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Review Article

Evolution of quality of life assessment in head and neck cancer

RANDALL P. MORTON, M.B., B.S., M.Sc., F.R.A.C.S.

Abstract

Quality of life assessment as part of clinical practice in head and neck oncology began over 40 years ago. Early studies were narrative and cross-sectional; these were followed, at first, by simple quantitative measures of various parameters and later by longitudinal studies of greater complexity. More recently quality of life has been employed in a randomized clinical trial of head and neck cancer.

Quality of life has evolved to become a standard means of assessing clinical outcomes, and an accepted end point measurement in clinical trials, to be considered alongside survivorship and side effects/complications.

Key words: Quality of life; Head and neck neoplasms; Review literature

Introduction

Most people have an intuitive understanding of the meaning of 'quality of life' (QL). The term is frequently referred to and used in relation to health in general and cancer in particular, but it is not often defined.

A generally accepted definition is: the perceived discrepancy between the reality of what one has, and what one wants, or expects, or has had (Padilla *et al.*, 1988; Gough, 1994). The concept embodied in this definition has been called the 'gap' theory, and a QL score utilizing this definition should measure the difference between: (a) expectations and present experience, and (b) perceived and actual goals (Calman, 1987).

There is general agreement that QL is a multidimensional construction, with contributions from several different aspects, or 'domains' of life (Aaronson, 1991; Gotay and Moore, 1992). It is more than just a reflection of health status (i.e. physical, psychological and social well-being) because it incorporates other life experiences such as economic, occupational and domestic/family domains (Fraser, 1993).

The presence of illness will of course affect the QL of an individual and may be referred to as health-related QL. This phenomenon has long been recognized: Lichtenberg (1742–1799) declared that 'the feeling of health is acquired only through sickness'. The actual impact of a specific disease probably depends on several factors, such as chronicity, the degree to which the disease is perceived as a threat, and the disruption, disability and dysfunction created by the disease and its treatment.

Head and neck cancer and its treatment can have a major impact on important and essential daily functions such as speaking, swallowing and breathing (List *et al.*, 1990), and may lead to considerable disfigurement. Moreover, because of the enormous personal psychological investment in the head and neck (Breibart and Holland, 1988) the QL of patients with head and neck cancer is of great interest and importance. It has resulted in a steadily increasing body of clinical research, which has been the subject of recent reviews (Pruyn *et al.*, 1986; Gotay and Moore, 1992; Morton, 1995a).

The potential importance of head and neck cancer to QL research is probably not appreciated by most otolaryngologists: Gotay and Moore (1992) see the situation from the social science perspective:

> 'While research in quality of life is a challenging area, in many ways head and neck cancer is ideally suited to such an endeavour . . .the development and application of vigorous scientific research in this field holds enormous promise'.

This paper reviews the historical development of QL assessment in head and neck cancer, identifies the important developments and discusses their implementation in current clinical practice.

From the Department of Otolaryngology, Green Lane Hospital, Green Lane West, Auckland 3, New Zealand.

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Historical review

Hippocrates (c460–377 BC) wrote:

> 'Some patients, though conscious that their condition is perilous, recover their health simply through their contentment with the goodness of the physician'.

Traditional approach

It is clear from the above quotation that Hippocrates recognized the importance of the patient's personal life-satisfaction or psychological well -being in the management of an illness. However the traditional focus of medical care has been on the treatment and control of disease, and the patient's concerns have generally been of secondary interest. Voltaire (1694–1761) commented on doctors' traditional lack of attention to patients' general concerns in a barb which hopefully does not apply today:

> 'Doctors are men who prescribe medicine of which they know little, to cure diseases of which they know less, in human beings, of which they know nothing'.

Until relatively recently, QL was not a prominent consideration even in patients with cancer where the impact of the disease was usually quite profound. Instead, it was common for the diagnosis to be withheld from patients – a situation hardly conducive to systematic psychosocial enquiry (Greer, 1994). Indeed, on occasions psychological enquiry of cancer patients was vigorously opposed. For example, Watson (1966), after referring to breast cancer as 'an affliction of an easily disposable utilitarian appendage' went on with this astonishing statement about radical mastectomy:

> '... evidence (of psychological trauma) will usually have been produced by the enquiry (into QL) rather than disclosed by it. The adoption of a casual attitude by the doctor before the operation and throughout the follow-up examinations will go a long way towards eliminating these untoward and unnecessary occurrence'.

