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# The Quality of Life of Head and Neck Cancer Patients: A Review of the Literature

by Jenny Morris

## **DISCUSSION PAPER 72**

### University of York Centre for Health Economics

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#### <u>Abstract</u>

There is an increasing awareness within the medical profession of the need to include quality of life as well as survival as an outcome measure. This paper reviews some of the evidence which assesses the quality of life of patients with cancer of the head and neck who have undergone surgery or radiotherapy.

Although the aim of treatment is to prolong life, the evidence shows that the quality of life of patients can be severely impaired by treatment for cancers in the head and neck region. In general the findings are incomplete and there is an obvious need for further investigation of the quality of survival of these acutely ill patients. For example, the majority of the studies were retrospective, largely descriptive in nature, and mainly focused on functional disability and based on small samples. It is acknowledged that an adequate sample of head and neck cancer patients will always be difficult to recruit in numbers sufficient to provide statistical robustness. Nevertheless a prospective study using validated instruments could more accurately quantify the impact of treatment for head and neck cancers upon quality of life.

Without appropriate measurement of the quality of life of patients with head and neck cancer, policy makers and clinicians making judgements about patient selection and treatment type will be doing so on the basis of beliefs and guesses.

#### 1. Introduction

The need to measure the quality of life of patients in cancer clinical trials is widely recognised as the treatment given is often disfiguring and/or may result in debilitating side effects. Thus in order to quantify the benefits of any particular treatment regimen, information needs to be collected about both the length and quality of survival.

Whilst there is a plethora of information regarding the quality of life of other groups of cancer patients such as breast cancer patients, patients with lymphoma and non-Hodgkins lymphoma, and patients with colo-rectal cancers, there is a paucity of data on the quality of life of patients with tumours in the head and neck region. Furthermore, those studies which been undertaken have been largely conducted in the United States on non-randomised and uncontrolled populations.

The purpose of this paper is to review some of the available evidence in order to highlight the extent to which treatment for different types of head and neck cancers can impinge upon the patient's quality of life, and also to identify the major methodological shortcomings in trials. The purpose of the review is to demonstrate the need for more systematic studies of the quality of survival of patients with head and neck cancer.

#### 2. <u>Background</u>

There are many different types of head and neck cancers, each of which may have a different prognosis and respond differently to treatment. The main

sites are the oral cavity, oropharynx, larynx, hypopharynx, nasopharynx and the salivary glands. The vast majority of the tumours in this region are squamous cell carcinomas arising from surface epithelium, although some may arise from the ducts of salivary glands and, therefore, originate below the surface of visible mucosa. The latter are more likely to occur in the floor of the mouth, the base of the tongue and the nasopharynx. The spread of the tumours will be determined by local anatomy with lymph node metastasis being predicted by tumour differentiation (the more poorly differentiated the tumour, the greater the risk of metastasis), the size of the primary cancer and the availability of capillary lymphatics. The lung is the most common site for distant metastasis, and the risk of distant metastasis is doubled in those patients who develop a recurrence above the clavicle. The disease is staged according to the size of the tumour, the extent of lymph node involvement, and metastasis.

Head and neck cancers are not amongst the most common cancers, although are amongst the most preventable as they are most prevalent in men aged 60 years and over who have a history of heavy drinking and/or smoking (Williams, 1983)

The most recent figures for England and Wales (OPCS, 1984) indicate an incidence of 62 per million males for cancer of the larynx, 13 per million for females; 20 per million males for cancer of the mouth, 11 per million for females; and 22 per million males for cancer of the pharynx and 13 per million females. In 1988, there were 761 deaths in males from cancer of the larynx compared with 192 in females; 320 male deaths from cancer of the mouth compared with 169 females; and 385 male deaths from cancer of the pharynx compared with 204 in females (Cancer Research Campaign, 1989). Five year

survival rates in England and Wales in 1981 for both males and females were generally poor: 15% males (18% females) for cancer of the hypopharynx, 26% (36% females) for cancer of the oropharynx, 31% (40% females) for tumours in the nasopharynx, 39% (52% females) for the floor of the mouth, 41% (58%) for gingiva, and 65% (53% females) for cancer of the larynx (Cancer Research Campaign, 1988). These rates are for people with tumours in all stages of development; however, the outlook for patients treated when the cancer is at an early stage is generally better than that for treatment of advanced disease although these figures are not currently available.

