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Widening Perspectives: Quality of Life as a Measure of Outcome in the Treatment of Patients with Cancers of the Head and Neck

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HEALTH-RELATED QUALITY of life is accepted as being an important indicator of treatment outcome and is being used more frequently in cancer clinical trials. With the purchaser–provider division being made explicit in the recent U.K. National Health Service reforms, health-related quality of life assessments are likely to be used more frequently as health care contracts have to include specifications regarding the quality of care. The current focus on clinical audit and outcome in general also highlights the role of quality of life indicators.

Health-related quality of life is a multidimensional construct which comprises four core domains: physical functioning, psychological functioning, social interaction and disease and treatment-related symptoms. There are additional parameters which need to be considered when studying specific patient groups. For example, cognitive functioning will be of relevance in studies with patients with brain tumours, and body image and self-esteem will be important when treatment involves mutilating surgery. Those interested in the psychometric issues surrounding the measurement of quality of life are referred to the ever-increasing literature on this topic [1, 2].

There are two main reasons why the measurement of quality of life is of relevance to the management of patients with cancers of the head and neck region. First, some patients present with advanced disease and treatment may, therefore, be planned with palliative rather than curative intent. In such cases, the quality of life patients can anticipate following diagnosis and treatment is of prime concern. Second, the physical dysfunction caused by some forms of treatment may affect adversely the patient's ability to undertake everyday activities, and their sense of self-esteem and mood and, therefore, have a negative impact upon quality of life. For example, radiotherapy may result in soft tissue necrosis, pain on swallowing or dysphagia, whilst surgery can result in severe disfigurement, nerve damage, dysphagia and altered taste perception.

Compared with the extent of psychosocial research undertaken on patients with cancers of the breast, lung and other cancers such as Hodgkin's and non-Hodgkin disease, there is a surprising lack of material on the psychosocial sequelae following diagnosis and treatment for cancers of the head and neck region. The relatively few studies which have been undertaken have revealed some of the problems experienced by this group of patients. For example, Natvig (1984) highlighted the difficulties associated with the acquisition of oesophageal speech and stoma management in patients with laryngeal cancer [3]; such problems often resulted in marital difficulties and extensive restrictions in social activities. Dhillon *et al.* (1982) reported that some patients became social recluses following surgical treatment for cancer of the larynx, as well as experiencing eating disabilities to such an extent that a fluid diet was necessary [4]. Strauss (1989) described the sense of stigma experienced by patients treated for tumours in the oral cavity: some felt "handicapped", others felt they were treated unfairly at work and some felt unable to work because of their disabilities [5].

There are other studies of a similar nature which have illustrated the psychological and physical problems experienced by patients with cancers in the head and neck region. However, the majority are retrospective, based on small samples of patients and do not include control groups. Furthermore, the quality of life instruments (or other measures of psychosocial outcome) are focused to a large extent on functional parameters. Relatively few studies used instruments designed or recommended for use with cancer patients such as the Rotterdam Symptom Checklist [6] or the Functional Living Index—Cancer [7]. Methodological problems such as these preclude any firm conclusions being reached about the magnitude of the impact of treatment upon quality of life, the extent to which problems are attributable to lifestyle factors (e.g. smoking and/or drinking), and the importance of individual differences such as coping style and the availability of social support.

Patients with tumours in the head and neck region have to cope with both a life-threatening disease plus the prospect of disfiguring treatment. This is similar to the situation faced by patients who are treated surgically for breast cancer. Unlike patients with breast cancer, any disfigurement or dysfunction cannot be hidden from external view. Patients with breast cancer have, however, been studied extensively and the results from such studies have been used to improve the care given to other patients, as well as to enhance the skills of health care professionals who work with cancer patients.

For example, a controlled trial undertaken by Maguire *et al.* showed that specialist nurses were able to recognise and refer patients treated for breast cancer who needed psychiatric treatment; a larger proportion of problems remained undetected in the patients who received routine care alone [8]. In a further study of the same patients, it was shown that those counselled by the specialist nurses showed evidence of better

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social recovery and return to work than the patients in the routine care group [9]. Maguire has also designed workshops to improve the communication skills of health care professionals [10]. Results of psychosocial studies have also shown that patients are able to make decisions about treatment when more than one option is available, and that active participation in the decision-making process can have a beneficial outcome on psychological state [11, 12]. Studies of this nature have been important in highlighting that some patients make decisions which may appear counterintuitive to health care professionals. For example, it might be assumed that women would prefer to undergo breast conserving surgery than mastectomy when offered a choice of treatment for early breast cancer. However, 65% (99 out of 153) of patients in one study chose mastectomy [14], as did two-thirds (43 out of 62 women) in the study undertaken by Fallowfield *et al.*, 1990 [12].

Furthermore, Sugarbaker *et al.* (1981) [13] demonstrated that contrary to their expectations, patients with soft tissue sarcoma in the lower limbs treated with amputations and chemotherapy showed a significantly better quality of life than did patients treated with limb-sparing surgery, radiotherapy and chemotherapy. The quality of life parameters which revealed significant differences between groups were emotional behaviour, body care and movement and sexual relationships. This illustrates the importance of considering such information when making decisions about which type of treatment is best. By presenting quality of life information together with clinical data, patients can judge for themselves which treatment they would prefer.