Around the same time, similar attitudes were encountered with respect to laryngeal cancer (Nahum and Golden, 1963):

> 'Since the common tendency of the physician and family is to be sympathetic toward the post-laryngectomy patient, it is often necessary to lean a bit in the opposite direction and to deal with the situation lightly'.

Fortunately, such disregard for the patients' psychological welfare was not universal: Green (1947) reviewed the results of treatment for laryngeal cancer, and emphasized that the psychological impact of a laryngectomy was just as important as the physical effects, and needed to be considered as part of post-operative management. Pitkin (1953) explored this further, enquiring into both social and psychological domains in patients who had had a laryngectomy. Also, at this time Hayes Martin, (Ewing and Martin, 1952) in discussing treatment of head and neck cancer in general, emphasized what today would be mainstream QL philosophy:

> 'In deciding the method of treatment we should not, in our eagerness to achieve cure, lightly disregard the crippling that may result from our surgical endeavours'.

Jaco (1958) was perhaps the first to point out the various QL domains affected by illness, identifying concerns that should be considered when treating a patient, and with which QL research in oncology today is involved specifically:

> '(The patient) is confronted with an entirely new set of expectations and assumes entirely different patterns of behaviour in carrying out the role of the patient (reacting) to the experience of pain, to the physician and his ministrations, and ... (who) is not only a sick biological organism but also a member of society with many duties, responsibilities, expectations, and values of a social and personal nature. These latter components of the individual become especially significant in the management of the patient before, during and after the treatment process'.

Quality of life considerations are now regarded as standard practice in clinical research, to the extent that QL has become a recommended endpoint in clinical trials (Troidl *et al.*, 1987).

Quality of life and palliation

Concern for the psychosocial aspects of patients facing death gathered momentum in the 1960s with the emergence of the Hospice movement pioneered by Cecily Saunders in Britain and Elizabeth Kubler-Ross in the USA (Holland and Zittoun, 1990). This phenomenon gave considerable impetus to the development of QL measures in oncology in general.

Today the assessment of effectiveness of palliation for patients with endstage recurrent disease is likely to be one of the most important and useful applications of QL research in head and neck cancer.

Quality of life measurements and measurers

Quantitative assessment of QL in cancer patients began in the latter half of the 1940s. The initiative has been generally ascribed to Karnofsky *et al.* (1948), who laid ground rules incorporating subjective response, functional status and tumour response parameters in the management of lung cancer. Karnofsky *et al.*'s functional status scale was adopted and has become a standard measure in head and neck oncology practice today (Hassan and Weymuller, 1993). Karnofsky *et al.*'s subjective (patient) response to treatment was an index they called 'SI' (Subjective Improvement), using a three-category scale: good, fair, or none.

The SI measure must have been thought too imprecise, as no other researchers of the time seem to have adopted it. In fact, the psychosocial impact of treatment was regarded as not generally quantifiable in those days. Elkington (1966) summed up the situation:

> 'Just what constitutes... quality of life for a particular patient and the therapeutic pathway to it often is extremely difficult to judge and must lie with the consciousness of the physician'.

The modern approach to QL measurement in oncology patients began when Priestman and Baum (1976) proposed a 10-item questionnaire for use in breast cancer. The study was small, the disease narrowly defined, and the test not adequately validated, but the concept was clearly a viable one (Schipper and Levitt, 1985). Since then there has been a growing appreciation of the importance of QL as a supplement to the traditional focus of disease control.

Clinicians have led the way in identifying important QL aspects in head and neck cancer. Sophisticated clinical research has been lacking, probably due in a large part to unfamiliarity with the methodology, and in a small part to the burden of more direct clinical demands. More recently social (behavioural) scientists have become involved with head and neck cancer QL research. New journals devoted to QL research have emerged, entitled '*Quality of Life Research*' and '*Psycho-oncology*' specifically for cancer research.

