

Prospective, longitudinal assessment of quality of life in patients with cancer of the head and neck and their primary carers

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Abstract

Cancer of the head and neck has profound psychosocial and physical effects on patients, so quality of life (QoL) is an essential consideration—not only is it of importance to the patient but it also provides a subjective measure of the success of treatment. However, we know of little work about its influence on carers. The aim of this study was to assess the impact of the diagnosis and treatment on the QoL of patients and their carers from baseline (preoperatively) to three months postoperatively. Thirty-six patients and 21 primary carers were enrolled, and patients completed one head-and-neck-specific measure, the University of Washington Head and Neck, Version Four (UW-V4), and three other questionnaires, both at the time of diagnosis and at one and three months postoperatively. The carers completed similar questionnaires except for the UW-V4. Analysis of the patients' data showed a serious deterioration in psychosocial and physical domains at one month postoperatively. However, the analysis of carers' data showed a highly significant deterioration in anxiety and depression domains ($p < 0.01$), which remained low after three months. These findings highlight the need for psychological support not only for patients but also for their primary carers during the management of carcinoma of the head and neck.

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Keywords: Head and neck cancer; quality of life; primary carer; assessment; impact

Introduction

In head and neck cancer, quality of survival is critically influenced by performance or functional ability in areas such as eating, swallowing, and speaking.^{1,2} Eighty percent of oral

cancers are squamous cell carcinoma (SCC),^{2,3} and the three main types of treatment are resection, radiotherapy (with or without chemotherapy), or chemotherapy alone.^{4–6} Their quality of life (QoL) after treatment is a matter of importance to every patient.

Measures of QoL in a clinical trial of patients with such cancers must be relatively comprehensive, short, concise, and easy to understand.^{7–9} Four main categories are currently in use: global, global cancer, head-and-neck-specific, and performance.^{10,11} QoL is therefore an important tool for

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evaluating outcome together with mortality, morbidity, survival, and recurrence. General satisfaction with life has been reported in many studies, while others have described the opposite effects.^{3,12}

The changes that patients experience as a result of the head and neck cancer and its subsequent treatment are often associated with unfavourable influences not only on the patient's quality of life, but also on that of the primary carer (father, mother, or wife, for example).^{13–15}

Although general QoL has been assessed in some studies of patients with head and neck cancer, we know of little if any work that has been done to assess the impact that treatment has on the patient and the patient's primary carers using different types of questionnaires.^{2,3,13–15}

The aim of this study was to assess in detail the impact that current treatment options have on the QoL of patients and their carers during the first three months after diagnosis.

Patients and methods

Participants in the study were consecutive new patients who were being treated for primary head and neck cancer and who were attending the head and neck clinic (September–December 2002) and their carers. Patients from the Department of Oral and Maxillofacial Surgery, and Ear, Nose, and Throat at the University Hospital of Wales were all approached. Personal and clinical variables of interest included age, sex, occupation, personal contact number, histological type of tumour, relevant past medical history, and current treatment. All the patients with a confirmed diagnosis of head and neck cancer had complex treatment included resection and reconstruction under general anaesthesia. Patients with lymphoma or skin cancer in the head and neck, and patients having radiotherapy or chemotherapy, or both, were excluded from the study.

After informed consent had been obtained the patients were given four questionnaires: the University of Washington Head and Neck Disease-Specific Questionnaire Quality of Life Version Four (UW-QoL V4), the Medical Outcomes

Study- Short Form 36 (SF-36), the Hospital Anxiety and Depression Scale (HADS), and the Davidson Trauma Scale (DTS).^{17–20} Patients were asked to complete the questionnaires preoperatively, and at one month and three months postoperatively. Most of the patients were approached directly at the clinics. Those patients who failed to attend were sent the questionnaires and asked to complete them and return them in a stamped, addressed envelope. No further questionnaires were given to patients who developed recurrent disease during the follow-up period.