#### Treatment

Given the site of head and neck cancers, any decision about the mode of treatment is going to be primarily influenced by stage of disease. Secondary considerations include the likely functional and cosmetic results, the state of the patient's health, and the preference of the patient. However, one of the major problems associated with some head and neck tumours is that early lesions may be asymptomatic, in which case patients are more likely to present with moderately advanced disease. For example, some tumours of the oral cavity (notably the floor of the mouth and the buccal mucosa) may only be discovered during dental examinations. The earliest symptom of cancer of the base of the tongue (oropharyngeal region) is a sore throat, with the tumour only being detected by indirect mirror examination; more commonly, a large neck mass is the first sign which is indicative of more advanced disease. Symptoms of tumours in the maxillary sinus tend to present once the tumour has extended beyond the walls of the sinus (Million, Cassisi and Wittes, 1985).

The above exemplify how difficult it can be to detect some tumours at a stage where it is possible to improve prognosis. However, the literature suggests that it is possible to detect head and neck cancers at an early stage and that treatment can be effective if instigated promptly (Thompson, 1989). There are two obvious courses of action which may be taken; first improving the rate of early detection and second, increasing public awareness of both the risk of heavy drinking and smoking and the signs and symptoms of malignancy. Prout (1987) outlined the importance of (i) recognising and screening those at risk (late middle aged individuals with a history of drinking and smoking), (ii) the correct assessment of symptoms associated with head and neck cancers (persistence of some or hoarse throat), and (iii) the systematic inspection and palpitation of the oral mucosa in those considered at risk.

Late diagnosis may occur as a consequence of patient delay in seeking medical attention for suspicious symptoms, and/or a delay by the physician in making a correct diagnosis. Neither of these issues have been fully explored, although one of the studies reviewed examined causes for delay in the diagnosis of head and neck tumours in a variety of sites in 46 children (Pratt et al, 1978). The commonest cause of delay was suspected infection which was often treated by antibiotics for up to eight weeks before further investigations were initiated. Other causes included failure to establish the correct diagnosis, history of trauma, prolonged observation of the tumour and delay in seeking advice. Time from onset of symptoms to diagnosis ranged from one week to 18 months with a median delay of two months; no delay in diagnosis was reported in only three of the 46 patients. Whilst some symptoms may be indicative of other non-malignant conditions, Pratt et al stated that

physicians should be made more aware that vague symptoms which are unusual in children may be associated with malignancy and warrant further investigation.

The importance of detecting any cancer in its earliest stage cannot be disputed, as outcome is likely to be more favourable than that for advanced disease both in terms of length of survival and quality of life following treatment. Early stage disease (T1NO1 or T2NO1) can be managed by either surgery or radiotherapy depending upon the site of the tumour, and the expected functional and cosmetic result. For example, tumours between 1-1.5 cm on the lower lip are best treated surgically as the cosmetic result is generally good. However, radiotherapy would be the preferred treatment for lesions on the upper lip, as surgery would involve reconstruction, and also for tumours on the tongue in order to avoid speech impairment and dysphagia. For any site, a combination of surgery and radiotherapy is generally avoided as it has been shown to be of little additional benefit. However, if either surgery or radiotherapy is selected as the primary mode of treatment, then the other treatment can be held in reserve.