It is likely that the amount of collaboration between clinicians and social scientists will grow. Certainly there is considerable interest in the QL paradigm from both disciplines. These developments were more-or-less predicted 40 years ago by Cassel (1958) who emphasized the importance of the QL domains of patients' beliefs, attitudes, knowledge and behaviour, and that: 'health care workers can receive invaluable assistane from social scientists'. An example of this is a paper from Sweden (Drettner and Ahlbom 1983) which was the first published collaborative effort between an otolaryngologist and a social scientist, and the first to provide a quantified QL index in head and neck cancer.

A new 'language'

Terminology

The term 'quality of life' was reportedly first coined by Dwight Eisenhower's Presidential Commission on National Goals in 1960 (Spitzer, 1987; Gough, 1994). Careful review of the 'Goals', however, shows no specific mention of QL. The term was actually used in an essay submitted to the Commission by Heckscher (1960). He stated:

> '... a society which puts a value on the quality of its national life will want to act resolutely...'

In 1977 'quality of life' became a 'key word' by which journal articles could be retrieved by the United States National Library of Medicine Medline Computer Search Program. More than 200 papers with the phrase 'quality of life' in the title were subsequently published in the period 1978–1980 (Fayers and Jones, 1993). Gough (1994) reports that since 1987 more than 400 articles referring to the quality of life are published per year. In fact, in 1993 the number was 1255!

Interpretation

Considering the proliferation of publications it is disappointing to see that no consensus has yet emerged as to which parameters should be measured, or which methods should be used specifically in head and neck cancer (van Knippenberg and de Haes, 1988; Gotay and Moore, 1992). All too frequently QL is not defined, and without such a focus, much of the research lacks direction and usefulness.

Moreover, the terminology has not been applied consistently, which has led to ambiguity, and it is from this pool of poorly-defined information that the clinician, unfamiliar with the social (behavioural) science methodology, tries to determine the current status of QL in head and neck cancer today. The result is that many clinicians are confused, wary, and sceptical (Aaronson, 1990).

Despite the problems, some guidelines have emerged from research in several different fields of oncology, which are generally accepted and can be applied to the study of QL in head and neck cancer (Sprangers *et al.*, 1993). These are summarized in Table I. The issue of definition, utilization and interpretation of QL measures in head and neck cancer has been addressed in more detail elsewhere (Morton, 1995 a).

The specific application of the principles of QL research has varied considerably between centres and tumour sites, including head and neck cancer. The domains of enquiry are summarized in Table II. Specific instruments are not cited because many that have been used do not have established validity and reliability at this stage. Some instruments, for example the EORTC QLQ-30 (Sprangers *et al.*, 1993; Bjordal *et al.*, 1994b) have been extensively field tested and show considerable promise. Methods by which the psychometric properties of such

TABLE I

GENERAL PRINCIPLES AND GUIDELINES FOR THE STUDY OF QL

(1) Decide the hypothesis to be tested.
(2) Decide on definition of 'quality of life' to be used.
(3) Design longitudinal study.
(4) Disease-specific questionnaire required, and to include:
    disease- and treatment-related symptom scores;
    health- and disease-status.
(5) Patient data to be self-reported.
(6) Enquiry into domains of functional status should include:
    psychological functioning;
    sociosexual functioning;
    physical functioning;
    global QL measurement (patient-generated).
(7) Field testing and fine-tuning of questionnaire.
(8) Instruments should have been proven, or be checked for:
    reliability;
    validity;
    responsiveness/sensitivity.

TABLE II

DOMAINS OF ENQUIRY WHICH SHOULD BE CONSIDERED WHEN PLANNING A QUESTIONNAIRE TO INVESTIGATE QL IN HEAD AND NECK CANCER

(1) Physical functioning (day-to-day activity).
(2) Symptoms (disease- and treatment-specific).
(3) Emotional functioning (anxiety/depression, etc.).
(4) Role functioning (family/occupation, etc, roles).
(5) Social functioning (interaction at home, with friends).
(6) Coping ability.
(7) Financial impact.
(8) Health status.
(9) Sexuality.
(10) Global index (single item, patient-generated).

instruments can be tested are discussed by Tulsky (1990), amongst others.

