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## Overview

## Follow-up and Survivorship in Head and Neck Cancer

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## Abstract

Treatments for head and neck cancer are improving, yet they remain toxic and challenging. The incidence of some forms of head and neck cancer (e.g. oropharyngeal) is rising. This creates an enlarging cohort of survivors with complex needs. These needs may be overlooked and undertreated. This overview presents evidence for the unmet survivorship needs of head and neck cancer patients and identifies strategies for the recognition and remedy of these needs in the clinic. There is sufficient evidence to challenge services to redesign follow-up strategies around unmet need using the full multidisciplinary team and to widen focus away from a sole aim of recognition and treatment of recurrent disease. Problems presented include depression, comorbid disease, second malignancy, alcohol and nicotine dependence, eating and drinking difficulties (including dysphagia, dental problems, trismus and sense disturbance) and hypothyroidism.

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*Key words:* Follow-up studies; head and neck neoplasms; outpatients; quality of life; survivors

## Statement of Search Strategies Used and Sources of Information

This overview reflects the opinion and experience of the authors and evidence has been presented accordingly. It is based upon our own research findings and clinical trial experience. It is not a systematic review.

## Introduction

Cancer treatments are improving on a background of rising incidence. This creates an enlarging cohort of patients who have been apparently successfully treated for their cancer but have continuing needs. Healthcare services face a rising burden to follow up these patients. In this context it is important to review the efficacy and utility of follow-up and judge whether survivorship needs are being met.

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Survivorship refers to the health and life of a person with cancer post-treatment until the end of life. It covers physical, psychosocial and economic issues beyond the diagnosis and treatment phases. Survivorship includes issues related to the ability to get healthcare and follow-up treatment, late effects of treatment, second primary cancers and quality of life. Family members, friends and carers should also be considered part of the survivorship experience.

It has been estimated that there are 2.5 million people living with cancer in the UK. These numbers are expected to rise and in one estimate to as high 4 million by 2030 [1]. Although the numbers of head and neck cancer patients within this cohort is relatively small (accounting for about 2% of all new cases and rising due to increasing numbers of oropharyngeal cancers) they are a complex group of patients [2]. The complexity arises from the technical expertise required to follow patients up (e.g. nasendoscopic examination), the comorbidities experienced by the group and the functional disruptions caused by both disease and treatment.

The treatment of head and neck cancer is made difficult by the potential functional impact through disruption of vital anatomy and the cosmesis, for example facial nerve

palsy or the presence of a tracheostoma. In the multidisciplinary clinic the conversation about the best treatment for a patient often now centres on the prospect of function preservation as much as organ preservation and the acute toxicities of therapy may often be a barrier to delivery of treatment. In addition to these difficult problems, head and neck cancer patients also have high levels of comorbidity frequently associated with nicotine and alcohol dependence.

This combination of comorbid problems and highly challenging radical treatments mean that patients successfully completing treatment face multiple other problems as a consequence of their cancer treatment.

In recent years there has been a rightful broadening of focus from radical approaches to head and neck cancers to include quality of life and the impact of treatment and disease on it.

This overview aims to set out some of the challenges facing patients after treatment and illustrates some strategies that multidisciplinary teams (MDTs) may wish to use to reduce symptom burden.

## Current Practice

The follow-up of cancer patients deserves attention because of the healthcare resource it consumes and the obligation it places on patients to attend clinics regularly. In some cancers an argument has been made that patients should not be asked to return regularly to clinics because it cannot be shown that those attendances affect survival. In breast cancer, for example, it has not been possible to unequivocally show that outcome of recurrence is influenced by follow-up practice and for that reason in many centres 'routine' clinical follow-up in the absence of symptoms is neither done nor recommended.

For some patients, follow-up reinforces the possibility of cancer recurrence and therefore this creates uncertainty and significant stress, often before visits.

Post-treatment follow-up protocols in head and neck have been built on the premise that most failures are locoregional and therefore close supervision is required to allow for surgical salvage. Early detection and subsequent salvage probably influences outcome. As the highest risk for disease recurrence is within the first 2 years, intensity of follow-up is usually greatest then. These observations have led to the common UK practice of 5 years of surveillance in a surgically led clinic (although some authors have suggested a longer follow-up to 7 years for larynx cancer) [3,4]. Despite the arguments that follow-up may allow salvage of early asymptomatic recurrence, there is very little evidence that this improves outcomes. Only one study has shown improved outcome among patients whose relapse was detected in follow-up compared with those who detected symptoms [5]. A US study has shown that compliance with follow-up was associated with improved outcomes, but these may reflect patient differences rather than follow-up models [6]. Some data suggest that regular follow-up does not influence survival, with only 2% of surveillance visits

resulting in detection of an asymptomatic recurrence and there being no difference in survival between those detected with asymptomatic or symptomatic recurrences (a Netherlands programme with 22 visits over 10 years) [7].

If the sole aim of follow-up is simply to improve overall survival through the detection of recurrence then much of the effort is redundant and could be replaced by an effective patient education scheme.

Multiple guidelines for the follow-up of head and neck cancer patients have been produced [8,9]. These guidelines almost exclusively focus on the value and conduct of clinical follow-up of the cancer with little discussion of more holistic concerns for the patient.

Some authors on showing no survival benefit from a clinical follow-up strategy have called for the clinical visit to be used to address survivorship issues [10]. The outpatient clinic provides a vital opportunity to review survivorship issues for the patient and address unmet need within a MDT. The issues outlined below need careful review by MDTs.

### Dental

The impact of radiation treatment on head and neck cancer patients is well documented. Xerostomia and a consequent shift to a more acidic oral environment and decalcification accelerate dental carious disease. Careful review by restorative dentistry is a vital component of pretreatment preparation for radiotherapy and a restorative dentist is considered to be an essential 'core member' of the specialist cancer MDT.

It has been suggested that dental status at 1 year would predict long-term dental outcomes. However, the continued dental decay may precipitate later problems [11]. In a study of 86 patients reviewed 5 years after their cancer treatment, authors found continued and progressive effects on quality of life with significant problems in multiple functional aspects for edentulous patients and dentate patients still experiencing significant dental pain [12].

In a UK head and neck clinic, 27% of attendees reported dental health as their significant concern and 19% said that the dentist was the member of the MDT that they wished to see [13].

A feared dental complication is osteoradionecrosis. The destruction of local tissues by osteoradionecrosis adds significantly to the survivor's symptom burden, with problems of pain, eating dysfunction, dysgeusia and frequent bouts of infection. Incidence rates after radiotherapy are estimated to be around 7%, with rates for intensity-modulated radiotherapy (IMRT) not significantly lower [14]. The problem is covered elsewhere in this issue but a key message for follow-up is the close involvement in expert dental care [15].

### Trismus

Trismus may be experienced in up to 45% of patients who have curative radiotherapy for head and neck cancer [16]. The symptom seems to evolve quickly in the first year, 9

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