Most problematic is the management of advanced disease when there is little chance of cure and it is important to avoid the morbidity associated with treatment. The decision then has to be made between attempting a curative approach, taking a palliative course of action, or just observing the patient (Million, Cassisi and Wittes, 1985). In a questionnaire study of 20 radiotherapists and 20 surgeons which used scenarios of three hypothetical patients with advanced head and neck cancer, Maher and Jefferis (1990) noted that there was increasing disagreement about whether treatment should be radical, palliative, or withheld as prognosis deteriorated. If a radical approach were adopted, the most likely mode of treatment was

radiotherapy and surgery, whereas if the aim was palliative, the most popular approach was radiotherapy alone. This highlights the problems which surround decisions about treatment and suggests that the time may be ripe for holding a consensus conference on the management of head and neck cancers, using the same format as those organised by the King's Fund on the management of primary breast cancer (British Medical Journal, 1986) and colorectal cancers (King's Fund, 1990).

Whichever method of treatment is chosen, there are likely to be side effects of sufficient magnitude to effect adversely the patient's quality of life. For example, radiotherapy may result in soft tissue necrosis, pain on swallowing or dysphagia, whilst surgery may result in disfigurement, flap necrosis (when reconstruction has been undertaken), nerve damage, dysphagia, altered taste perception or the formation of fistulae.

The following section presents a brief review of some of the available literature to illustrate how treatment for head and neck cancer can effect quality of life. As relatively little work has been undertaken in this area, the studies are described in more detail than is usual for a review. The further relevance of this approach will be seen in the fourth section which addresses some of the methodological problems with the studies undertaken.

#### Measurement of the Quality of Life

Rawlinson (1983) investigated 128 patients (111 male and 17 female, mean age 61 years) who had been treated for a variety of stages of laryngeal cancer 9-15 months prior to interview. Of the 128, 113 had completed a successful course of radiotherapy and required no further treatment, whilst

15 had undergone salvage surgery as the radiotherapy had failed. No further details were provided in the paper. The results indicated that the radiotherapy patients reported better voice quality, were better able to return to work and enjoy their usual life-style and generally reported a better quality of life. The major problems reported by the surgical patients were speech related; three needed the aid of an artificial larynx, a further three could not develop oesophageal speech and one could communicate only by writing. Additionally, those who underwent surgery reported fewer problems with swallowing and taste compared with the radiotherapy patients.

Natvig (1984) investigated the quality of life of 186 people undergoing laryngectomy and their spouses. This was also a retrospective study with the patients having undergone surgery two to four years prior to interview. Loss of normal voice was the greatest current problem for 40% of the sample, a problem made worse for some who were also assumed to be deaf. acquiring oesophageal speech were also highlighted, as were the factors which adversely affected this capability. These included nervousness, poor voice in the morning, the presence of infection, and also cold weather; some of these factors were experienced by 82% of the patients. Stoma management or stomal breathing caused problems for approximately 25% of the sample, and a further one-third reported difficulties associated with glottic closure. Loss of glottic closure influences efficiency of coughing, and also increases the risk of water aspiration during hairdressing, bathing etc. Further problems included eating and swallowing difficulties, marital difficulties, and restrictions on social activities. Noting that the above occurred some years post-operatively and that one-third of the patients felt that follow-up appointments failed in terms of practical and psychological support, the need for longer term monitoring and rehabilitation is evidently crucial. Natvig

suggested four areas which should be covered in a rehabilitation programme aimed at both patients and members of their family: speech rehabilitation, stoma management, psychosocial care, and vocational rehabilitation.

Dhillon et al (1982) examined the impact of laryngectomy and the "commando procedure" in an uncontrolled study of patients with cancer of the larynx. The latter involved excision of the tumour, removal of half the lower jaw bone and radical neck dissection. Eighty-six per cent of all patients had adjuvant radiotherapy, and 37% of the laryngectomy and 71% of the commando patients had chemotherapy. The mean age of the 35 laryngectomy patients was 65 years, and they were interviewed, on average, 29 months post-operatively (range of 5 to 172 months); the mean age of the 14 "commando procedure" patients (three of whom also underwent laryngectomy) was 70 years, and they were interviewed 33 months post-operatively (range of 5 to 123 months). The patients were asked to complete a questionnaire (which they were encouraged to discuss with relatives and friends) which covered five main areas: speech, eating, cosmetic problems, employment and social activities.