Clinical studies

QL in head and neck cancer: 1950–1985

Most early efforts to study QL in head and neck cancer patients came from clinicians, and focussed not only on one disease (i.e. cancer of the larynx), but on one operation i.e. laryngectomy. Moreover, enquiry was generally unidimensional, looking at either physical status, sexuality, or psychological status (depression), rarely exploring more than one domain. The perspective slowly broadened: in a 'state-of-the-art' conference on head and neck cancer Moore (1978) stated that co-morbidity is prevalent in head and neck cancer patients, and that while 'the economic, emotional and practical lifestyle change for patients (after treatment) is hard to overestimate', these aspects are 'often overlooked'.

Natvig (1983a, b) made a valiant effort to cover all aspects of the impact of laryngectomy in a series of articles, exploring physical, social, psychological and occupational aspects of life in patients who had survived their disease and its treatment. Like all other QL research in head and neck cancer patients to that time, Natvig's study in 1983 was cross-sectional, in selected patients (survivors), at various intervals after treatment (in his case: between 6 months and 18 years). Such studies provide descriptive, information full of insight but the results are not generalizable nor necessarily indicative of the changes that can occur over time.

Table III summarizes the early studies that have been concerned with more than just the physical functioning of head and neck cancer patients. A trend is evident: the first studies were cross-sectional, descriptive and narrative in nature. The subsequent studies, while still cross-sectional and therefore of limited application, were quantitative and attempted to correlate QL outcomes with specific variables of interest, such as treatment modality, and presence or absence of pre-operative counselling.

The first longitudinal study (Johnston *et al.*, 1982) was concerned with somatic and physical functioning, and therefore the scope of the QL content was limited. However, the subjects were followed-up for six months, and only two other other studies since then have been of longer duration (Krouse *et al.*, 1989; Morton, 1995b). The other early longitudinal study (Keefe *et al.*, 1985) was limited in duration, size and scope, concentrating on somatic functioning (pain). In general, the early studies were only concerned with larygneal cancer, and laryngectomy. A few reports included oral and pharyngeal cancers, and these indicated that rehabilitative concerns were often greater than those generally encountered after laryngectomy.

QL in head and neck cancer: 1985–1994

Over the past decade, the interest and activity in QL research has increased many-fold. Many studies have still been cross-sectional in design (e.g. Jones *et al.*, 1992; Bjordal *et al.*, 1994a), but some longitudinal studies have appeared, and those reported so far are summarized in Table IV.

There has been one prospective, randomized clinical trial reported (Browman *et al.*, 1993). QL indices were used to assess toxicity in head and neck cancer patients being treated with radiotherapy. More studies of a similar nature are needed. This study is very site- and treatment-specific and limited in its scope, but it is carefully designed and well reported. Survival rate in the study was not reported, but it is nevertheless an important consideration whenever cancer treatments are compared (Skeel, 1989).

TABLE III

EARLY STUDIES OF QL IN HEAD AND NECK CANCER PATIENTS

Year	Author(s)	Study	No. in study	Domains studied	Type of study/outcome analysis
1953	Pitkin	Cross-section	61	Psychosocial	Descriptive
1966	Gardner	Cross-section	177	Sociosexual	Descriptive
1973	Gilchrist	Cross-section	50	Multiple	Correlated QL and counselling
1978	Olsen and Shedd	Cross-section	51	Multiple	Laryngectomy *versus* other
1979	Minear and Lucente	Cross-section	60	Multiple	Correlated QL and counselling
1982	Dhillon *et al.*	Cross-section	49	Multiple	Laryngectomy *versus* other
1982	Johnston *et al.*	Longitudinal	31	Pain/appetite/radiotherapy	Correlates of weight loss
1983	Natvig (a and b)	Cross-section	188	Multiple	QL correlated with coping
1983	Harwood and Rawlinson	Cross-section	129	Speech/occupation	QL in radiotherapy success *versus* failure
1983	Drettner and Ahlbom	Cross-section	52	Multiple	QL correlated to prognosis
1984	Morton *et al.*	Cross-section	48	Multiple	QL correlated to treatment
1985	Keefe *et al.*	Longitudinal	30	Pain	Prediction of pain