The results from studies of the psychosocial sequelae following treatment for different types of cancer could help identify the areas in which quality of life research is needed to improve the management of patients with head and neck cancers, and also provide guidance on the design of such studies. Whilst some problems associated with treatment are predictable and unavoidable, for example, those relating to changes in voice quality following treatment for laryngeal cancer, the distress associated with such difficulties may be exacerbated both by the lack of information given to patients and inadequate rehabilitation. "... If I had known all the circumstances and known how I would look afterwards I would not have had the operation done at all" (Dhillon *et al.*, 1982, p. 323) [4]. "... Some patients did not even know that they would be unable to speak after surgery" (Pruyn *et al.*, 1986, p. 471) [15]. Some patients were not informed about the possibilities of learning to talk again. Indeed, the fact that many problems are predictable should alert all health care professionals to the difficulties some patients will encounter. Furthermore, the results from one retrospective study indicated that 18% of patients in a sample of 66 felt that the disadvantages of treatment outweighed the advantages [16]. This highlights the need to include quality of life assessments as indicators of outcome as for some patients, no treatment may be the preferred option. Data relating to quality of life would provide more comprehensive information about the likely consequences of treatment, and help identify those individuals most at risk of developing such problems.

If clinicians, or purchasers, are expected to use quality of life information in the decision-making process, then the information needs to be presented in a suitable format. Most health care professionals are unlikely to have either the time or the inclination to review the published literature to determine the important quality of life issues. One approach is to construct a model to synthesise relevant information which can then be used as an aid to medical decision making. This has been undertaken by Maas (1991) who developed a model of quality of life following laryngectomy. For the purpose of the model, Maas defined good quality of life as being a "lack of cancer stress" (p. 1374) [17]. The amount of stress associated with laryngectomy was considered to be a function of rehabilitation in three areas: speech (acquisition of artificial speech), vocational (relevant for those who wish to work), and psychosocial. Data from studies reported in the literature were used to highlight the factors which influenced the outcome of the three types of rehabilitation. For example, it was found that younger people, those who were married and those who used problem solving behaviours were more likely to acquire artificial speech than others; vocational rehabilitation was influenced by socioeconomic status, age and problem solving behaviour and psychosocial rehabilitation was effected by the extent of surgery-related problems (e.g. facial disfigurement, stoma care and breathing), problem solving behaviour and the social environment of the patient. As would be expected, the model also illustrated the interrelationships between the three forms of rehabilitation.

One of the main advantages of a flowchart or a model is that patients, doctors and key workers such as psychologists experienced in quality of life research can work together to come to a decision about the best method of treatment. Maas argues that information presented in this way will help patients to think about the possible complications following treatment, rather than focus only on getting rid of the tumour. This method would obviously be appropriate with those patients able and interested in participating in decision making in this way. Maas is undertaking further work with patients to test the feasibility of the approach.

There is a need for further work to quantify the magnitude of the psychosocial and the physical problems experienced by patients with cancers of the head and neck, and to reach a consensus about how best to plan treatment and rehabilitation programmes. In-depth, prospective studies are required to explore fully the physical and psychosocial issues in order to identify the quality of life domains most affected by treatment, and how different methods of treatment impact upon quality of life.

An opportunity to assess prospectively the quality of life of patients treated by radiotherapy for cancers in the head and neck region has arisen following the publication of a pilot study which indicated that continuous, hyperfractionated, accelerated radiotherapy (CHART) resulted in a significant improvement in survival and tumour control when compared with the outcome of patients who had been treated with conventional radiotherapy [18]. Following publication of this report, a multicentre, clinical trial was set up to compare the outcome of patients with tumours in the head and neck region randomised to receive either CHART or conventional radiotherapy. Recruitment of patients to this trial is due to end in December 1994. Whilst the relative effectiveness of the two radiotherapy regimes is being assessed in terms of survival, local tumour control and morbidity (as indicated by the presence and severity of acute and late side effects), this will not encompass the psychological and social effects of treatment on the patient. For example, side-effects such as mucositis resulting in a fluid only diet [19] may cause considerable distress for patients. Furthermore, there may be variation in the psychological reactions to the radiotherapy regimes followed. For some, the short regime may be preferable to undergoing more protracted therapy necessitating many visits; for others, the strain of receiving treatment three times daily may be great. Thus a secondary aim of the trial is to compare the effects of the two forms of radiotherapy on the patient's quality of life. The focus of the quality of life assessment is upon differences between CHART and conventional radiotherapy in the ability of patients to undertake everyday activities, levels of anxiety and depression, and the numbers of physical and psychological complaints reported by patients.

To conclude, quality of life data can be used to help clarify the views of clinicians when making decisions about treatment, especially when there are likely to be major differences between two treatments in the *quality* of patients' lives without any significant improvement in survival or local tumour control. Furthermore, such data can provide more information which patients can understand about the likely side-effects and consequences of treatment, and quantify the extent to which levels of psychosocial morbidity vary acording to treatment regimes and thus provide a focus for investigating ways in which such morbidity could be reduced. Finally, given the ever dwindling financial resources for health care, quality of life assessments provide outcome data which can be incorporated with cost information to help determine the relative cost-effectiveness of different methods of treatment.

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