To assess the impact of the diagnosis and treatment on the primary carers the person concerned was asked to complete three of the questionnaires: the HADS, SF-36, and DTS.

Ethical approval was obtained for this study by the Local Research Ethics Committee, Temple of Peace and Health, Cardiff.

Statistical analysis

Data are given as number of patients, and mean (SD), and were analysed with the aid of the paired samples *t* test and the Wilcoxon signed ranks test as appropriate. Probabilities of less than 0.05 were accepted as significant.

Results

Patients

A total of 36 patients (24 men and 12 women) were included (mean (range) age 79 (41–88) years. Twenty-five were retired, seven unemployed, two employed, and two were housewives. Thirty-three were smokers and 33 consumed alcohol. The sites of the tumours included the larynx (*n* = 9), oral tongue (*n* = 5), floor of the mouth and parotid glands (*n* = 4 each), tonsils and neck (*n* = 2 each), and buccal mucosa and alveolar mucosa (*n* = 1 each).

Five patients did not complete the study: one could no longer fill in the questionnaires during the postoperative period, one stopped for unknown reasons, and three patients

Table 1
Mean (SD) patients' scores for the UW-QOL V4 domains.

Domain	Preoperative (<i>n</i> = 36)	One month postoperatively (<i>n</i> = 32)	P value	Three months postoperatively (<i>n</i> = 31)	P value
Pain	73.8 (22.5)	62.2 (19.6)	–	70.5 (18.5)	–
Appearance	87.7 (17.2)	65.5 (14.6)	<0.001	66.1 (14.1)	<0.001
Activity	74.4 (23.9)	55.5 (17.3)	<0.001	61.1 (18.7)	–
Recreation	72.8 (24.6)	60.1 (22.6)	–	72.6 (20.8)	–
Swallowing	83.5 (22.7)	67.1 (19.3)	<0.001	76.6 (15.8)	–
Chewing	78.2 (28.8)	63.7 (18.4)	<0.001	68.4 (20.1)	–
Speech	80.4 (20.9)	69.6 (18.2)	–	79.7 (16.6)	–
Shoulder	97.1 (8.1)	82.5 (6.9)	–	85.5 (6.2)	–
Taste	79.6 (25.5)	66.4 (20.1)	–	73.4 (22.5)	–
Saliva	84.7 (20.6)	75.1 (18.2)	–	83.2 (16.8)	–
Mood	75.0 (22.6)	57.7 (16.2)	<0.001	65.4 (14.9)	<0.001
Anxiety	73.8 (16.6)	58.5 (13.6)	–	64.9 (13.2)	–

Table 2
Mean (SD) patients' scores for the SF-36 domains.

Domains	Preoperative (n = 36)	One month postoperatively (n = 32)	P value	Three months Postoperatively (n = 31)	P value
Physical functioning	22.2 (6.6)	19.7 (5.2)	–	20.1 (5.0)	–
Role limitation: functioning	6.5(2.8)	5.4 (2.1)	<0.01	6.1 (1.8)	–
Role limitation: mental	4.9(1.6)	4.2 (1.3)	–	4.6 (1.5)	–
Social functioning	7.4(3.1)	6.8 (2.9)	–	7.1 (1.2)	–
Mental health	23.6(4.4)	21.8 (5.1)	–	22.5 (3.9)	–
Energy/vitality	16.3(4.1)	15.3 (3.5)	–	16.6 (3.1)	–
Pain	7.2(2.67)	6.8 (2.4)	–	6.9 (2.1)	–
Health perception	16.4(4.8)	15.9 (4.1)	–	16.7 (3.9)	–

Table 3
Number of patients classified by the Hospital Anxiety and Depression scale.

