



# A Return to "Normal Eating" After Curative Treatment for Oral Cancer. What are the Long-term Prospects?

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The ability to eat determines not only a patient's nutritional status, but also influences quality of life. A retrospective investigation of the incidence of side-effects affecting eating and their effect upon quality of life more than 1 year after treatment, was undertaken to evaluate long-term patient rehabilitation. 25 patients with oropharyngeal carcinoma were interviewed. Nutritional intake and effect on diet were assessed by analysis of patient diet diaries. Nutritional status was measured from weights recorded at time of treatment and anthropometric measurements at time of study. All patients completed a quality-of-life questionnaire and the importance of side-effects was measured by a ranking exercise. Seventy-two per cent of patients required modifications of dietary consistency. Energy and protein intakes decreased with increasing degrees of dietary modification. Side-effects affecting eating persisted in 23 out of 25 patients, with 80% still having a dry mouth at a mean of 3.5 years post-treatment. Forty per cent had not regained weight lost during treatment. The top ranked side-effects perceived to be of greatest importance to quality of life all related to the ability to eat. A return to "normal eating" is not possible in all patients.

**Keywords:** oral cancer, eating, quality of life, rehabilitation

*Oral Oncol, Eur J Cancer*, Vol. 30B, No. 6, pp. 387-392, 1994.

## INTRODUCTION

PATIENTS TREATED for oral cancer pose a unique problem in both achieving an optimal nutritional intake and maintaining an acceptable quality of life, not only during the treatment period, but during the follow-up and rehabilitation processes.

We are now moving into an era where advances in cancer treatment have led to prolonged survival, and cancer as an illness has moved from being an acute to a chronic disease, for which the rehabilitation and recovery process is prolonged [1].

Length of survival alone is an unsatisfactory measure of the success of treatment. The quality as well as the quantity of survival needs to be evaluated [2]. Several standardised instruments have been developed to measure quality of life, including the Karnofsky performance scale [3], the linear analogue self assessment [4], the quality of life index [5] and the Rotterdam symptom checklist [6]. Very few of these assessment methods address the specific problems relating to head and neck cancer, where both the disease and its treatment can affect every day activities such as eating and speaking [7].

The side-effects of treatment, such as dry mouth, chewing and swallowing difficulties, have been demonstrated to persist at follow-up after 1 year. These effects were found to contribute to loss of appetite and lack of weight gain, and to have an influence upon psychological distress [8]. The head

and neck cancer patient often has, in addition, a significant history of alcohol abuse, heavy smoking, poor eating habits and a lack of proper funds to sustain adequate nutrition, all of which will exacerbate a compromised nutritional intake [9].

In patients who have received treatment for oral cancer, the ability to eat determines not only the patient's nutritional status but also influences their quality of life.

The aim of this study was to retrospectively investigate the long-term effect of treatment upon nutritional intake and quality of life. This information will be used to evaluate the rehabilitation of head and neck cancer patients locally.

## PATIENTS AND METHODS

### Patients

Patients were identified from the disease index in the Clinical Oncology Departments at Kings College Hospital and Guy's Hospital. Those presenting after January 1985 with a diagnosis of oropharyngeal carcinoma, who had completed treatment at least 1 year previously, and who had no evidence of recurrent or secondary disease were eligible for inclusion.

### Methods

Prediagnosis and pretreatment information were taken from the clinical notes and radiotherapy records. Data included normal and pretreatment weight, weight changes during treatment, side-effects noted and social history including smoking and alcohol intake.

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Manuscript received 21 Mar. 1994; accepted 25 Apr. 1994.

Each patient was interviewed and a verbal account of the diagnosis, treatment and rehabilitation episodes documented to verify the information taken from the clinical records. Specific questions were asked regarding saliva production, taste, length of time needed to eat meals, speech and social activities, especially eating in public places or outside the home.

#### Measurement of nutritional status

1. *Anthropometric measurements.* Body mass index (BMI) was calculated for pretreatment, end of treatment and at the time of study, using the quetelet index [10]:

$$\text{BMI} = \frac{\text{Weight (kg)}}{\text{Height (m)}^2}$$

Anthropometric parameters of the upper arm, namely the mid-upper arm circumference, the triceps skinfolds thickness, and the mid upper arm muscle circumference were measured at the midpoint of the upper arm and evaluated against age- and sex-specific percentile distribution standards of Bishop *et al.* [11].

