



## Audit

# A national survey of health-related quality of life questionnaires in head and neck oncology

AN Kanatas<sup>1</sup>, SN Rogers<sup>2</sup>

<sup>1</sup>Examinations Department, Liverpool University Dental Hospital, Liverpool, UK

<sup>2</sup>Regional Centre for Maxillofacial Surgery, University Hospital Aintree, Liverpool, UK

**Aims:** To identify the health-related quality of life (HRQOL) questionnaires employed by the physicians and surgeons who manage patients with head and neck cancer. Also, to gain an impression of the perceived difficulties and advantages of their use.

**Methods:** A national survey was performed of active UK consultant clinicians on the mailing list of the British Association of Head and Neck Oncologists.

**Results:** Of 267 questionnaires, there were 191 replies (71.5%) from clinical oncologists (40), ENT surgeons (53), general surgeon (1), oral and maxillofacial surgeons (59), and plastic surgeons (38). Fifty-five consultants (29%) used HRQOL questionnaires and the most popular questionnaire was the University of Washington Head and Neck Cancer (65%). Questionnaires were most likely to be used both before and after treatment (67%) and administered in clinic by either nursing staff or consultants. The main reasons for not using HRQOL questionnaires included lack of resources and proven value.

**Conclusions:** Despite the vast amount of literature on the importance of HRQOL in head and neck cancer, this survey shows that there is still a substantial amount of work required before HRQOL measurement becomes an established part of routine practice.

**Key words:** HRQOL – Head and neck oncology – Survey

The inclusion of health-related quality of life (HRQOL) measurement in the management of patients with head and neck cancer is integral to best patient care.<sup>1</sup> It is appropriate that the evaluation of outcome includes HRQOL in addition to survival, recurrence rates and complications. HRQOL is a component of the British Association of Head and Neck Oncologists' data set. The literature recognises the difficulty in defining and quantifying patients' HRQOL.<sup>2-5</sup> Generally the term 'quality of life' incorporates all aspects of patients' well-

being and may include socio-economic and environmental factors. Health-related quality of life is more focused and taps issues concerning the clinical effects of the disease and its treatment. It points to those aspects of life which are affected by healthcare interventions and is used with increased frequency.<sup>6</sup> Rather than being clinician-rated,<sup>7</sup> patients now complete validated questionnaires<sup>8</sup> that assess subjectively key parameters of HRQOL in head and neck cancer. There are many potential benefits from measuring HRQOL and these include: (i) the provision of better

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**Correspondence to:** Mr AN Kanatas, Hospital Practitioner in Oral and Maxillofacial Surgery, Examinations Department, Liverpool University Dental Hospital, Pembroke Place, Liverpool L3 5PS, UK

Tel: +44 151 706 5060; Fax: +44 151 706 5807; E-mail: md0u01a1@liv.ac.uk

information for the patient and multidisciplinary team; (ii) more effective multidisciplinary team working; (iii) identification of potentially poor outcome groups; and (iv) areas of dysfunction. In turn, these approaches provide the opportunity to target intervention aimed at improving specific aspects of HRQOL. The HRQOL relates to parameters such as size, stage, site of tumour and treatment.<sup>9</sup> There are at least 14 validated head and neck questionnaires and most workers in this field recognise that there is no one instrument ideal for all purposes.<sup>10,11</sup> Questionnaires commonly used in the UK include the European Organization for Research and Treatment of Cancer (EORTC),<sup>12</sup> the Functional Assessment of Chronic Illness Therapy (FACIT),<sup>13</sup> and the University of Washington Head and Neck Cancer (UW-QOL)<sup>14</sup> version 4.

The purpose of this study was to identify the HRQOL questionnaires employed by the physicians and surgeons who manage patients with head and neck cancer. Also, to gain an impression of the perceived difficulties and advantages of their use. This information will be useful to members of the multidisciplinary team, to clinical researchers and to those who promulgate the need of HRQOL as a routine component of outcome.

