-assessment questionnaires that measure psychiatric morbidity is that it does not probe the somatic symptoms characteristic of some psychological states that could also be due to the physical disease process. The authors have produced data to support their contention that the subscales are not affected by physical illness, that these two subscales do permit discrimination between the two mood disorders of anxiety and depression, and that the subscale scores allow assessment of severity[21].

The HAD is extremely easy and quick to complete and score; furthermore, patients appear to appreciate an opportunity to comment on their emotional responses to treatment. It is currently being employed by one of us (LJF) as part of the assessment of the psychosocial sequelae associated with the diagnosis and treatment of early breast cancer; it is easy to instruct nurses how to administer it on the wards or in outpatient clinics, and the patients do not find it an unpleasant intrusion. If nothing else, this particular test could alert the clinician to the possible presence of psychological problems which might well provoke a confused clinical presentation or negative response to treatment.

Discussion

The perfect test to measure the somewhat ill-defined concept of quality of life has yet to be developed, but the assessment scales outlined here provide useful indications of the psychosocial impact that disease and treatments make. A wide variety of interventions are then possible which could alleviate some of the distress treatment might be producing. There is evidence that professional counselling services might prevent the development of psychiatric morbidity in early breast cancer and enhance quality of life in advanced disease[23,26]. Cognitive behaviour therapy has been used with good effect in depressed cancer patients[27], those with uncontrolled pain[28] and problems such as anticipatory vomiting prior to chemotherapy sessions[29,30]. Several good reviews of other techniques for measuring quality of life are available[31,32], together with papers concerned with the more theoretical aspects of measurement and design in psychometric testing[33-37].

The prejudice that abounds amongst many medical scientists toward social scientists is often ill-founded. The assumption that only medicine produces objective 'hard' science, whilst disciplines such as psychology deal only with subjective 'soft' science, cannot remain unchallenged. Many of the supposedly more objective parameters on which response to treatment is based, such as palpation of tumour size, are open to subconscious bias and error[38]. When patients are given full information about the possible side effects of treatment and likely survival estimations, they are frequently unwilling to accept the 'life at any cost' philosophy that many doctors assume[39-41].

Psychosocial assessment is difficult, and demands as rigorous a scientific appraisal as the proper measurement of organic disease. Improvements in medical practice are only achieved by subjecting standard techniques to constant critical review and applying more novel techniques alongside them. We hope that this paper will encourage more medical teams to employ psychometric tests when treating oncology patients.

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(Accepted 25 September 1985. Details of how to obtain the tests discussed in this paper can be supplied by the authors)