	Preoperatively (n = 36)	One month postoperatively (n = 32)	Three months postoperatively (n = 31)
Patients who scored 11 or more on the anxiety scale (probable anxiety)	6	4	2
Patients who scored 8-10 on the anxiety scale (possible anxiety)	7	4	5
Patients who scored 11 or more on the depression scale (probable depression)	3	2	2
Patients who scored 8-10 on the depression scale (possible depression)	4	6	3
Total number of patients who scored 11 or more on either the anxiety <u>or</u> the depression scale	7	5	3
Total number of patients who scored 8 points or more on <u>either</u> the anxiety <u>or</u> the depression scale *	14	11	7

* Patients who scored high on both scale were counted only once.

were treated with radiotherapy or chemotherapy alone, having completed the preoperative questionnaires. Thirty-six patients completed all four questionnaires preoperatively, 33 completed the one-month ones, and 31 the three-month ones (Tables 1–3).

The DTS was used as a self-rating scale to measure the severity of symptoms of post-traumatic stress disorder. Preoperatively, 13 patients had none at all, which had reduced to 4 at three months follow-up, and the number who had scores of 2 or more decreased from 23 to 20 patients. Similar changes were noted on the severity scales. When the results from the three-month follow-up were compared with the preoperative results the number of patients with extremely distressing symptoms decreased from 20 to 15 and those recording none at all reduced from 11 to 8. The number of patients who were moderately distressed remained constant throughout the study.

The most notable changes were on the severity scale. Between the preoperative and the three-month assessments the number of patients with extremely distressing symptoms decreased from 20 to 15, and those who had none from 11 to 8. The number of patients with moderately distressing symptoms was constant throughout the study.

Primary carers

Twenty-one primary carers were recruited, 5 men and 16 women, female:male ratio 3.2:1 (mean (range) age 53 (32–74) years). One person dropped out for unknown reasons. Five were employed, 11 retired, and five were housewives.

Table 4
Primary carers' SF-36 domains preoperatively and three month postoperatively.

Domain (for definition see Table 3)	Preoperative (n = 21)	Three months postoperatively (n = 20)
Probable anxiety	9	4
Possible anxiety	2	6
Probable depression	2	6
Possible depression	5	5
Total number with probable anxiety/depression	9	10
Total number with both probable and possible anxiety and depression	11	12

All the participants answered three questionnaires, the SF-36, HADS, and DTS. The most obvious changes in the SF-36 were noted for physical problems: physical function; role function, and social functioning (Table 4). Table 5 shows the results of the HADS, which was used to assess psychiatric disorders among the primary carers, and Table 6 shows the results of the DTS.

Discussion

The measurement of performance of patients with head and neck cancer is important in the evaluation of outcomes of treatment and rehabilitation. Traditionally, control of the disease and survival have been the measures of the effect of treatment. Today, however, with increasing disease-free sur-

Table 5

Primary carers' results from Hospital Anxiety and Depression scale preoperatively and three months' postoperatively.

Domain	Preoperative (n = 21)	Three months postoperatively (n = 20)
Probable anxiety	9	4
Possible anxiety	2	6
Probable depression	2	6
Possible depression	5	5
Total number with probable anxiety/depression	9	10
Total number with both probable and possible anxiety/depression	11	12

Table 6

Degree of distress among primary carers according to the Davidson Traumatic Scale.

Variable	Preoperative (n = 21)	Three months postoperatively (n = 20)
Frequency:		
Not at all	6	2
Twice or more	15	18
Severity:		
Not at all	6	3
Minimal	1	1
Moderately	2	5
Markedly	0	5
Extremely	12	6

vival, the psychosocial dimensions and the quality of survival have become areas of concern.

A total of 36 patients and 21 primary carers were included in the study. Five patients did not complete the study: two died and three dropped out, as did one carer. The male:female ratio was 2:1, and most of the patients smoked and consumed alcohol, which is not unusual. The mean age of the study group was 79 (41–88) years, which compares favourably with that in the studies of Tansskey et al and Hammerlid et al.^{4,19} The group was relatively elderly, but this did not influence the results of most of the questionnaires. Most of the tumours were SCC, and the most common sites were the larynx (n = 9) and oral tongue (n = 5).