2. *Percentage weight change.* Weight change was recorded as the difference in weight from pretreatment level to end of treatment, and from pretreatment level to time of study. This is expressed as a percentage weight change using the following formula:

$$\frac{\text{Difference in weight}}{\text{Pretreatment weight}} \times 100 = \% \text{ weight change}$$

3. *Dietary intake.* Each subject completed a 5-day diet diary at the time of study. Nutrient intakes were calculated as a mean of the 5 days using the Micro-diet dietary analysis package [12].

Any dietary modification made was categorised as either:

- (i) normal diet, of normal texture and consistency,
- (ii) diet containing no dry foods,
- (iii) diet of soft consistency foods,
- (iv) liquidised diet.

4. *Quality of life measurement.* This was determined by the following two methods.

- (i) Patient self-administered exercise to rank perceived side-effects of treatment in order of importance [13]. See Appendix 1 for details.
- (ii) Modified quality of life index [5]. Patients answered a five-section questionnaire with one multiple choice question per section, defining the patients quality of life. Each section consisted of three statements reflecting a decreasing quality of life from statement A to statement C. Patients were asked to choose one statement from each section which best described their situation. Two points were awarded to statement A, one point to statement B and zero points to statement C. A total score out of a maximum of 10 was obtained. The higher the score achieved the better the quality of life for that individual. See Appendix 2 for details.

## RESULTS

#### Patients

The total number of live patients registered in disease index was 154. The total number available for study was 48; the reasons for exclusion are shown in Table 1. After gaining written informed consent, 25 patients completed the study. Reasons for failing to complete the study are shown in Table 2.

#### Site of cancer

The sites treated are shown in Table 3.

#### Age and sex distribution

Fifteen males and 10 females were studied with a mean age of 62 years (range 40–80), see Fig. 1.

Table 1. Reasons for exclusion from study

Reason	Number of patients
Age (over 80 years/effect of old age)	19
Moved out of area/country	24
Recurrence	22
Treated elsewhere/no treatment	34
Records lost	7

Table 2. Reasons for failure to complete the study

Reason	Number of patients
Declined to take part	8
Did not attend	15

Table 3. Sites of cancer treated in the patients studied

Site	Number of patients
Buccal mucosa	4
Tongue	7
Nasopharynx	2
Parotid	5
Other salivary gland	4
Tonsil	1
Alveolar margin	1
Unspecified part of mouth	1

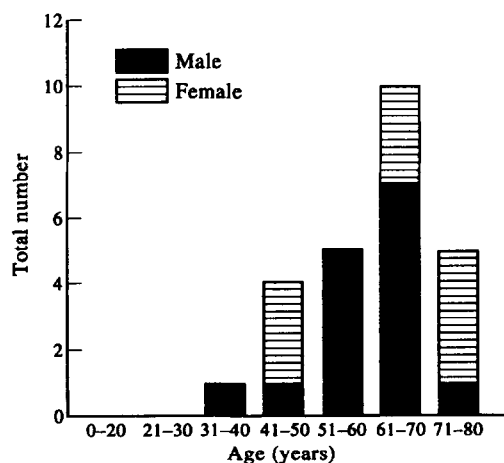


Fig. 1. Age and sex distribution of the study group.

Mean length of time elapsed from completion of treatment to the time of study was 3 years 5 months (range 18 months–7 years). All patients had been treated with either radiotherapy or with a combination of surgery and radiotherapy.

#### *Social history—smoking and alcohol*

At diagnosis, 18 (72%) patients smoked and 9 (36%) drank alcohol. 8 patients (32%) both smoked and drank alcohol. At the time of study, 6 (24%) still smoked and 6 (24%) still drank.

#### *Body mass index (BMI)*

Pretreatment body mass index calculated from the pretreatment usual weight was within the normal range ( $\geq 20$ ) in 24 patients, with 10 being overweight (BMI greater than 25), see Table 4.

