Eur J Cancer, Vol. 28A, No. 10, pp. 1748–1752, 1992.
Printed in Great Britain

0964–1947/92 $5.00 + 0.00
Pergamon Press Ltd

Progress, Problems and Priorities in Quality of Life Research

Penelope Hopwood

Considerable progress has been made in the methodology of quality of life research and we now need to judge the clinical utility of this approach in clinical trials. Some of the logistic problems in implementing these studies are formidable, however, and this has contributed to a slow uptake of quality of life research in clinical practice. Pragmatic guidelines are now needed to help overcome problems of implementation and analysis. Further adaptation and refinement of instruments will be needed to meet new challenges in the field, but we must be selective in our research initiatives and ensure that quality of life becomes translated into improved patient care.
Eur J Cancer, Vol. 28A, No. 10, pp. 1748–1752, 1992.

INTRODUCTION

THE CONCERN to measure quality of life was borne out of a need to balance treatment toxicity against the benefits of therapy in the palliative setting. More recently, quality of life after primary treatment for cancer has also been evaluated. Breast cancer treatment provides a good example, where evidence from earlier psychosocial research of psychological distress, body image disturbance and sexual dysfunction [1, 2] led to the inclusion of quality of life end-points in treatment comparisons [3]. As patients have become more actively involved in treatment decision making, quality of life has become an important consideration for them too. Thus, progress has been made in widening the clinical domain in which quality of life evaluation may be relevant.

However, the value of such research is best judged when results lead to improvements in treatment practice, or highlight areas of need where psychosocial interventions can be targeted. A review of the literature has been modestly encouraging in this respect, but much more evidence of benefit to patient care is required. The need for a more systematic enquiry into patients' quality of life has also been endorsed by the realisation that patients are reluctant to disclose their concerns and difficulties, and professionals are equally reluctant to enquire [4]. We cannot afford to let quality of life research become a substitute for better doctor–patient communication, but a potential benefit of this approach is that questionnaires used may assist in the identification of patients who need help.

Not surprisingly, as the field has grown, new problems have come to light, such as the need for sound statistical methods to analyse quality of life data and for more specific scales to measure problems such as emesis, sexual dysfunction and body image disturbance. Further, as the management of cancer evolves, new challenges emerge; for example, trials of the chemoprevention of breast cancer and the counselling of women at high risk of breast cancer are now valid targets for study. We, therefore, need to define our goals carefully and select priority areas for research.

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Revised 27 Feb. 1992; accepted 17 Mar. 1992.

PROGRESS

Definition

Progress in the measurement of quality of life has resulted from extensive contributions from behavioural scientists and psychosocial researchers. After a decade of discussion and debate, a consensus of agreement has been reached that quality of life is a multidimensional concept and should include, minimally, an evaluation of physical, psychological and functional status together with, where resources permit, an evaluation of social functioning. Questionnaires completed by patients themselves are advocated as the most reliable means of obtaining information [5].

Instruments

A great deal of progress has been made in the design and development of self-report questionnaires for use with cancer patients, and past efforts are beginning to bear fruit. Issues concerning choice of instrument and psychometric properties of questionnaires have been well reviewed elsewhere [6], and descriptions of many scales developed in Europe and the USA are now available in the literature [7]. Thus, clinicians have access to a wide range of questionnaires that have been either purpose-designed or shown to be valid when used with cancer patients. In Britain, recommendations have been made regarding certain instruments for use in clinical trials [8] so that newcomers to this field can benefit from the experience of others. Such guidelines will need constant updating to remain useful, as the field of measurement continues to be developed and refined. A number of other measures warrant individual mention, however, because of interesting features of their approach.

No scale is likely to fulfil the needs of all clinical trials, so a core questionnaire with add-on disease- and protocol-specific modules is an attractive concept. This was the approach developed by the EORTC Quality of Life Group [9] and the core instrument, now field-tested to establish its psychometric properties, will shortly be available for general use. Its unique feature is that it has been validated in the major European languages, and this creates the opportunity for cross-cultural comparisons in an international research context.

