

Care of long-term survivors of head and neck cancer after treatment with oral or facial prostheses, or both

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Abstract

The current evidence of good practice in the delivery of long-term supportive care to patients who have been treated for head and neck cancer is sparse. We recruited 10 survivors so that we could follow their experience after their acute treatment was over. There were six men (mean (range) age 72 (54–86) years) and four women (mean (range) age 69 (67–73) years). After ethics committee approval had been given, we used structured interviews and questionnaires to investigate the impact of the resection and reconstruction, the patients' perceived needs, and their use of supportive care services. Their experiences were in line with current treatment of head and neck cancer. Whether they would survive the cancer was an initial fear (up to a year postoperatively), and some subjects reported problems more than five years after treatment, particularly with swallowing, quality of saliva, and intelligible speech. This small group of survivors of head and neck cancer maintained a good quality of life physically, socially, and emotionally. Limitations were put down to their age rather than their diagnosis of cancer or their rehabilitation. Analysis of their perceived needs showed that supportive care services were readily available and were valued by the patients, and that all their needs were met.

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Introduction

Head and neck cancer may arise in various sites, including the oral cavity. It is the sixth most common cancer worldwide, accounting for 3.2% of all malignancies.^{1–3} Optimal management is multidisciplinary, and the mainstays of treatment are surgery, radiotherapy, and chemotherapy.⁴ Treatment is often complex, and efficacy and likelihood of survival must be balanced against potential functioning and quality of life (QoL).^{5,6} The head and neck region is critical to speech, eating, swallowing, salivation, taste and smell, vision, and also central to body image and personal identity. The treatment

selected depends largely on the site of the primary tumour, the stage of the disease, and the patient's overall health. Most early cancers are treated by surgery or radiotherapy, with a 60%–95% chance of cure. Multiple treatments are often used for locally advanced disease because of the higher risk of recurrence and the development of distant metastases.⁷

Survivors often experience problems after treatment, such as unintelligible speech; difficulty in eating and swallowing; loss of salivation; and no sense of taste or smell, or both.⁸ With improvements in diagnosis and treatment patients may survive for many years, but may encounter a range of issues and concerns at different times, including functional deficits, facial disfigurement, psychological distress, depression, anxiety, and disorders of mood.^{9,10} Recurrent cancer is feared by many.^{11,12} Caregivers often experience psychological distress too.¹⁰

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However, with appropriate supportive care, patients can experience their recovery better.⁴ *Improving supportive and palliative care for adults with cancer*, produced by the Department of Health, lays out a plan to ensure that patients with cancer, and their families and caregivers, are given adequate support and care to help them cope with the disease and all stages of treatment.⁴

The Queen Victoria NHS Foundation Trust provides head and neck cancer services for several local multidisciplinary teams. Existing programmes produced by local networks have focused on referral, diagnosis, and treatment.^{13,14} We know of no specific guidelines on care after treatment, as these patients are usually returned to their local hospital, or community-based, teams for supportive care and rehabilitation, and there are few reports of patients' perceived need and use of supportive care services.^{14–17} We need evidence about what patients and their caregivers need from their cancer services.^{18–20}

Patients and methods

We wanted to find out the experiences of a group of survivors of resection and reconstruction of head and neck cancers of their long term care after their acute treatment had finished, and explore its impact by analysing their need for, and use of, supportive care services and which were most valued by them.

Design of study

We made both qualitative and quantitative studies using semistructured interviews and questionnaires, and contacted 10 long-term survivors of head and neck cancer (five years or more after treatment) who still attended for follow up, had had resection and reconstruction, and used oral or facial prostheses, or both. In summary, the inclusion criteria were patients with more than five years' survival after treatment of head and neck cancer and who had a prosthesis, who spoke English, and who were mentally competent (Table 1).

Potential subjects were identified from patients currently attending the prosthetics revision clinic, and invited to participate. Information about the study was provided verbally and by an information sheet. Those who agreed to participate were interviewed later.

Informed consent to participation was obtained by the research worker (EW), and each patient completed two health-related QoL questionnaires. Themes were identified, and grouped into clusters. Connections were established between main themes (Table 2) and subordinate themes.^{21,22}

Outcome measures related to the health of the patients and their health-related QoL questionnaires.²³ The University of Washington-Quality of Life (UW-QoL) contains 12 domains: pain, appearance, activity, recreation, swallowing, chewing, speech, shoulder, taste, saliva, mood, and anxiety.²⁴ In addition, three global questions were asked about how patients felt

Table 1
Study subjects.

Case No	Sex	Oral or facial prosthesis, or both	Age at operation (years)	Current age (years)	Years after operation	Diagnosis	Site	Tumour stage	Treatment	Chemotherapy or radiotherapy
1	F	Oral prosthesis	30	68	38*	Adenocystic carcinoma	Maxillary sinus	N/K	Hemi-maxillectomy	Radiotherapy
2	M	Oral + facial prosthesis	37	73	36	Adenocystic carcinoma	Maxillary sinus	N/K	Radical maxillectomy	None
3	F	Oral + facial prosthesis	50	69	19*	Extensive antral carcinoma	Maxilla and orbit	T2N0M0	Radical maxillectomy and orbital exenteration	Radiotherapy
4	M	Facial prosthesis	24	75	51*	Nasopharyngeal Carcinoma	Nose	N/K	Complete rhinectomy	Radiotherapy
5	F	Oral + facial prosthesis	56	67	11	Adenocystic carcinoma	Maxilla and nose	T2N0M0	Hemi-maxillectomy and rhinectomy	Radiotherapy
6	F	Oral prosthesis	66	73	6	Squamous cell carcinoma	Premolar region	T2N0M0	Hemi-maxillectomy Level IIb	None
7	M	Facial prosthesis	55	66	10	Adnexal carcinoma and keratinising squamous cell carcinoma	Nose	T4N0M0	Complete rhinectomy	Radiotherapy
8	M	Oral prosthesis	71	86	15	Maxillary ameloblastoma	Left maxilla	T2N0M0	Hemi-maxillectomy	None
9	M	Oral prosthesis	67	80	13	Maxillary ameloblastoma	Maxillary sinus	T2N0M0	Hemi-maxillectomy	None
10	M	Facial prosthesis	47	54	6	Squamous cell carcinoma	Nose	T4N0M0	Complete rhinectomy	Radiotherapy

NK = not known.

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