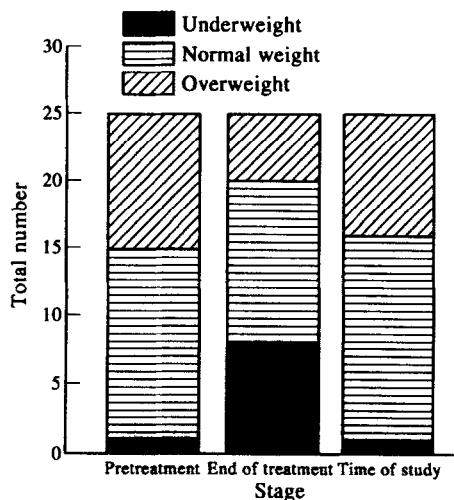
At the end of the treatment period only 17 patients were of normal weight, with 5 remaining overweight, and 8 becoming underweight with a BMI of less than 20.

At the time of study the number of patients with BMI's within the normal range had returned to 24, however, only 9 were now overweight, see Fig. 2.

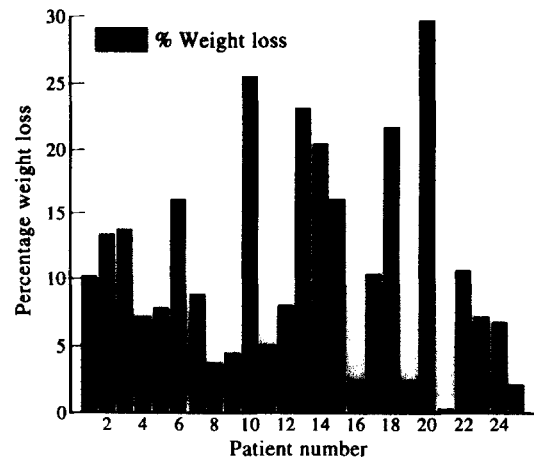
#### *Weight change*

Percentage weight change from pretreatment levels to the end of the treatment period was a negative figure, giving a mean weight loss for the study group of 10.84% (range 0–29.3%), see Fig. 3.

At the time of study, 10 (40%) patients had not yet regained lost weight, still having a mean weight loss of 7.4%, 12 (48%)



**Fig. 2.** Changes in body mass index recorded pretreatment, at end of treatment and at time of study for the study group.



**Fig. 3.** Percentage weight loss distribution for the study group.

patients lost more than 10% of their body weight during treatment. Of these, 8 (66%) have not yet fully regained weight to their pretreatment levels. Those who have regained weight have taken an average of 9 months to do so.

#### *Anthropometric measurements*

Mid upper arm muscle circumference, an assessment of total body muscle mass, was below the 50th percentile in 17 (68%) patients. Triceps skinfolds thickness, an assessment of total body fat, was at or above the 50th percentile in 17 (68%) patients.

8 (32%) patients have both a mid upper arm muscle circumference below the 50th percentile and a triceps skinfolds thickness above the 50th percentile, indicating muscle wasting and fat deposition.

Of those with a mid upper arm muscle circumference below the 50th percentile, 7 (41%) patients had a weight loss of greater than 10% during treatment.

#### *Dietary intake and modification*

Five-day dietary diaries were completed by 24 out of the 25 patients. Energy intake ranged from 2.91 to 13.62 MJ (692–3244 kcal) per day, mean = 8.09 MJ (1926.6 kcal). Protein intake ranged from 35 to 119 g protein per day (mean 75.1 g).

Dietary modifications were required by 18 (72%) patients. 12 patients ate no dry foods, 5 ate foods of soft consistency only and 1 patient liquidised all foods. Only 7 patients were able to eat a diet of normal texture and consistency. Energy and protein intakes decreased with the degree of dietary modification required, see Table 5.

*Table 4. Body mass index*

	Number of patients		
	Pretreatment	End of treatment	Time of study
Underweight (BMI < 20)	1 (4%)	8 (32%)	1 (4%)
Normal weight (BMI = 20–25)	14 (56%)	12 (48%)	15 (60%)
Overweight (BMI ≥ 25)	10 (40%)	5 (20%)	9 (36%)

Table 5. Energy and protein intakes with dietary modification

Dietary modification	Number of patients	Mean energy intake		Mean protein intake (g)
		MJ	kcal	
Normal texture and consistency	7	9.6	2275.2	85.4
Diet containing no dry foods	12	7.8	1852.9	80.9
Soft consistency diet	5	7.5	1791.0	74.95
Liquidised diet	1	2.9	692.0	35.0

### Quality of life

Side-effects which specifically affect eating were present in 23 out of the 25 patients, see Table 6.