The Cancer Rehabilitation Evaluation System (CARES) [10] consists of 139 questions, and its length (and cost) renders it unsuitable for many clinical trials. However, an attractive feature of the scale is that patients indicate problems or symptoms with which they would like help, and this could provide valuable

feedback to clinicians in identifying individual needs. The clinical utility of this approach still needs to be confirmed, but it has already received some support [11]. A shortened version is in preparation, which is likely to be preferred.

A new concept advocated for the clinical trials setting is an adaptation of the concept of quality-adjusted life years, namely Q-TWiST (Quality of Life Oriented Time Without Symptoms and Toxicity) [12]. The concept allows individual weightings of symptoms or toxicity to be made, and for these to be summed and translated into time penalties, subtracted from survival time, when treatment outcomes are compared. There are still formidable design and psychometric hurdles to be overcome before the concept can be fully implemented.

Implementation in clinical trials

The introduction of quality of life research into clinical trials has enabled the subjective impact of treatment to be measured in a small number of cancer therapies. In trials of breast cancer surgery, outcome measures of psychological distress and body image disturbance have been reported, and despite methodological differences, some of these studies confounded certain expectations [3]. It was hoped that conservative breast surgery would result in reduced psychological morbidity, but this was not found. The expected benefit in better preservation of body image was confirmed. Thus, whilst quality of life studies may support clinical impressions, they may also challenge clinical thinking. Other counterintuitive results have been reported in the use of adjuvant chemotherapy in postmenopausal women with operable breast cancer [13] and in surgery for extremity soft-tissue sarcoma [14].

Perhaps the greatest potential for quality of life research is expected in the palliative treatment setting, where the need to balance the cost–benefit equation has been widely advocated. Despite growing interest, however, there has been considerable hesitancy in including the relevant measures in clinical trials, and the number of published studies with such data remains disappointingly small.

Challenging assumptions in palliative treatment

Many oncologists have held the view that toxic treatment will inevitably worsen quality of life, and that patients with extensive disease and functional impairment will suffer greater emotional distress. This has led to the design of treatment protocols using aggresive chemotherapy more sparingly, or at a lower dose. Randomised controlled trials have evaluated the use of lower dose chemotherapy [15] and limited duration chemotherapy [16] in metastatic breast cancer. Tumour response was less favourable for the less aggressive treatment policy in both studies but toxic effects were favourably reduced. Interestingly, when other dimensions of quality of life were examined (such as pain, general health, mood, appetite) greater improvement was found in patients receiving the more aggressive regimens, implying better palliation of the disease, despite side-effects. Tannock [15] cautioned against being misled into assuming a simple linear relation between intensity of treatment and palliation since there would be an optimum trade-off between response and toxicity at some point. Both studies were valuable because of their counter-intuitive results, indicating that treatment-related symptoms may not inevitably influence patients' subjective experience of quality of life.

An interesting study from Souhami's group [17] assessed the value of palliative chemotherapy in small cell lung cancer on a fixed 3-weekly schedule or given only when there was disease progression or for symptom control. Asymptomatic patients in the 'as required' treatment arm were seen regularly for assessment. It was anticipated that the less aggressive regime would result in better quality of life but this was not evident from the patient questionnaire data, which showed less favourable scores for the 'as required' group on 6 out of the 8 variables measured. Preliminary results from a non-small cell lung cancer study, comparing aggressive with minimal treatment, followed the same trend [18].

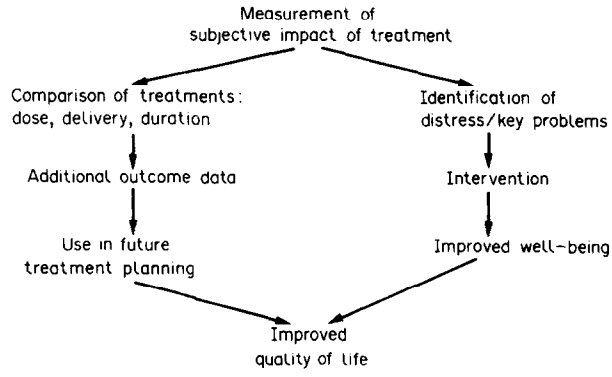

Fig. 1. Aims of quality of life measurement.

