



# Patient-reported outcomes following parotid-sparing intensity-modulated radiotherapy for head and neck cancer. How important is dysphagia? ☆

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## SUMMARY

**Objectives:** Swallowing can be significantly affected during and following radiotherapy for head and neck cancer (HNC). The purpose of this study was to understand: (1) the trajectory of swallowing recovery following parotid-sparing intensity-modulated radiotherapy (IMRT) and (2) overall physical and social-emotional wellbeing and how patients prioritise swallowing following treatment.

**Materials and methods:** Sixty-one HNC patients completed questionnaires as part of a prospective study exploring patient-reported swallowing outcomes following parotid-sparing IMRT. Participants were asked to complete the M.D. Anderson Dysphagia Inventory (MDADI) and University of Washington Quality of Life Questionnaire (UW-QoL) v.04 before treatment and 3, 6 and 12 months after treatment. Given the rise in human papilloma virus (HPV) and associated oropharyngeal cancers, we completed a sub analysis of the data in those participants.

**Results:** There was a significant reduction in the MDADI composite scores 3 months after completion of treatment. Improvements were observed by 12 months, however, scores did not recover to baseline. The recovery in physical function was limited in comparison to social-emotional recovery at 12 months. When oropharyngeal cancer scores were analysed, there was not a substantial difference to the whole group results. There was a shift in priorities following treatment. Swallowing was highlighted as a concern by 44% of HNC patients up to 12 months after treatment with swallowing-related factors (saliva, taste and chewing) rated highly.

**Conclusions:** Patient reported swallowing outcomes were significantly affected from baseline to all follow-up time points and remained a priority concern at 12 months following treatment. Overall social-emotional functioning does improve, suggesting that patients have the potential to adapt to their “new normal” following IMRT for HNC.

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## Introduction

Both clinician and instrumental evaluation of swallowing provide invaluable information on cancer and treatment-related effects on swallowing. However, studies have shown that instrumental findings may be inconsistent with patient reported swallowing outcomes [1,2]. In addition, patients may rate their dysphagia more severely than clinicians [3]. In studies where clinician-rated scales, such as toxicity measures are used, the true impact of dysphagia may be underestimated [4].

Health-related quality of life (HR-QoL) is a vital outcome measure following HNC treatment, given the significant effect of

treatment on function and well-being. National bodies recommend that measures evaluating HR-QoL should be collected longitudinally [5]. As well as collecting data for research purposes to inform clinical practice, the routine use of questionnaires may function as patient-reported screening for a variety of issues including swallowing disorders [6]. A recent questionnaire-based longitudinal study reported that 12 months following treatment with conventional (chemo-) radiation, a majority of patients rated swallowing as a priority concern [7]. In addition, there was a significant deterioration in patient-reported swallowing outcomes following treatment with little improvement after 3 months [7].

There is a strong association between dysphagia and reduced HR-QoL [7–9]. Swallowing difficulties may exclude people from sharing in mealtimes with friends and families. Food may require special preparation, and consequently, may limit where patients eat. However, while swallowing difficulties have attracted much attention in the literature, it is important to look at dysphagia in the context of other symptom issues that result from treatment, such as pain, xerostomia and psychological issues. There has been an increasing emphasis on survivorship issues for people living with longer term effects of their treatment [10]. This is particularly relevant in HNC where there has been a rise in HPV related disease [11]. Given that these patients seem to respond better to a variety of treatments and are generally younger, they may survive for many years with significant treatment effects and functional impairment [12].

The aim of this study was to evaluate patient-reported swallowing outcomes before and following treatment in a cohort of HNC patients treated with parotid-sparing IMRT. We also wanted to assess overall physical and social-emotional wellbeing and how patients prioritise swallowing as a concern as they recover from their treatment. We evaluated outcomes using two questionnaires that are validated specifically for use in HNC.

## Methods

This study was reviewed by the Royal Marsden NHS Foundation Trust Clinical Committee for Research (study number CCR 3237) and the Local Research Ethics Committee (REC reference number 09/H0801/56) provided scientific and ethical approvals for this study.

### Participants

Patients were recruited prospectively over a 28-month period from the HNC oncology service at the Royal Marsden NHS Foundation Trust (see Table 1). Patients were eligible if they had been newly diagnosed with cancer of the larynx, hypopharynx, oropharynx, nasopharynx, or unknown primary (UKP). Patients were referred for either IMRT or chemo-IMRT, with or without induction chemotherapy, with curative intent and were excluded from this study if they had undergone major surgery or had pre-existing conditions that may have resulted in swallowing difficulties (e.g. stroke). Patients were treated with 65 Gy in 30 fractions to planning target volume 1 (PTV 1) (primary tumour and involved nodes) and 54 Gy to the elective neck (PTV 2), as previously described [13]. Patients diagnosed with unknown primary disease received 60 Gy to the operated neck and 54 Gy to the entire mucosal tube and contralateral neck. One patient on a trial was treated with 67.2 Gy to PTV 1 in 28 fractions. Parotid sparing was achieved based on models developed in the PARSPORT Trial [14].

### Assessments

Patients were invited to complete two questionnaires, the M.D. Anderson Dysphagia Inventory (MDADI) [15] and University of Washington Quality of Life questionnaire (UW-QoL) v.04 [5]. Both

**Table 1**

Treatment details, patient and disease characteristics (n = 61).

<i>Tumour site n (%)</i>		
Oropharynx	39	(63.9)
Hypopharynx	4	(6.6)
Larynx	3	(4.9)
Nasopharynx	10	(16.4)
Unknown primary (UKP)	5	(8.2)
<i>T-Stage</i>		
T0	5	(8.2)
T1	12	(19.7)
T2	25	(41)
T3	12	(19.7)
T4	7	(13.1)
<i>N-Stage</i>		
0	12	(19.7)
1	11	(11.5)
2	42	(68.9)
<i>AJCC</i>		
I	2	(3.3)
II	3	(4.9)
III	11	(18)
IV	45	(73.8)
<i>Treatment schedule</i>		
Dose to Planning Target Volume (PTV) 1		
65 Gy in 30 fractions	55	(90.2)
67.2 Gy in 28 fractions	1	(1.6)
Unknown Primary Protocol		
54 Gy to entire mucosal tube and 60 Gy to operated neck	5	(8.2)
<i>Chemotherapy</i>		
Induction chemotherapy + chemoIMRT	44	(72.1)
ChemoIMRT	4	(6.5)
IMRT only	13	(21.3)
<i>Neck dissection</i>		
Before treatment	6	(9.8)
After treatment	10	(16.4)
<i>Smoking history</i>		
Never	26	(42.6)
At diagnosis	15	(24.6)
Ex-smoker	20	(37.8)
<i>Age</i>		
Mean	56	
Range	25–73	
<i>Gender</i>		
Male	52	(85.2)
Female	9	(14.8)

questionnaires were administered pre-treatment and at 3, 6 and 12 months following treatment completion.

### M.D. Anderson Dysphagia Inventory (MDADI)

The MDADI is comprised of 20 questions using a 5-point scale ranging from “strongly disagree” to “strongly agree”. There is one question that is scored separately and provides a global score of swallowing difficulty. The scores from the other 19 questions regarding physical, emotional and functional subscales are added and a total, composite score is generated. Scores range from 1 to 5 for each question. A higher score indicates a better level of functioning and swallowing-related QoL.

### University of Washington Quality of Life Questionnaire (UW-QoL) v.04

The UW-QoL is comprised of 12 domains that include physical symptoms, social and emotional functioning. A score is provided from each domain (ranging from 0 to 100) with higher scores indicating better function. A composite physical function

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