Ranking of perceived side-effects in order of importance—the mean number of physical symptom cards selected was 5 (range 0–16) and the mean number of non-physical symptom cards selected was 2 (range 0–8), giving a mean total number of symptoms selected by patients of 7 (range 1–24).

The ranking of the 10 highest scores of perceived importance calculated for each symptom are summarised in Table 7.

### Quality of life score (Spitzer)

Mean quality of life score achieved was 8.4 (range 4–10) with a standard deviation of 1.63.

Table 6. Persisting side-effects affecting eating

Side-effect still present	Number of patients
Dry mouth	20 (80%)
Taste changes/loss	7 (28%)
Unable to eat out in public	7 (28%)
Takes longer to eat meals	14 (56%)

Table 7. Relative severity of side-effects

Symptom on card	Rank
Dry mouth	1
Takes me longer to eat my meals	2
Difficulty with swallowing	3
Changes in the way things taste	4
Difficulty in speaking clearly	5
Constantly tired	6
Increased thirst	7
Lack of energy	8
Sore mouth	9=
Feeling bad tempered	9=
Feeling that the treatment has affected my speech	9=
Dry skin	10

## DISCUSSION

The ability to eat is fundamental to life. It is well known that treatment side-effects for oral cancer persist, but their long-term effect on a patient's ability to eat has not been evaluated. This study was undertaken to look at the prospects for a return to "normal eating" in patients who have completed curative treatment for oral cancer, evaluating the impact on nutritional status and quality of life.

The subjects studied were treated in two hospitals as part of the South East London Radiotherapy Centre. Both are located in inner city areas, with populations affected by the social, environmental and health problems associated with inner cities. Only 25 out of a registered number of 154 patients completed the study. Head and neck cancer has a poor 5-year survival rate—Cancer Research Campaign 1989 [14] limiting the numbers of disease-free patients available. The patient group consisted of the local population from the lower socio-economic groups who are less likely to attend non-essential hospital appointments, and patients who attended the hospitals as a regional centre for treatment and are now followed up in their local area. In a retrospective study these factors will influence patient recruitment.

The reporting of nutritional parameters and oral intakes varied greatly. Weight was the only consistently documented form of nutritional assessment. At the end of the treatment period there was a mean percentage weight loss of 10.8%. At the time of study, a mean of 3.5 years post treatment, 10 patients had not returned to their pretreatment "usual" weights. According to body mass index, 24 were at or above the normal level for weight and height ratio, indicating a discrepancy between normal range "ideal" weights and patient's "usual" weights. Failure to regain lost weight did not have quality of life implications. As a side-effect on the patient perception ranking scale, failure to regain lost weight was not ranked amongst the top five side-effects selected by any patient.

Anthropometric measurements of body compartments before and after treatment and at the time of study showed a change in weight distribution, with a greater proportion of body fat and a lower proportion of lean muscle mass in the study sample when compared to the age- and sex-specific standards of Bishop [11]. This suggests that regained weight is laid down more as fat than as lean body mass. A mean percentage weight loss of 10.8% at the end of treatment is indicative of malnutrition [15], however, as a long-term problem weight change did not affect quality of life.

The failure to regain lost weight may be explained by the continued need to modify dietary consistency. Few patients had returned to normal eating, with dietary modifications being employed in 18 out of 25 subjects. The use of eating strategies in response to symptoms has been documented [16]. Side-effects which influenced eating persisted in 23 out of the 25 patients. A dry mouth was perceived as the most severe side-effect, followed by the increased length of time needed to eat meals. Swallowing difficulties, taste changes and a sore mouth were also within the 10 highest ranked side-effects and compromised normal eating.