## Materials and Methods

All the active UK consultant clinicians on the mailing list of the British Association of Head and Neck Oncologists were sent a short 9-item survey. The initial questionnaires were sent in May 2002 with reminding questionnaires 2 and 4 weeks later (Appendix 1). From the 267 questionnaires were sent, there were 191 replies (71.5%). The specialties involved were clinical oncologists, ENT surgeons, general surgeons, oral and maxillofacial surgeons, and plastic surgeons. The

survey asked about the types of questionnaires and their administration. It also gave the opportunity for free-text comment on issues relating to the potential benefits and difficulties in using questionnaires.

## Results

Of the 191 replies, there were 40 clinical oncologists, 53 ENT surgeons, 1 general surgeon (who did not collect HRQOL data), 59 oral and maxillofacial surgeons, and 38 plastic surgeons (Table 1). Oral and maxillofacial surgeons and clinical oncologists were most likely to collect HRQOL data. Oral and maxillofacial surgeons and ENT surgeons tended to collect data before and after treatment in contrast to clinical oncologists who mainly collected before treatment. The UWQOL instrument was favoured most by the oral and maxillofacial surgeons and clinical oncologists and least so by the plastic surgeons (who did not favour the use of any one questionnaire).

Questionnaires were distributed by all grades of staff, mainly nurses and consultants (Table 2). Two-thirds distributed questionnaires at clinic whilst the rest gave them out either in the ward or by post. The main reasons for not using QOL questionnaires were to do with the lack of resources, time, and manpower, not being convinced of their value, and not being part of routine departmental practice (Table 3). The clinicians who used HRQOL questionnaires identified a series of benefits (Table 4). These were mainly associated with identifying problems with the treatment proposed or given, the provision of more information about the patient and about research issues. Major disadvantages were said to be the difficulty in analysing the data once collected, patient compliance

Table 1 Data about the type of questionnaire use, timing and group of patients among the different clinical specialties

|                     | ENT surgeons<br>(n = 53) | OMF surgeons<br>(n = 59) | Plastic surgeons<br>(n = 38) | Clinical oncologists<br>(n = 40) | All specialties<br>(n = 190) |
|---------------------|--------------------------|--------------------------|------------------------------|----------------------------------|------------------------------|
| Using questionnaire | 12 (23%)                 | 20 (34%)                 | 9 (24%)                      | 14 (35%)                         | 55 (29%)                     |
| Questionnaire type  |                          |                          |                              |                                  |                              |
| EORTC               | 4 (33%)                  | 3 (15%)                  | 3 (33%)                      | 2 (14%)                          | 12 (22%)                     |
| FACIT               | 2 (16%)                  | –                        | 3 (33%)                      | 1 (7%)                           | 6 (11%)                      |
| UW-QOL              | 6 (50%)                  | 17 (85%)                 | 3 (33%)                      | 10 (71%)                         | 36 (65%)                     |
| Other: NHP, HADS    |                          |                          |                              | 1 (7%)                           | 1 (2%)                       |
| Timing              |                          |                          |                              |                                  |                              |
| Pre-treatment       | 2 (16%)                  | –                        | 3 (33%)                      | 7 (50%)                          | 12 (22%)                     |
| Post-treatment      | 1 (8%)                   | 3 (15%)                  | 1 (11%)                      | 1 (7%)                           | 6 (11%)                      |
| Combination         | 9 (75%)                  | 17 (85%)                 | 5 (56%)                      | 5 (36%)                          | 36 (67%)                     |
| Patient group       |                          |                          |                              |                                  |                              |
| All                 | 7 (58%)                  | 16 (80%)                 | 4 (44%)                      | 6 (43%)                          | 33 (60%)                     |
| Selected            | 5 (42%)                  | 4 (20%)                  | 5 (56%)                      | 8 (57%)                          | 22 (40%)                     |