TABLE IV

RESULTS/PRINCIPAL FINDINGS FROM PROSPECTIVE STUDIES OF QL IN HEAD AND NECK CANCER

Author(s)	Results and principal findings
(1) Johnston *et al.* (1982)	Weight loss related to size of radiotherapy field, dysphagia, and pain
(2) Keefe *et al.* (1985)	Pain at presentation: a significant predictor of pain at three months after treatment
(3) Padilla *et al.* (1988)	QL item scores deteriorate during radiotherapy; pain changes most
(4) Krouse *et al.* (1989)	Post-operative radiotherapy associated with poorer QL scores at 12 months; oral/oropharyngeal cancer patients more severely affected
(5) Hassan and Weymuller (1993)	QL declines in period of treatment and tends to recover by three months; QL tends to be related to tumour stage
(6) Browman *et al.* (1993)	Adjuvant chemotherapy produces a significant short-term decline in QL in patients receiving radical radiotherapy
(7) Bunston and Mings (1994)	About 50 per cent of head and neck cancer patients have unresolved needs
(8) Langius *et al.* (1994)	Deterioration in psychosocial functioning related to extent of surgery; coping ability correlated with good QL scores
(9) Morton (1995b)	Pain, dysphagia and speech are the principal determinants of QL at 12 months

Rider and Harwood (1982) articulated the 'Toronto philosophy' in this respect very clearly:

> 'We must also consider the question of survival and life for the head and neck cancer patient. When two methods of treatment produce equivalent cure rates one of the major factors determining which treatment should be chosen is the post-treatment quality of life.'

Fayers and Jones (1983) take this a step further and present an intriguing proposal for future clinical trials:

> 'In a cancer clinical trial survival, from treatment to some key endpoint such as death or relapse, is very likely to be an important, and perhaps paramount, outcome measure. However, one theoretical solution is to combine duration and quality of survival in a single model for the purposes of comparison'.

Such integration of survivorship and QL measures is some way off. The QL-dependent variable that seems to have most relevance is subjective 'well-being' (Bjordal and Kaasa, 1992). This has been measured by some, using a life-satisfaction score (Dropkin 1989; Stam *et al.*, 1991; Kreitler *et al.*, 1993; Morton, 1995b), and related to various independent variables. Perhaps Gotay and Moore (1992) should have the 'last word' on this subject. They summarize the current status of QL indices in head and neck cancer thus:

> '. . . this area of research can properly be regarded a being in its infancy'.

Like all young life, it is growing rapidly and has considerable untapped potential.

Conclusions

Measurement of health-related QL in head and neck cancer patients is here to stay. QL status does not equate with disability or functional status, and needs to be accounted for in future clinical trials of alternative treatments. The techniques for assessing QL are evolving, and have received considerable input from the social scientists. Clinicians unfamiliar with the methodology will need to acquire the skills required to understand the implications of a rapidly expanding area of clinical medicine.

Few would deny that it is important for patients with head and neck cancer to achieve a good QL level after they had been treated. The basic tenet for cancer treatment is to cure the disease if at all possible, but probably not at any cost. Thus, QL has become an outcome measurement in clinical practice and research. If survival outcomes are comparable, then QL outcomes may determine which treatment is preferable.

Given the diverse nature of head and neck cancer, and the heterogeneous nature of the disease- and treatment-specific symptoms it may ultimately be appropriate to stratify for subsites of head and neck cancer when analysing results. At present the most pressing need is to expand research on the clinical and social usefulness/validity in our QL measures. A review of the literature shows that this need for validity has not yet been met (Katz, 1987).

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Address for correspondence:
Professor Randall Morton,
Department of Otolaryngology,
Green Lane Hospital,
Green Lane West,
Auckland 3,
New Zealand.