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

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ABSTRACT

INTRODUCTION With an increasing number of publications on health-related quality of life (HRQOL) following head and neck cancer, the recognition of a number of well-validated questionnaires and a growing awareness of the potential role of HRQOL in practice, it was our aim to repeat the survey of 2002 reported in the *Annals* to see how practice changed.

MATERIALS AND METHODS A postal survey of members of the British Association of Head and Neck Oncologists was undertaken in January 2006 with reminders sent in February, March and April.

RESULTS The response was 50% (106 of 210) of which 53% were using or had used HRQOL questionnaires. The main reasons for not using HRQOL questionnaires were that they were too time-consuming or intrusive in a clinic setting and that there was a lack of resources.

CONCLUSIONS Clinicians still see the use of questionnaires as a research-tool only, rather than an adjunct to giving patient information, promoting choice, and identifying patients with problems. The burden on HRQOL evaluation in routine clinical practice remains a substantial barrier. Advances with IT support in clinic should make it easier to collect and use these data in the future. As surgeons, we still need to be persuaded of the benefits of HRQOL outcomes in our practice.

KEYWORDS

UW-QOL – Validation – Health-related quality of life – Head and neck cancer – Surgery – Questionnaires

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Health-related quality of life (HRQOL) following head and neck cancer is of great importance given the functional, psychological and social impacts of the disease and its treatment.^{1–3} HRQOL influences which primary treatment strategy is best for individual patients and informs decision-making regarding adjuvant and palliative treatment.⁴ HRQOL is particularly relevant as patients treated for head and neck cancer can have a relatively long life expectancy compared to other cancers such as lung cancer. We reported a national survey undertaken in 2002 of UK consultant clinicians registered with the British Association of Head and Neck Oncologists (BAHNO),⁵ which concluded that the use of HRQOL questionnaires in clinical practice was limited and that there were barriers hindering their general use. With an increasing number of publications on HRQOL following head and neck cancer, the recognition of several

well-validated questionnaires and a growing awareness of the potential role of HRQOL in practice, it was our aim to repeat the survey. This new survey will allow us to reflect on how perceived problems and benefits of recording HRQOL have changed, to enable a re-exploration of clinician questionnaire preferences and to see if changes in consultant practice and preference have occurred. Also, since our 2002 survey, there have been three other surveys in different head and neck settings; another purpose of our study was to compare to these in terms of utilisation, commonly used questionnaires and perceived barriers. These surveys were of the Australian and New Zealand Head and Neck Society,⁶ of the Association of Consultants and Specialists in Restorative Dentistry (ACSRD),⁷ and of international experts in nasopharyngeal cancer at an international symposium held in Canada in June 2005.⁸

Table 1 Details about the use of HRQOL questionnaires for the 55 responders who used or who had used them (multiple answers were possible)

	%	n
What do/did you use the questionnaires for		
Routine follow-up of patients	39	19/49
Quality of life research	59	29/49
Randomised controlled trial outcome	39	19/49
Other ^a	10	5/49
Who distributes and collects the questionnaires		
Consultant	30	14/47
Specialist registrar	15	7/48
Speech and language therapist	13	6/48
Medical students	6	3/48
Clinical nurse specialists	46	22/48
Research staff	33	16/48
Other ^b	25	12/48
Which questionnaire have you used		
EORTC	52	26/50
FACT	26	13/50
UW-QOL	72	36/50
Other ^c	23	9/40
When have you used questionnaires		
Pre-treatment	85	40/47
Post-treatment	96	45/47
Which group of patients		
All patients	42	19/45
Selected patients	58	26/45

^aIncludes three for annual survey.^bClinic/ward nurse (6), SHO (3), radiographer (2), foundation director.^cOwn (2), head and neck (2), LENT-SOMA (1), mad/mh15 (1), swallowing/voice/EQ-5D (3).

data to specific questions from responders are reflected in the results by reduced denominators.

Results

The response was 50% (106 of 210) with 12 excluded (nine not relevant to their clinical practice, *e.g.* histopathologist; three retired). Some of the non-responders may also have been unsuitable for this survey. The speciality of responders was maxillofacial for 44, ENT head and neck for 34, clinical/medical oncology for 21 and plastic surgery for seven. Almost all (94) were NHS consultants, with seven university professors/senior lecturers, one speech and language therapist, and four not known. HRQOL questionnaires were used or had been used by 53% (55 of 104), unknown for two. Oncology responders had the highest rate of use with 67% (14 of 21), with 58% (19 of 33) for ENT head and neck and 45% (20 of 44) for maxillofacial. HRQOL questionnaires were used in quality of life research for 59%, as randomised controlled trial outcome measures for 39% and in routine follow-up of patients for 39% (Table 1). Clinical nurse specialists (46%), consultants (30%) and research staff (33%) were the main distributors and collectors of questionnaires. The UW-QOL (72%) was the most used questionnaire, then EORTC (52%) and FACT (26%). Questionnaires had been used by almost all responders both before and after treatment. For 42% of responders, the target survey population was 'all patients' whilst for 58% some selection took place – including trial patients (5), laryngectomy (3), research (2), all MDT (1), cancer (1), head and neck (1), new patients (1), oropharyngeal (1), and radically treated (1).