Dietary modification had a negative effect upon the ability to maintain nutritional intakes. Energy and protein intakes

decreased with an increasing degree of dietary modification. Estimated average requirements (EAR) for energy in adults (mean age 62 years) is 9.93 MJ (2380 kcal) for men, and 7.99 MJ (1900 kcal) for women [17]. In the patients studied, mean energy intakes for all categories of dietary modification are below these levels. Lack of energy was ranked eighth in the perceived severity of side-effects. Estimated average requirements for protein are 42.6 g for men and 37.2 g for women. Protein intakes are above these levels in all patients except for the patient consuming a liquidised diet. The need to avoid dry carbohydrate foods may lead to a higher proportion of energy being consumed as protein foods. The decreasing trend in mean nutrient intakes reinforces the fact that energy and protein intakes will fall with the need to modify dietary consistency, making it harder for lost weight to be regained.

Improving salivary function post-treatment could reduce the need for dietary modification. There is great interindividual variation in the recovery of salivary flow rate [18]. Altered radiotherapy techniques may cause less dryness [19].

Overall quality of life scores gave a high mean value of 8.4. In validating this tool, Spitzer gained mean scores for a healthy population of 8.9, and for cancer patients of 7.0. In this sample, 28% of subjects scored equal to or less than 7.0, none of which were able to eat a diet of normal texture and consistency. The distribution of scores was centred around the maximum of 10, suggesting an overall high quality of life. This is open to bias, with over-representation of patients with positive treatment outcomes being a drawback of retrospective studies [20]. More importantly this may reflect the failure of quality of life assessment tools to address the aspects of lifestyle concerned with eating and oral function.

Quality of life tools are now being developed to assess more specific problems relating to head and neck cancer, including ability to eat, quality of speech and levels of energy [7]. These should be adapted as part of patient follow-up, leading to appropriate multidisciplinary input and allowing for better advice and coping strategies to be offered as part of patient rehabilitation.

Quality of survival is an important issue. In the future, refinements in radiation treatment planning, conformal therapy to protect normal tissues and better targeting of treatment volumes may lead to fewer long-term side-effects. Until then, the symptom distress of head and neck treatments will continue to compromise the ability to eat and the quality of life of patients.

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## APPENDIX 1

Patients were presented with two sets of cards.

Set A = Physical side-effects (see Table 8)

Set B = Non-physical side-effects (see Table 9)

The patient was asked to look at the cards one set at a time, and select any cards which describe a side-effect currently present, which they attribute to their disease or treatment. The patient was then asked to rank the cards selected in each set, and the top five cards from each set were then combined.

The patient finally selects the five most severe symptoms, and places them in order from most to least severe.

Five points are allocated to that symptom, ranked as most severe decreasing to one point for the symptom ranked as fifth.

Table 8. Set A. Physical symptoms

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Feeling sick	Constantly tired
Being sick	Dizziness on standing
Shaking all over	Loss of appetite
Changes in the way things taste	Sore mouth
Changes in the way things smell	Sore throat
Constipation	Passing more water than usual
Diarrhoea	Dry skin
Failure to regain weight	Increased appetite
Loss of weight	Trouble with swallowing
Feeling full quickly	Cannot taste things
Dry mouth	Difficulty sleeping
Increased coughing	General aches and pains
Lack of energy	Periods stop/irregular
Difficulty with chewing	Increased thirst

Table 9. Set B. Non-physical symptoms

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Loss of sexual desire
Feeling low or miserable
Thought of coming for treatment/check-up
Length of time it takes at clinic
Feeling bad tempered
Affect it has on my family/partner
Feeling of not coping with treatment/clinic visits
Feeling of having had treatment which I don't think will do me any good
Crying more often
Feeling angry
Cannot concentrate
Affects my home/work duties
Affects my social activities
Prevents me from eating out/in public
Takes me longer to eat my meals
Forget things
Cannot get clothes to fit
Feeling anxious or tense
Feeling that the treatment has damaged my body
Feeling that the treatment has affected my speech
Has taken away my enjoyment/desire in eating

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The points allocated to each symptom are then added and expressed as a percentage of the number of patients in the study to give an overall score of perceived importance to each symptom.

## APPENDIX 2

Section one: activity  
 Section two: daily living  
 Section three: health  
 Section four: support  
 Section five: outlook