The study indicated that laryngectomy results in more speech related difficulties, whereas the commando procedure led to more problems associated with eating. For example, the laryngectomy patients reported constant speech difficulties or an inability to speak (four patients had not received any speech therapy at the time of interview), and problems with loss of taste as a result of loss of olfaction, whereas, the commando patients reported severe eating disabilities (43% had to reply upon a fluid diet), dysphagia, and severe dribbling. Furthermore, the more visible nature of the problems experienced by the commando patients resulted in more of these patients becoming social recluses (43% compared with 11%), and experiencing frequent

or constant episodes of depression (21% compared with 14% laryngectomy patients).

In a study designed primarily to test the appropriateness of linear analogue self assessment scales in assessing voice quality, Llewellyn-Thomas et al (1984) measured 16 attributes of voice quality in two groups of laryngeal cancer patients treated by radiotherapy which included dryness, hoarseness, voice loss, and the ability to use voice in normal circumstances. One group of patients (n=30) was interviewed twice at the beginning and twice at the end of radiotherapy treatment, each interview one to two days apart, and a second group (n=29) was interviewed on two occasions (six weeks apart) approximately 18 months post treatment. The mean age of both groups was 60 years and the majority of the patients were males. Il (early stage) disease was diagnosed in 70% of the treatment group and in 59% of the post treatment group. The results which related to voice quality indicated changes in <u>all</u> aspects from beginning to end of radiotherapy, some of which were statistically significant: dryness of the mouth and throat, effort to speak, voice fatigue, ability to whistle, and the ability to use the voice normally. However, it was not possible to examine the duration of such changes as comparable results were not presented for the post-treatment group.

In a pilot study to assess the effects of treatment upon the quality of life of buccopharyngeal cancer patients, Morton et al (1984) investigated 48 male patients all of whom were aged over 60 years and retired from work. The sample consisted of 19 patients treated by radiotherapy, 12 who underwent one of five surgical procedures, and 17 who had radiotherapy followed by salvage surgery. All the patients had been treated within three years prior to interview. Eight quality of life measures were used: four physical (hand

grip strength, Karnofsky score, functional disability, pain and discomfort), and four psychological (depression using questions from the Geriatric Mental State Schedule, Bradburn Affect Balance Scale to measure psychological wellbeing, body satisfaction and life satisfaction). The questions to assess depression were based on the DSM III criteria so it is assumed that physical as well as psychological symptoms were included. This is not an appropriate method for assessing depression in patients with physical disease as symptoms of anxiety and depression may also be symptoms of physical disease or the consequences of treatment. However, despite the length of time between treatment and interview, significant differences existed between the two The radiotherapy patients reported lower disability and greater groups. satisfaction in body image (p<.05), although more were depressed, reported lower scores of well-being on the Bradburn Affect Balance Scale, and a lower life satisfaction score than the surgical patients. Overall, clinical depression was high in both groups (39.6% of the total sample) but this may be a function of the scale used as discussed above.