Of those who had used HRQOL questionnaires, 42% (19 of 45) were still using them. The main reasons for stopping use were that they were too time-consuming or intrusive in a clinic setting (71%; 17 of 24) and that they did not add value to the clinical management of the patient (33%; 8 of 24). Other reasons were that they were not wanted by patients (2), that current questionnaires did not fulfil the

Materials and Method

Of 239 members on the BAHNO dataset as of the 2 January 2006, 17 were excluded as they were known to have retired or known to be no longer involved in the care of head and neck cancer patients. Questionnaires (Appendix 1) were mailed to the remaining 222 BAHNO members in January 2006, with reminders to non-responders in February, March and April 2006. Members were asked which HRQOL questionnaires they use or had used, why they used them, for which patient groups, how questionnaires were distributed and collected and when within the patient journey they were used. Those who had never used or who no longer used questionnaires were asked why not and were asked to indicate factors that would encourage their use. Missing

Table 2 Reasons for not using HRQOL questionnaires

All specialties (n = 41)	
Time consuming	21 (51%)
Patient compliance	4 (10%)
Forgot to distribute	6 (15%)
Unable to include all data	2 (5%)
Difficult to analyse	7 (17%)
Skewed distribution	1 (2%)

Table 3 Benefits of collecting HRQOL data

A form of standardised data collection, useful comparison between subgroups, identify patient problems
Assessing impact of new treatment, audit against national standards
Assessing morbidity
Audit
Better communication, identification of needs
Can guide surgery
Change in practice, monitoring outcome, inform patients
Compare palliative treatment costs, patient subjective view point
Compare techniques
Curiosity
Flagging up problems not raised in consultation
Guide head and neck nurses
Inform patients with respect to treatment
Improve patient care
Objective assessment of treatment
Patient view, better MDT management, surrogate outcome measure
Research tool
Self reflection to how we are performing to patients
Semi-quantitative assessment of real outcome
Team focus on holistic management for awareness, patients voice opinions
To identify patients that need more support
To increase knowledge of post-treatment quality of life, and to enable us to give more accurate information about understanding morbidity
Vague measure of unit quality of service

needs of respondents (2), respondents did not know what to do with the information (2), research or trial had stopped (4), conflicting suggestions as to which questionnaire to use (1) and inertia (1). The main problems associated with the use of HRQOL questionnaires were comparable with those that arose in our previous study in 2002 (Table 2).

There were 75 respondents who either never used HRQOL questionnaires or who had stopped using them. Their main reasons for not using them were that they were too time-consuming or intrusive in a clinic setting (57%; 26 of 46) and that there was a lack of resources to do and process (70%; 32 of 46). Other reasons were that HRQOL questionnaires did not add value to the clinical management of the patient (8), respondents did not know what to do with the information (8), current questionnaires did not fulfil the needs of respondents (5), questionnaires were not wanted by patients (2), colleagues were not keen (1) and

inertia (1). The main factors that would encourage HRQOL questionnaires to be used were a database manager to collate and input data (76%; 34 of 45), a short validated consensus HRQOL questionnaire (44%; 20 of 45) and computerised data collection such as touch screen (31%; 14 of 45). Other factors mentioned were questionnaires specific to primary site (6), ability to be used in research activities (4) and a more detailed/comprehensive questionnaire (1). In our study, clinicians who used HRQOL questionnaires were able to identify a series of benefits associated with their use, the main ones reported in about a quarter of these were more information about patient, and the identification of problems (Table 3). When asked about whether the UK National Institute for Health and Clinical Excellence (NICE) guidelines and the Improving Outcomes Guidance (IOG) documents would make the respondent more likely to measure HRQOL in clinical practice 18 said 'Yes', 22 'No', 24 'Not sure', whilst the question was left blank by 42 of the 106 responders.