Cella [19] has shown that sick patients may be more resilient than expected, and that performance status and extent of disease played only a small part in reducing quality of life of patients with lung cancer. Against expectations, Kaasa and the Norwegian group [20] also failed to find a significant correlation between psychosocial well-being, measured by their own scale, and chemotherapy or radiotherapy related side-effects in patients treated for non-small cell lung cancer.

This first wave of quality of life studies have usefully informed clinicians about patients' reactions to the impact of treatment and have encouraged a rethink of previously held views about treatment toxicity and disease palliation. Further evidence is required in support of these findings before they can be taken as a general trend.

PROBLEMS

There are still a number of barriers to the implementation of health status measurement in oncology that apply equally to other areas of medical practice [21].

Ethical implications

Two parallel objectives of assessment are shown in Fig. 1. To date, most work has focused on the comparison of treatment outcomes in clinical trials and on the development of instruments for that purpose. Often data are assiduously collected, but self-reported adverse effects, such as depression or anxiety evaluated only on completion of the clinical study. Consequently patients may not have the benefit of active intervention as they proceed through treatment, yet the early recognition of psychological distress, and its appropriate treatment, could lead to both improved quality of life and greater treatment compliance. Many quality of life scales are not designed to 'screen' for such distress, and the necessary staff trained in assessment skills may not be available in some centres. There can be few clinical parameters, however, that are measured prospectively but without clear threshold values to indicate the need for intervention.

Whether or not such monitoring is an expressed aim of quality

of life assessment, the consequence of data collection does carry ethical responsibilities.

The need for clear research questions

Often the decision to measure quality of life is quoted without reference to the specific purpose. An intention to 'compare treatments' is imprecise and there should be a clear research question to support a quality of life protocol, which should relate to expected treatment differences or their likely impact. The decisions regarding choice of instrument, frequency and timing of assessments, and other aspects of methodology will then more logically follow.

The problem areas that are currently detracting from a wider use of quality of life assessment are practical and conceptual barriers, trial selection, methodological problems, compliance and attrition rates and difficulties of statistical analysis.

Practical and conceptual barriers

A frequently quoted obstacle concerns the time and personnel needed for questionnaire administration. It is often impractical for clinic staff to give this priority, so there are resource implications for data collection—as well as its management and analysis. Investigators must be confident of the value of quality of life measurement if they are required to ask for additional support from institutions and funding bodies. Moreover, there has been little guidance in the literature as to how to implement quality of life measurement in clinical trials [22], to encourage this practice.

Oncologists request short, simple scales that are quick to use, without perhaps recognising their limitations. Others remain sceptical about the validity and reliability of questionnaire data and whether available scales are sensitive to change. They believe that they are better informed by their own clinical judgement, yet there is evidence that clinicians' assessments of quality of life are less accurate than those completed by the patient [5, 23].

Trial selection

The controversy over trial selection has often concerned the utility of quality of life evaluation in phase II studies, since it has been suggested that such research may be too labour-intensive and therefore too costly to justify [23]. On the other hand, advocates have claimed that benefits may include better symptom detection and control in phase II studies and improved design of phase III trials [24]. It has been suggested that phase II quality of life data may help to influence the speed of approval of new drugs in the USA [25], facilitating their earlier introduction into clinical practice. Some reported policy recommendations advocate the routine assessment of quality of life in clinical trials [26], but this remains controversial given the lack of resources and limited evidence of a benefit to patient care from such an approach.