Teichgraeber, Bowman and Goepfert (1986) interviewed 51 patients approximately six months post treatment, including 26 who had a tumour in the anterior two-thirds of the tongue, nine who had a tumour at the base of the tongue, and six with tumours in the floor of the mouth. Twenty of the patients were treated by surgery alone, 20 with radiotherapy, and 11 with both surgery and radiotherapy. Variables examined included speech intelligibility, articulation, tongue mobility, swallowing ability, pain, taste, employment status and daily activities. Overall, the best results of oral function (speech and tongue mobility and swallowing) were obtained using radiotherapy, and the worst for those undergoing both surgery and radiotherapy. Best general health was reported in those who underwent surgery

or radiotherapy and was worst in those who had the combined programme. As would be expected, articulation problems were dependent upon the site of the tumour with best results reported for those with tumours in the tongue, and worst for those with tumours in the buccal mocosa, alveolar ridge and the floor of the mouth. Swallowing problems were most severe for those who had buccal mucosa tumours, and tumours in the anterior portion of the tongue. All groups reported an increase in eating time (independent of treatment modality, size or site of tumour) ranging from 12 minutes in tumours of the tongue to 38 minutes for those with buccal mucosa tumours.

Strauss (1989) also documented problems experienced by 28 patients treated surgically for tumours in the oral cavity who were interviewed, on average, three to four years post-operatively. Of interest, and consistent with reports from other cancer patients (e.g. MacDonald and Anderson, 1984) is the fact that 57% of the patients felt stigmatised as a consequence of the cancer experience. Some felt "handicapped", others felt they were unfairly treated at work, and nine of the group felt unable to work because of their disabilities. Clearly some of these problems could be minimised by appropriate counselling, a fact recognised by Strauss, who emphasised the need for preoperative psychological preparation in order to reduce post-operative distress.

Only two of the studies reviewed were prospective, and in both cases a before and after design was used with patients acting as their own controls. These were undertaken by Davies, Davies and Delpo (1986) and Krouse, Krouse and Fabian (1989).

Davies, Davies and Delpo (1986) wanted to examine mood disturbance in patients at the outset of their illness who were undergoing biopsy for possible buccopharyngeal cancer. Seventy-two patients were given the Leeds scales for anxiety and depression and the General Health Questionnaire (GHQ) on the day prior to biopsy. The biopsy results indicated that 28 of the patients had cancer. Data obtained from the questionnaires suggested that biopsy outcome was significantly related to pre-biopsy levels of depression, but not anxiety, with age and sex as covariates. Pre-biopsy assessments of anxiety and depression revealed higher scores in the patients subsequently found to have a malignancy. Two possible explanations were given for the high levels of depression: first, depression may present as an early symptom of cancer and second, depression may be the consequence of the patient's perception of the seriousness of the manifest symptoms.

However, as discussed earlier, and also noted by Davies, Davies and Delpo, the Leeds scales include physical symptoms of depression which may also be symptoms of physical disease. Therefore, these results would need to replicated using more appropriate measures of anxiety and depression. The Leeds scales have since been revised and the HADS (Zigmond and Snaith, 1983) is now the more widely used instrument in quality of life studies. Unfortunately, Davies, Davies and Delpo did not collect any other data (e.g. sociodemographic, personality) which might have provided additional insight into why there were differences between groups prior to biopsy. Without such information, it is not possible to conclude that any differences in scores are wholly attributable to existing symptoms or presence of disease.

Krouse, Krouse and Fabian (1989) investigated 33 patients, the majority of whom underwent surgery for laryngeal cancer (of whom 17 had a laryngectomy) and tumours in the oral cavity. Patients were interviewed preoperatively and followed up three and nine to twelve months post-operatively using postal The preoperative interview focused on expectations of surgery, specific problems such as pain, social and vocational activity, and expected stresses after surgery. Additionally, all patients completed the Beck Depression Inventory and the Body Image Questionnaire. The follow-up material consisted of the two self-report questionnaires, plus a questionnaire containing questions relating to work, the perceived success of the operation, levels of pain, affect on usual activities, appearance, and health services received since surgery. The results showed that the patients with tumours in the oral cavity and oropharynx were more depressed and experienced greater physical limitations than the others. Twenty-one per cent of the sample reported loss of voice by the end of the study, but unfortunately no assessment was made of voice quality nor of the difficulties associated with the acquisition of artificial speech so the extent of the problems reported Consistent with some of the results reported may be an underestimate. earlier, those who underwent radiotherapy as well as surgery experienced more physical limitations and difficulties with eating than others, and experienced more negative changes in social and work activities.