A QoL outcomes monitoring system for head and neck cancer requires tools that are not only valid and reliable but also that deal with the general health as well as being specific to the head and neck. The combination of specific and general measures, therefore, provides the most comprehensive assessment. Four questionnaires were given to the patients: UW-QoL V4, SF-36, HADS, and DTS. Three questionnaires SF-36, HADS, and DTS were given to the primary carer's group.

In 1996, Hassan and Weymuller reported 75 patients with surgically-treated head and neck cancer.³ The patients completed QOL questionnaire UW-QoL V4 preoperatively, immediately postoperatively, and three months later. The survey UW-QoL V4 assessed pain, disfigurement, activity,

recreation, chewing, swallowing, speech, and shoulder disability. They found that most patients reported that their overall QoL was less than excellent. Roughly one third of subjects reported pain that interfered with their daily activities with the obvious impact on their social activities. Our study gave similar results, but with the addition of the SF-36 questionnaire. We showed that the most common complaints in the UW-QoL V4 questionnaire preoperatively were pain, anxiety, activity, and mood, whereas the most notable complaints in the SF-36 questionnaire were pain and vitality. Compared with Hassan and Weymuller, who showed that roughly one third of their patients had pain that interfered with their daily activities, we showed similar findings in two thirds.³ Pain was the main feature in both studies.

When we compared the results from one month and three months follow-up, we found quite a bit of improvement in both UW-QoL V4 and SF-36 scores. The two pain scales in UW-QoL V4 and SF-36 suggested the same outcome, namely of slow improvement during the first three months. A longitudinal study by Rogers et al¹¹ showed that pain on the scales UW-QoL V4 and SF-36 showed a slow improvement between three and six months, and then a greater improvement by 12 months. Not unexpectedly, pain, functional ability (swallowing, chewing, speech, and so on), and problems with social functioning, were the most common symptoms related to treatment that interfered with patient's daily life after operation.

We included the HADS⁸ and DTS²⁰ in the study because they screen for psychiatric disorders, and they showed that there were psychological problems (indicating psychiatric disorders) in many patients preoperatively. We also found considerable variability in the degree of recovery at the three-months' follow-up. This finding confirms that of a previous prospective, longitudinal QoL study of patients with head and neck cancer.^{16,19} Further investigation is needed to find out if the improvement in psychological distress and anxiety lessened over time. A study by Bjordal and Kaasa confirmed that psychiatric distress persisted long after successful treatment.¹⁰

When we compared the preoperative results of DTS with the results after one and three months' follow-up there was a tendency toward decreasing measures of severity and frequency scales. The corresponding results from the two different questionnaires (HADS and DTS), showed that most deterioration in the psychological aspects happened before and after resection, whereas there was a remarkable improvement by three months.

Little is known, however, about the impact that the disease has on the primary carers. A total of 21 carers (5 men and 16 women with a mean (range) age of 53 (32–74) years and female:male ratio of 3.2:1) were included in the study. Changes that the patients experienced in their lives as a result of the illness and subsequent treatment also affected the life of their carers. When we compared the preoperative results with the results three months' postoperatively we found that most of the domains (physical functioning, role limitation,

and social functioning) of the SF-36 questionnaire showed a deterioration in the scores obtained. The primary carer had reported a number of psychological disorders, particularly during the postoperative period. It therefore seems likely that the carers, who supported the patients throughout their illness, were more anxious and depressed both preoperatively and postoperatively than the patients themselves. We also suggest that the reaction of the primary carer had an impact on some of the results obtained from the patients in the scores obtained from most of the questionnaires.

Limitations of this study include the fact that it was a small, short-term study with relatively old patients, which limits the conclusions that can be drawn from the findings about some of head and neck cancer domains.

Conflict of interest

We have no conflicts of interest.

Ethics statement/confirmation of patients' permission

Ethics approval was obtained for this study by the Health Authority, and the Local Research Ethics Committee, Temple of Peace and Health, Cardiff. Informed consent was obtained from all the participants.

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