

Original Article

Pretreatment Information on Dysphagia: Exploring the Views of Head and Neck Cancer Patients

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Abstract

Context. Swallowing difficulties (dysphagia) are a common acute and chronic side effect of head and neck cancer (HNC) treatment. Dysphagia is associated with medical concerns such as malnutrition and pulmonary health as well as quality of life outcomes. Providing information on the likely changes to swallowing is an important component of pretreatment preparation. There is little research providing the patients' perspective in this area.

Objectives. This is a qualitative study to describe patients' views on pretreatment information regarding changes to eating, drinking, and swallowing after chemoradiotherapy treatment for HNC.

Methods. A purposive sample of 24 patients with HNC with a range of post-treatment dysphagia severity, up to two years after chemoradiotherapy, was selected to participate in focus groups or semistructured interviews. Thematic analysis was conducted by two researchers, and results were verified with three participants.

Results. Half of the participants presented with mild dysphagia, with the remainder having moderate to severe dysphagia. Mean age was 59 years, and mean time post-treatment was 10 months. Data were grouped into three main themes and subthemes: expectations about treatment outcomes and whether information correlated with pretreatment information; presentation of information, including the format and delivery; and the difficulties with absorption and retention of information.

Conclusion. Patients require information on the impact and prognosis for their swallowing ability. There was a general preference for verbal information, from someone knowledgeable about dysphagia. However, there are also individual preferences for the manner and pace at which this information is delivered. Further research is indicated to explore ways of providing information that is individually tailored to patients' needs and preferences. *J Pain Symptom Manage*

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Key Words

Head and neck cancer, swallowing, dysphagia, pretreatment, qualitative

Introduction

Setting realistic expectations is important in supporting head and neck cancer (HNC) patients to cope with the effects of treatment on day-to-day function. High-quality information can reduce distress and anxiety during cancer treatment and increase active patient participation and satisfaction with care.^{1,2} An HNC survey found that patients were generally satisfied with their pretreatment information.³ However, better preparation for long-term effects on functioning and quality of life was a suggested area for improvement, with setting realistic aims for recovery time frames being highly important.^{3–5} U.K. HNC guidelines also stress the importance of providing written information to support verbal explanations.¹

There are numerous U.K. sources available in the form of booklets and Web sites.^{6–8} However, the focus is largely on doctor and nurse consultations, delivery of a cancer diagnosis, and preparation for treatment and acute side effects, with minimal reference to chronic or late onset effects, in particular dysphagia. Furthermore, content can be too general to accommodate personalized tailored information.^{4,9}

Dysphagia is the most common chronic side effect of chemoradiotherapy treatment for HNC.¹⁰ Reduced swallow function is associated with higher risk of pneumonia, poorer oral intake, prolonged tube feeding, and weight loss, as well as fundamental changes to eating patterns, social lives, and consequently poorer quality of life.^{11,12} Provision of pretreatment information on potential swallowing problems after HNC treatment is recommended practice.¹ To date, it remains unclear whether information regarding long-term swallowing outcomes matches patients' requirements. There remains minimal evidence for how best to prepare patients for chronic treatment side effects, despite it being recommended as good clinical practice.

The aim of this study was to address this issue through an exploration of HNC patients' views on pretreatment information regarding changes to eating, drinking, and swallowing after chemoradiotherapy.

Methods

This was a qualitative research study, using a combination of focus groups and interviews. This was a service evaluation with no interventions or changes to management proposed for the participants. No ethical approval was required as this study aimed to evaluate the patients' experiences of a current pretreatment information-providing service. The study was based in two hospitals in northeast England. In both hospitals, it is routine practice for all HNC patients planned for chemoradiotherapy to be referred to the Speech and Language Therapy Department for a pretreatment information appointment to discuss the impact of treatment on their swallowing. The appointment is arranged at a time convenient for the patient, usually alongside radiotherapy planning appointment.

Patients

HNC patients, from the two hospitals, treated with primary chemoradiotherapy over the previous two years were screened for the study. Patients with recurrent or active disease were excluded as they may have received or been referred for further treatment. Patients who were too unwell to attend the hospital also were excluded. Participants were sampled from a range of time points after treatment, representing early and late changes to swallowing ability. Patients' dysphagia severity was rated by specialist speech and language therapists (SLTs), according to the Common Terminology Criteria for Adverse Events (CTCAE) (dysphagia subcategory),¹³ using details from their SLT notes. The CTCAE is a five-point

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