Given the opportunity to undertake a prospective study, it is disappointing that the authors chose to use postal questionnaires rather than interviews to collect the follow-up data as this limits the amount and nature of the data which may be collected. Furthermore, as with so many studies in this area, the sample size was small, but of greater concern was the use of analyses of variance on what were essentially ordinal data. Noting the

limitations with the above two studies, it is argued that an adequately designed prospective study has yet to be undertaken.

Only one of the studies reviewed used a control group (Drettner and Ahlbom, 1983) in which a questionnaire (initially designed for use in primary care and other specialties) was given to 52 patients with various head and neck tumours. There were 33 males and 19 females, mean age 64 years who were interviewed between three months and two years post-diagnosis. Two controls matched for age and sex for each patient were randomly selected from a local population and asked to complete a postal version of the questionnaire. questionnaire included questions about general health, how general health compared with that of others of the same age, quality of life, as well as an index composed of 10 questions which included the ability to work, carry out usual activities, physical and mental well-being, ability to speak or communicate, sleep, and the ability to eat and enjoy food (scores of less than 65 on the index were taken as representing poor health). Patients were classified into those with a good and those with a poor prognosis by an independent rater. As might be expected, more individuals with a poor prognosis reported poor health than those with a good prognosis (p<.001). Results from the index revealed significant difference between good prognosis patients and controls with the good prognosis patients reporting better health and being more able to appreciate their hobbies (p<.05) which may be a consequence of favourable prognosis resulting in greater life satisfaction. Work, mental and physical well-being, ability to eat and enjoy food, hobbies and communication were more impaired amongst the poor prognosis patients than those with a good prognosis (p<.05).

#### 4. <u>Methodological Issues</u>

There are several limitations with the studies reviewed which may be summarised as follows:

- and did not include control groups. Thus it was not possible to establish the extent to which pre-existing problems influenced quality of life. Furthermore, the results are likely to be distorted as retrospective studies lead to an over-representation of patients with positive treatment outcomes (Pruyn et al, 1986).
- (ii) The measures of quality of life used tended to be rather crude and largely focused on functional parameters; none of the studies used instruments utilised in studies of other cancer patients, for example, the Rotterdam Symptom Checklist, the Spitzer QL index and the Functional Living Index for Cancer. A review of these and other scales appropriate for use with cancer patients is provided by Clark & Fallowfield (1986) and Maguire and Selby (1989).
- (iii) The majority of the studies were descriptive, with few analytical techniques being used.
- (iv) With the exception of the study undertaken by Harwood and Rawlinson (1982), little reference was made to how quality of life was influenced by stage of disease.

- (v) None of the studies investigated the role of individual differences (eg. coping style, levels of self-esteem, social support) and how these might influence outcome.
- (vi) There was little discussion of the quality of life of the carers of cancer patients. The relevance of this can be appreciated from the results from studies which have investigated the quality of life of both cancer patients and their next of kin (eg. Cassileth et al, 1985; Morris and Royle, 1988).

In conclusion, the comments made by Pruyn et al (1986) are as appropriate today as they were in 1986: "A final conclusion is that the very limited insight into physical, psychological and psychosocial aspects of rehabilitation and the problems experienced particularly applies to the patient with cancer of the oral cavity or oropharynx" (p.473).