Methodological problems

The development of a multiplicity of potential research questionnaires has led to a lack of standardisation in measurement, and this, together with small—and frequently differing—patient samples and variations in trial design, has prohibited useful comparison of results. For example, the lack of similarity in research design in studies comparing mastectomy with breast-conserving surgery made it difficult to evaluate and compare these trials [27], although the overall psychosocial impact was apparent. Aaronson [28] has endorsed the need for common rules and language, and has emphasised the importance of using existing instruments, be they generic or disease-specific, rather than beginning again from first principles. Although standardisation may thus be improved, there remain important unanswered questions regarding the measurement of 'cost' and 'benefit' in the treatment equation, as summarised in Table 1.

Table 1. Methodological problems in the assessment of palliative treatment

Measuring cost
Are treatment effects clear cut?
How accurate are the measures of toxicity?
Are chronic mild symptoms as important as acute, severe effects?
Measuring benefit
How can palliation be accurately assessed?
What changes in symptom ratings are clinically meaningful?
How can duration of palliation be measured?

Measuring cost. To date, chemotherapy toxicity has usually been reported using clinical measures of haematological toxicity, or the incidence of dose reduction or delay. Relatively few studies have reported nausea and vomiting [29], and details of measurement may not be included. It may be assumed that such side-effects are clear-cut, yet a number of factors, such as anxiety, may influence nausea and vomiting, and increase their reported prevalence. Disease and treatment effects may overlap, for instance, in the reporting of general symptoms such as anorexia, malaise and fatigue, confounding attempts to balance the cost and benefit of palliative intervention. Further data supporting the validity and reliability of measures of toxicity and physical symptoms are needed, so that treatment comparisons can be made accurately.

It is also important to avoid making assumptions about the impact of individual symptoms, since although severe acute effects such as emesis are likely to be highly aversive, chronic mild symptoms such as nausea and its associated malaise, and anorexia, may also have a significant impact on quality of life.

Measuring benefit. The traditional outcome measures of response and survival are likely to correlate closely with symptom relief, but few studies have specifically reported symptom control [29, 30], and criteria are needed for measuring the extent of palliation. Statistically significant changes in symptom scores from questionnaire assessments may not amount to meaningful symptom relief for the patient. The duration of symptom control is of importance to the patient, yet there are few guidelines on how best to assess duration of palliation. It is more difficult to estimate benefit from treatment when symptom relief has to be weighed against deterioration in some other domain, such as psychological well-being. Some advocate reliance on a global measure of quality of life, others feel this is too reductionist. Other confounding factors such as time spent in treatment, or the impact of hospitalisation for complications, may also influence quality of life, yet many questionnaires do not evaluate such events or effects.

Given that expertise now exists in the field of health status measurement, it is important that clinicians work in collaboration with behavioural scientists to tackle these problems in the design and evaluation of quality of life studies, and that such protocols form an integral part of the clinical trials.

Attrition and compliance rates

Little attention has been paid to the logistics of assessment in the palliative treatment setting, where there is inevitable attrition from death or patients becoming too ill to participate. Treatment delays, episodes of sepsis and other complications may preclude assessment at designated time points, and even when patient compliance is high, these practical problems result in missing data or considerable scatter of data collection around assessment points.

Some studies have achieved only modest compliance. For example, Ganz reported a disappointingly low compliance (58%) with the 'Functional Living Index—Cancer' and was unable to report quality of life data as a result [31]. Particular difficulty has been encountered with daily diary cards despite their advantage in sensitivity to short-term change. In a multicentre palliative treatment study of small cell lung cancer patients, 51% of patients failed to return any cards [32]. Poor compliance within specific centres contributed to this low rate, but impaired functional status will also adversely affect compliance. Geddes' group achieved a better overall compliance of 68% [33] using a modified version of the Medical Research Council (MRC) diary card, but patients with very poor performance status (< 70%) were excluded since it was felt the daily diary card might be too burdensome.

Statistical analyses

Missing data inevitably leads to problems in conducting statistical analyses, and as yet there have been few guidelines in the literature as to how to deal with this [34, 35].