Table 2 Administration of questionnaires

|            | ENT surgeons<br>(n = 12) | OMF surgeons<br>(n = 20) | Plastic surgeons<br>(n = 9) | Clinical oncologists<br>(n = 14) | All specialties<br>(n = 55) |
|------------|--------------------------|--------------------------|-----------------------------|----------------------------------|-----------------------------|
| Person     | Responses = 13           | Responses = 26           | Responses = 9               | Responses = 17                   | Total = 65                  |
| Consultant | 4 (31%)                  | 8 (31%)                  | 3 (33%)                     | 4 (24%)                          | 19 (29%)                    |
| SpR        | 3 (23%)                  | 4 (15%)                  | 1 (11%)                     | 3 (18%)                          | 11 (17%)                    |
| S&LT       | 1 (8%)                   | 2 (8%)                   | –                           | –                                | 3 (5%)                      |
| Nurse      | 5 (38%)                  | 11 (42%)                 | 5 (56%)                     | 9 (53%)                          | 30 (46%)                    |
| Student    | –                        | 1 (4%)                   | –                           | 1 (6%)                           | 2 (3%)                      |
| Place      | Responses = 21           | Responses = 26           | Responses = 15              | Responses = 17                   | Total = 79                  |
| Clinic     | 9 (43%)                  | 17 (65%)                 | 9 (60%)                     | 14 (82%)                         | 49 (62%)                    |
| Ward       | 5 (24%)                  | 5 (19%)                  | 3 (20%)                     | 2 (12%)                          | 15 (19%)                    |
| Postal     | 7 (33%)                  | 4 (15%)                  | 3 (20%)                     | 1 (6%)                           | 15 (19%)                    |

More than one response was given in this section of the survey.

Table 3 Reasons of not using HRQOL questionnaires according to specialty

|   | ENT surgeons<br>(n = 39) | OMF surgeons<br>(n = 36) | Plastic surgeons<br>(n = 24) | Clinical oncologists<br>(n = 26) | All specialties<br>(n = 125) |
|---|--------------------------|--------------------------|------------------------------|----------------------------------|------------------------------|
| Lack of resources                           | 23 (59%)                 | 14 (39%)                 | 19 (79%)                     | 15 (58%)                         | 71 (57%)                     |
| Unable to process the data collected        | 4 (10%)                  | 1 (3%)                   | –                            | 2 (8%)                           | 7 (6%)                       |
| Lack of information about questionnaire use | 1 (2%)                   | 6 (17%)                  | 1 (4%)                       | 1 (4%)                           | 9 (7%)                       |
| Not convinced of value                      | 7 (18%)                  | 4 (11%)                  | 2 (8%)                       | 7 (27%)                          | 20 (16%)                     |
| Not part of departmental practice           | 4 (10%)                  | 8 (22%)                  | 1 (4%)                       | 1 (4%)                           | 14 (11%)                     |
| Forget to distribute                        | –                        | 3 (8%)                   | 1 (4%)                       | –                                | 4 (3%)                       |

Table 4 The benefits resulting from the measurement of HRQOL are varying according to specialty

|                                    | ENT surgeons<br>(n = 12) | OMF surgeons<br>(n = 20) | Plastic surgeons<br>(n = 8) | Clinical oncologists<br>(n = 10) | All specialties<br>(n = 50) |
|------------------------------------|--------------------------|--------------------------|-----------------------------|----------------------------------|-----------------------------|
| None                               | 4 (33%)                  | 3 (15%)                  | –                           | 3 (30%)                          | 10 (20%)                    |
| Identification of problems         | 2 (17%)                  | 5 (25%)                  | 3 (38%)                     | 1 (10%)                          | 11 (22%)                    |
| More information about the patient | 2 (17%)                  | 4 (20%)                  | 3 (38%)                     | 5 (50%)                          | 14 (28%)                    |
| Research benefits                  | –                        | 4 (20%)                  | 1 (13%)                     | –                                | 5 (10%)                     |
| Terminate aggressive surgery       | 1 (8%)                   | –                        | –                           | 1 (10%)                          | 2 (4%)                      |
| Unit improvement                   | 1 (8%)                   | 1 (5%)                   | 1 (13%)                     | –                                | 3 (5%)                      |
| QOL as an outcome                  | 2 (17%)                  | 3 (15%)                  | –                           | –                                | 5 (10%)                     |