#### 5. The Importance of Individual Differences

Given the nature of the disease and its associated treatment, it is predicted that there will always be some degree of physical and psychological morbidity in these patients, but it is argued that the severity of such morbidity will be worse in some patients than others. However, little attention has been given to the role of individual differences such as personality and coping style and how these can influence outcome. This is in marked contrast with the work undertaken with other groups of cancer patients where individual differences have been found to influence both susceptibility

to certain types of cancer, and also outcome following diagnosis and treatment (e.g. Greer et al, 1979; Pettingale, 1984; Rogentine et al, 1979; Graydon, 1988; Funch and Mettlin, 1982; and Watson et al, 1984). Evidence from the literature suggests that variables which merit further investigation in head and neck cancer patients include coping style, social support networks, and emotional expression. Such research would help quantify the extent to which any changes in quality of life following diagnosis and treatment were influenced by patient factors. Furthermore, given the problems associated with age, drinking and smoking, it is argued that rehabilitation of these patients can be aided and the risk of recurrence reduced by taking account of individual differences in rehabilitation programmes.

#### 6. Conclusions and Recommendations

This review demonstrates that both surgery and radiotherapy for cancers of the head and neck result in varying degrees of physical and psychosocial morbidity. Some of the problems are predictable and a direct consequence of treatment, for example those relating to changes in voice quality, whilst others are exacerbated both by the lack of information given to patients and their relatives, 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); "... some patients did not even know that they would be unable to speak after surgery" (Pruyn et al, 1986, p. 471) and some patients were not informed about the possibilities of learning to talk again. Earlier in this review, it was reported that four of 38 laryngectomy patients had not received any speech therapy (Dhillon et al, 1982). The fact that many problems are predictable should alert all

relevant professionals to the difficulties some of these patients will encounter.

Shapiro and Kornfield (1987) recommend early contact with liaison psychiatrists who would be best able to detect those unable to cope with the consequences of the diagnosis and treatment. It is obvious from the literature that patients do not disclose the full extent of their problems to physicians. As indicated by Harwood & Rawlinson (1982) "...one of the important findings of this study was that the patients rarely told the clinician in detail the problems they had after treatment" (p.337). Additionally, Rawlinson (1983) stated that patients minimised the severity of their symptoms to physicians and were more open with interviewers, and Strauss (1989) reported that 36% of the patients in his study denied anything was wrong until they were persuaded by others to seek help. Furthermore, input from such professionals may help change behavioural patterns associated with an increase in the risk of recurrence. The extent to which patients continue to smoke and/or drink following treatment has not been well researched, although Strauss (1989) reported that 32% of a sample of 28 patients continued to do so. The significance of continued smoking is shown in the results reported by Harwood & Rawlinson (1982) where there was a higher rate of recurrence in patients with laryngeal cancer who continued to smoke (n=48, 27% recurrence) than those who stopped prior to radiotherapy (n=77, 14% recurrence).

Further insight into the magnitude of the problems which can be experienced by this group of patients is provided by Breitbart and Holland (1988) who reported that cancers of the lung, larynx and tongue accounted for almost half the numbers of suicides in cancer patients over an eight year

period. It has to be remembered that unlike surgery for breast and colo-rectal cancer those undergoing surgery for head and neck cancer cannot hide their disfigurement.

More systematic work needs to be undertaken to identify the extent of psychosocial morbidity in these patients using validated instruments which have been used in studies of other cancer patients, and whether such morbidity is influenced by individual differences. Ideally, studies should be prospective with a reasonable follow-up period. Given the small numbers of patients, multi-centre studies and international as in thrombolytic therapy (TPA) and other trials are essential and would help establish the success of different modes of treatment with regard to five year survival, risk of recurrence and the impact upon quality of life. Harwood and Rawlinson (1982) have argued that the survival data are equivalent following primary surgery and radiotherapy with surgery held in reserve. If this is well supported empirically, then there is a case for giving patients the choice of treatment (a choice which also allows patients to ask the doctor to make the decision).

The success of such an approach can be seen with the management of early breast cancer patients where surgical research undertaken over the past decade has shown that five year survival and disease-free interval are similar following simple mastectomy, and wide excision plus radiotherapy (Fisher et al, 1985). Such findings have led to alternative treatment possibilities and a greater involvement of patients regarding choices that may be made. Preliminary work on breast cancer patients has shown that those patients who are offered a choice of surgery experience less anxiety and depression (Morris and Royle, 1988) and have a more favourable adjustment (Morris and Ingham, 1988) post-operatively than those patients not offered a choice. It would be

interesting to widen the base of such findings to determine whether such results are found in other groups of cancer patients where survival figures are equivalent for different treatments and a choice of treatment can be offered.