Fayers and Jones acknowledged the problems of missing values and outlined appropriate methods of data analysis [34], suggesting that sophisticated analysis would be inappropriate, given the problems of data definition and data collection. An alternative approach was more recently proposed by Zwinderman in which missing data could be modelled statistically, and change in quality of life explained using a latent logistic regression model [35]. As yet, there is no consensus as to the best model to use, and other methods need to be explored.

PRIORITIES

Attention to neglected areas

Some areas remain to be adequately assessed in a quality of life framework. Cognitive impairment, for example, is intrinsically difficult to measure in a clinical trials setting, and clinicians have been reluctant to get involved. Late effects of treatment, such as fatigue, infertility or sexual dysfunction have also been largely neglected, and need closer scrutiny to assess adequately the quality of life of survivors.

There is already worrying evidence of the costs of surviving Hodgkin's disease, in terms of cognitive impairment [36], and decreased ability with work tasks [37]. Further data is required on which to plan the rehabilitation of such patients after cancer therapy. An important new focus should be an assessment of the burden of cancer treatment on the families of patients and significant others.

Need for new subscales

There is a lack of brief but specific measures to reflect the impact of the sequelae outlined above. Several groups have devised their own scales or subscales to target body image and sexual dysfunction, but very few have reported psychometric data in support of them [3].

Mediating factors

We need a better understanding of the way social support and personal coping strategies mediate the distressing effects of cancer and its treatment, and hence affect quality of life. This would help us to target patients or families at risk and indicate future areas for intervention. Quality of life research should not be an end in itself, but should stimulate enquiry, such as the design of new treatment strategies, methods of treatment delivery, and psychosocial interventions.

Our lack of clear predictors of patients most likely to suffer a poor quality of life prevents us from successfully directing support services where they would be of most benefit.

CONCLUSION

It has been claimed that the Europeans have been in the forefront of a multidimensional approach to quality of life assessment and that for the Americans it was 'time to catch up' [24]. However, we have to acknowledge the American Cancer Society's activity in more clearly voicing their policy recommendations and in assessing their past achievements and future priorities [26, 38]. We are in unison in stating that quality of life research will have limited value unless the findings are used by clinicians and other health care agencies in ways that positively affect patient care. The clinical utility of quality of life assessment must continue to be demonstrated, othewise it will become an academic exercise.

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Eur J Cancer, Vol. 28A, No. 10, pp. 1752–1755, 1992.
Printed in Great Britain

0964–1947/92 $5.00 + 0.00

Cancer Incidence in the Province of Limburg, The Netherlands

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INTRODUCTION

THE IKL cancer registry in the province of Limburg was established in 1984 as part of the Comprehensive Cancer Centre, Limburg (Integraal Kankercentrum Limburg: IKL). Within the structure of the centre, the hospitals, the university of Limburg and the radiotherapeutic institute of Limburg are collaborating. The aim of the centre is the improvement of the care for cancer patients.

Besides cancer registration, the centre is involved in cancer research and treatment and coordinates regional activities on cancer prevention, screening, education and psychosocial care. The cancer registry provides important information on which several of these activities are based. The IKL cancer registry is one of the nine regional cancer registries in The Netherlands. Together, these registries will comprise a nationwide cancer registry. After the IKL cancer registry started in 1984, it has gradually expanded in the following years. From 1986 onwards, all hospitals and pathology laboratories in the region have been participating in the registry. The registry publishes annual reports with respect to the registered malignancies [1–3]. Incidence rates have been published recently [4–6]. For this publication data for the period 1986–1988 are used.

METHODS OF CANCER REGISTRATION

The cancer registry receives lists of newly diagnosed cases on a regular basis from the seven pathology departments in the region. In addition, lists of hospitalised cancer patients are obtained from the medical records departments of the nine hospitals. Following this notification, the medical records of newly diagnosed patients (and tumours) are collected and the relevant information for the cancer registry is abstracted from the medical records by trained tumour registrars.

Tumour data are coded according to ICD-O. Completeness

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Received 8 Aug. 1991; accepted 22 Nov. 1991.