Table 5 Problems associated with the use of HRQOL questionnaires

|                            | ENT surgeons<br>(n = 9) | OMF surgeons<br>(n = 17) | Plastic surgeons<br>(n = 8) | Clinical oncologists<br>(n = 7) | All specialties<br>(n = 41) |
|----------------------------|-------------------------|--------------------------|-----------------------------|---------------------------------|-----------------------------|
| Time consuming             | 6 (67%)                 | 9 (53%)                  | 3 (38%)                     | 3 (43%)                         | 21 (51%)                    |
| Patient compliance         | 1 (11%)                 | –                        | 2 (25%)                     | 1 (14%)                         | 4 (10%)                     |
| Forget to distribute       | –                       | 5 (29%)                  | 1 (13%)                     | –                               | 6 (15%)                     |
| Unable to include all data | –                       | –                        | 2 (25%)                     | –                               | 2 (5%)                      |
| Difficult to analyse       | 2 (22%)                 | 3 (18%)                  | –                           | 2 (28%)                         | 7 (17%)                     |
| Skewed distribution        | –                       | –                        | –                           | 1 (14%)                         | 1 (2%)                      |

and, most commonly, the time required to include questionnaires in the patients' management (Table 5).

### Discussion

This postal survey raised several issues about the administration, perceived benefits and problems with HRQOL questionnaires in head and neck cancer practice. The issue of questionnaire administration must be addressed. Although many different members of the multidisciplinary team were administering questionnaires, consideration should be given to identifying one leading member. This person could be from clerical staff, audit department, medical, specialist nurse, or other allied staff in the MDT. A nominated individual could help to ensure that the questionnaires are given out at appropriate times and returned. Linked to lack of resources was the lack of time to collect data. This appeared to hinder significantly the intention to collect and use HRQOL data among all specialties. Even in the units collecting HRQOL data, the issue of time of distribution/collection/processing appeared to be the biggest problem. The issue of time may be possibly improved by a dedicated H&N audit/data clerk. In addition, data analysis through links with clinical audit will save time as well as ease the interpretation of the data collected. Real-time information collection during patient presentation in the clinic could augment the consultation and make the collection of data more relevant. Computerised data entry on oncology database or hospital based networks could make this easier.

Only around one-quarter of clinicians involved in the management of head and neck cancer patients employed HRQOL data in their practices. In fact, this might be an over estimation. Analysis of the responses to item seven of the questionnaire indicated that many clinicians still do not value the use of HRQOL data for other than research purposes and, therefore, do not include it in the day-to-day care of their patients. To date, it seems very few centres in the UK are routinely measuring HRQOL in their patients either by cross-sectional or prospective study. The reasons are multifactorial and include the lack of guidance on which measure to use, time constraints and manpower restrictions. There is a need for patients, clinicians and other members of the multidisciplinary team to derive positive gain from acquiring HRQOL data in order to inform clinical practice and have direct relevance to improving patient care. The adoption of a common questionnaire would allow for multicentre HRQOL data

collection and facilitate both specific sub-site and treatment analysis which is not possible with single-site data collection.

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See Appendix 1 on p10

## Appendix 1

### Health-related quality of life questionnaires survey

Please tick the most appropriate response

1. Do you use health-related quality of life questionnaires in patients with H&N cancer?  
 No  Yes  If no, please go to question 9 -----
  
2. Which questionnaire(s) do you use?  
 i. EORTC  ii. FACIT  iii. UW-QOL   
 iv. Other questionnaire  (please state) -----
  
3. When do you use the questionnaire(s)?  
 i. Pre-treatment No  Yes  if yes when (*e.g.* day before) -----  
 ii. Post-treatment No  Yes  if yes when (*e.g.* 6-monthly) -----
  
4. Which group of patients?  
 i. Used for ALL patients No  Yes   
 ii. Selected patients No  Yes  If yes, which groups -----
  
5. Who helps distribute and collect the questionnaires?  
 (*e.g.* consultants, SpRs, nurses, clinical nurse specialist, S&LT, medical students) (please state) -----  
 -----  
 -----
  
6. Where are questionnaires distributed?  
 (*e.g.* clinic, ward, postal, telephone, patient computer input) (please state) -----  
 -----
  
7. Please list the benefits for you in using HRQOL questionnaire (s)? -----  
 -----
  
8. If you are using questionnaires, please list any problems/disadvantages -----  
 -----  
 -----
  
9. If you DO NOT use HRQOL questionnaire (s) please could you list some of the reasons? -----  
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