Presenting patients with information about outcomes from different treatment regimens is a complex process and may involve decisions which result in a trade-off between length of survival and quality of life. For example, Slevin et al (1990) investigated treatment preferences in five groups of individuals: 100 patients about to receive chemotherapy for a variety of solid tumours, 100 controls matched for age, sex, ethnicity and occupation, cancer doctors (60 medical oncologists and 88 radiotherapists), 790 general practitioners, and 303 nurses from the Royal College of Nursing Oncology Nursing Society. Individuals were asked to indicate their willingness to undergo chemotherapy which produced either severe or mild side effects in three circumstances: (i) the treatment offered a chance of cure; (ii) cure was not possible but the treatment could prolong life; (iii) the treatment could only relieve symptoms. The results showed that significantly more of the cancer patients would accept treatment which resulted in <u>less benefit</u> (p<.001), and that the radiotherapists required more benefit than any other group (p<.01). The large differences between the cancer patients and the control group indicate that attitudes to treatment can change dramatically when individuals are faced with cancer diagnosis, and also that some patients will accept any treatment which offers some benefit. Slevin et al point out that the patients who participated in the study had agreed to undergo chemotherapy and, therefore, may not be representative of all patients offered chemotherapy.

However, others have used more direct methods of eliciting preferences for length or quality of survival. McNeil et al (1978) used the standard gamble technique (described in Pauker & McNeil, 1981) to quantify attitudes to survival and risk taking in 14 patients being treated with surgery or radiotherapy for operable cancer of the bronchus. Twelve of the patients were found to be "risk averse" which means that life for them in the near future is more important than life many years later. Thus it would be predicted that such individuals would choose radiotherapy if given the choice between radiotherapy and surgery as the latter carries a risk of operative mortality. Further results illustrated the percentages of patients who "should" receive radiotherapy according to whether five year survival or expected utility was used as the measure of treatment efficacy. If the patients were aged either 60 or 70 years, the five year survival figures would indicate that radiotherapy would have been an appropriate treatment for patients only when the operative mortality rate approached 15%, whereas measures of expected utility indicated that radiotherapy would be appropriate for more patients even when the operative mortality rate was 5% or 10%.

In a further study of 37 healthy volunteers McNeil et al (1981) demonstrated that approximately 20% of the volunteers would choose radiotherapy rather than surgery when presented with scenarios which illustrated the outcome following surgery or radiotherapy for a localised T3 laryngeal tumour. This indicates that some individuals would prefer to trade quantity for quality of life as the scenarios indicated that radiotherapy had a lower survival rate but preserved speech, whereas surgery had a higher survival rate but resulted in a loss of normal speech.

To conclude, it can be seen that more work needs to be undertaken using controlled trials to measure the quality of life in head and neck cancer patients. Instruments which have been shown to be both reliable and valid in studies with other cancer patients should be used to assess the impact of diagnosis and treatment on psychological, social, occupational and sexual functioning. Where possible, questionnaires should be completed by the patients themselves as this has been shown to be a more reliable method than relying on quality of life assessments made by doctors and nurses (Slevin et al, 1988).

Despite the nature of the problems experienced by many patients with cancers in the head and neck region, and indeed by those with malignancies in other sites, their quality of life can be improved by ensuring that patients and their relatives are adequately counselled pre and post-treatment, that rehabilitation is well structured, and that those individuals unlikely to cope with the consequences of diagnosis and treatment are identified and offered additional support. The benefits of these interventions, like all other treatments, need to be carefully evaluated in terms of enhancements in the length and quality of life.

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