

Perspectives of the multidisciplinary team on the quality of life of patients with cancer of the head and neck at 2 years

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Abstract

We aimed to assess the extent to which core members of the head and neck multidisciplinary team (MDT) use data on health-related quality of life (HRQoL), and their familiarity with specific HRQoL outcomes for different groups of patients with cancer of the head and neck. We surveyed members of the head and neck MDT in the Merseyside Regional Head and Neck Cancer Centre (consultants, clinical nurse specialists, and allied health professionals) about their views on patient-reported outcomes for 8 common clinical situations after treatment for cancer. A total of 17/27 responded (63%), and of them, 12 use the data. Participants' estimates of patient-reported outcomes varied widely, and there were no notable differences between consultants and others. For speech, saliva, and swallowing, estimates tended to be worse than the outcomes reported by the patients themselves. Although HRQoL information is used by most clinicians, it is often used for research and not to inform them about the patient. Its use can enable discussions with patients and carers to be more relevant, but it is important to remember that individual HRQoL outcomes can differ. There is scope for further study to explore the decision-making process for different types of treatment that have equivalent survival from the perspective of both the MDT and the patient.

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Introduction

Alterations in physical, social, and emotional functions can have detrimental effects on the health-related quality of life (HRQoL) of patients treated for cancer of the head and neck. The Department of Health requires that high-quality information is provided for patients with cancer,¹ and patients

themselves indicate a desire to be given HRQoL data on outcome. However, patients report that information is lacking, particularly on financial support and overall QoL,² and most would like access to more.^{3,4} A mismatch between the information provided and that required by individual patients has been linked to anxiety and depression^{2,5} regardless of whether too much or too little is provided.⁶ Conversely, better HRQoL has been linked to the provision of information that is needed.^{7,8} Other factors such as personality type also affect the patient's perception of, and satisfaction with, the information they receive.⁹

There are several patient-reported outcome measures (PROM) for HRQoL, and one of the most commonly used questionnaires specific to patients with cancer of the head and

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neck is the University of Washington Quality of Life scale (UWQoL).¹⁰ Outcomes reported show that patients with more advanced tumours, oropharyngeal and hypopharyngeal tumours, and those who have combined treatments such as operation and postoperative radiotherapy, or chemotherapy and radiotherapy, tend to report poorer HRQoL.^{11,12} UWQoL outcome data at 2 years broadly reflect longer-term outcome,^{11,13} as by this time, most patients seem to have stabilised and have adapted to their situation.

Clinical teams can now use HRQoL data to find out about the likely outcome in various situations,^{11,12} and they can also use an interactive searchable database online.¹⁴ Information can help patients and carers to make decisions about treatment and can indicate what functional outcomes to expect at 2 years and in the longer term. It can help them “normalise” their outcome by referring to similar patients by site, stage of disease, and treatment, and help them to cope and adapt. As HRQoL outcomes can be included in discussions with patients and carers, it seems appropriate that core members of the multidisciplinary team (MDT) are familiar with those often reported for common clinical situations.

We therefore aimed to assess the extent to which core members of the head and neck MDT use HRQoL data, and their familiarity with specific HRQoL outcomes for different groups of patients with cancer of the head and neck.

Methods

We included members of the head and neck MDT at the Merseyside Regional Head and Neck Cancer Centre who were the most likely to use HRQoL information during the planning of treatment and subsequent review of patients in clinic. We therefore excluded pathologists and radiologists, as they are not directly involved with the patient in clinic. Training grades were also excluded. We included consultant oncology surgeons, consultant oncologists, clinical nurse specialists (including those at peripheral clinics), speech and language therapists, physiotherapists and dieticians, the consultant in oral rehabilitation, and nurses involved in clinical trials. The survey was done between February and April 2014. To obtain informed consent to participate and to ascertain the preferred method of completion, clinicians were approached in advance and given an information sheet about the study either online through Adobe® FormsCentral (Adobe Systems Incorporated, USA) or on hard copy.

Participants were asked about their role in the MDT and their familiarity with HRQoL data, in particular the UWQoL. They were also asked when they used HRQoL data. They were then given 8 clinical situations (Table 1) and for each, some of the response options for the chewing, speech, saliva, and swallowing domains, as well as overall QoL. For chewing, the response given was “I can chew as well as ever”; for speech: “I have difficulty saying some words but I can be understood over the telephone” and “My speech is the same as always”; for saliva: “I have less saliva than normal but it is enough” and “My saliva is of normal consistency”; for

swallowing: “I cannot swallow certain solid foods” and “I can swallow as well as ever”; and for overall QoL: “good”, “very good” and “outstanding”. Participants were asked to estimate the percentage (in deciles) of patients they thought would choose each response at around 2 years after treatment.

The UWQoL questionnaire is well established, and version 4 comprises 12 single-question domains each with between 3 and 6 responses scaled from 0 (worst) to 100 (best) according to the hierarchy of response. Patients can indicate their health and QoL over the previous 7 days. It also has a single-item overall QoL question that asks them to consider not only their physical and mental health, but also other factors such as family, friends, spirituality, or personal leisure activities that are important to their enjoyment of life. UWQoL data have been collected since 1995 by the Merseyside Regional Head and Neck Cancer Centre.

Questionnaires completed closest to 2 years from primary operation (or from diagnosis if no operation) were selected for analysis. Statistical analysis focused on the accuracy of the participants’ estimates relative to the results reported by patients. Discrepancy scores were computed for each participant to reflect the number of percentage deciles away from the category chosen by the patients. For example, if 4% of patients said they could chew as well as ever then the reference category was 0–9%, if a participant thought that 10%–19% of patients would say this, then the discrepancy score was 1 as it was one category away from the patients’ reference; if another thought 20%–29% then the discrepancy score was 2, and so on. All discrepancies were scored positively, irrespective of under or over-estimation. The Mann-Whitney test was used to compare discrepancy scores of consultants with those of others, and of those who used HRQoL data compared with those who did not.

Approval for the study was obtained from the Clinical Audit Department, Aintree University Hospital (666-13).

Results

A total of 17/27 (63%) members of the MDT participated. They comprised 6 consultants, 3 clinical nurse specialists, and 8 others (3 research nurse practitioners and one each of data manager, dietician, physiotherapist, speech and language therapist, and not stated). Most (12/17) used HRQoL data; 3 of the consultants and 2 of the clinical nurse specialists did not. HRQoL data were used for research purposes (9/12), to inform about the patient (4/12), at MDT meetings (2/12), when evaluating treatment (2/12), and when making decisions about treatment (2/12). All but one consultant was familiar with the UWQoL questionnaire.

The sample of patients comprised 2624 patients treated curatively for primary squamous cell carcinoma of the head and neck between 1995 and 2010, of whom 2334 were alive after follow up of 9 months. Two-thirds (1511/2334, 65%) of them had completed at least one questionnaire after 9 months, and their record closest to 2 years (median (IQR) 24 (20–29) months) was taken for analysis. A full description of

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