Discussion

It was timely to undertake another survey to get an indication of change in the use of HRQOL in head and neck practice since 2002. Also, the views of consultant colleagues regarding the value of HRQOL data and of the problems associated with collection, interpretation and clinical relevance help to shape strategies for encouraging the wider use of HRQOL data. The response rate to the survey (50%) was disappointing, but this may be an underestimate because some of the non-responders in the sampling frame may have been unsuitable for the study. We have to be cautious, however, in the interpretation of the findings. It seems probable though that this survey still reflects clinical practice since most non-responders are unlikely to be using HRQOL questionnaires. Over half of responders were using, or had used, HRQOL questionnaires and this compares to just over a quarter of respondents in our 2002 national survey. In our earlier survey, the main reason for not using HRQOL questionnaires was lack of resources (57%); in this recent survey, the same problem persists with around three-quarters citing this reason. In the study by Mehanna *et al.*,⁶ the reasons for not measuring HRQOL included the clinicians' perceptions that QLQs were too time-consuming and conferred no proven benefit for clinical management. In the study by Ringash *et al.*,⁸ participants questioned the ability of current HNC QOL questionnaires to measure issues unique to nasopharyngeal cancer patients. The background of the clinician made a notable difference with around half of the radiation oncologists and medical oncologists having experience of HRQOL questionnaires. This is most likely to reflect the use of questionnaires as part of research protocols, a finding mirrored in the Ringash *et al.*⁸

survey of international experts in nasopharyngeal cancer. In our study, the UW-QOL was the most used questionnaire, then EORTC and FACT; in the study by Ringash *et al.*,⁸ the most commonly used questionnaires were the EORTC and the FACT instruments. In our study, the main benefits reported were more information about patient and the identification of problems (Table 3). This compares with the Ringash *et al.*⁸ study that reported the use of quality-of-life data to inform patients or as an aid to the choice of treatment. It is disappointing that about one-fifth of the sample in this current survey not using HRQOL questionnaires perceived them as being of no benefit. There is still a need for clinicians working in the field of HRQOL to demonstrate clearly the clinical value. It is disappointing that HRQOL questionnaires have not been more widely used in the 4 years since our previous survey. HRQOL data facilitate the transfer of information between healthcare professionals and patients, which is critical to diagnosis, management and patient support.¹¹ The British Association of Head and Neck Oncologists (BAHNO) and the British Association of Otolaryngologists, Head and Neck Surgeons (BAO-HNS) have both included HRQOL measures as part of their cancer data set. Despite this, it is still hard to incorporate HRQOL as a routine outcome measure in clinical practice. In our previous survey,⁵ we found that only 29% of those managing head and neck cancer patients relied on HRQOL data for successful evaluation of their practices. The survey of the Australian and New Zealand Head and Neck Society (ANZHS) found the vast majority did not use quality of life as a clinical outcome measure, though most indicated a readiness to use a short consensus quality-of-life questionnaire in routine clinical practice and for research, if one was available.⁶ Practical, methodological and attitudinal barriers using patient-based measures of health in routine practice have been reviewed by Greenhalgh and Meadows.¹² If the role of questionnaires in clinical practice is to be realised, these barriers and attitudes need to be addressed. Greenhalgh *et al.*,¹³ in a review of literature, stated that educational methods alone were not enough to bring about change in clinician behaviour in implementing changes in clinical practice, whereas provision of specific management guidelines, using disease-specific instruments and linking provision of information to patient visits could increase the impact of patient-based measures of health in the process and outcomes of care. An educational drive to increase awareness of the benefits of HRQOL and to promote routine use in clinical practice may only be of partial benefit at the present time. Of more benefit might be formal teaching at undergraduate level with HRQOL being seen as integral to best patient care and married to further research in this field. Most clinicians are not trained in the evaluation of questionnaire data and may be uncertain how to interpret and respond to the results.¹ There is growing evidence

that computer-based methods of survey administration are robust, acceptable to patients and feasible to run in oncology clinics.^{14,15} Computer-based approaches enable patient responses to be collected, scored and transcribed in an instant, so that information is available to guide the consultation. Detmar and Aaronson¹⁶ looked at the feasibility of introducing individual quality-of-life assessments into the daily routine of an out-patient oncology clinic. Patients' responses were computer-scored and transformed into a graphic summary. The most notable observation was the increased responsibility taken by physicians in raising specific quality-of-life issues for discussion. Millsopp *et al.*¹⁵ reported on a feasibility study of using touch screen technology (TST) in review clinics using the UWQOL v.4; although 76% of 41 patients had never used a computer, their feedback was broadly positive and they found the task relatively easy to complete. The quality and quantity of HRQOL research has increased markedly in the years since our last survey. There is no doubt that administration of questionnaires is time-consuming. Available time clearly has implications on the smooth running of what are already busy, potentially over-booked clinics. Head and neck cancer patients still suffer significant functional limitations related to their disease and its treatment.

Conclusions

This study highlights the current state of use, understanding and processing of HRQOL data in head and neck cancer patients. The results suggest that we are a long way from the routine and universal utilisation of HRQOL data in the management of head and neck cancer patients. The use of a short, validated instrument together with undergraduate training in the clinical value and processing of HRQOL data is likely to have a significant impact on the integration of such data in the management of every head and neck cancer patient.

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APPENDIX 1

Quality of life questionnaire survey of the British Association of Head and Neck Oncologists members

1. What is your speciality?

Clinical/medical oncology
General surgery
ENT head and neck

Plastic surgery
Maxillofacial
Other (please state) _____

2. What is your grade?

University professor/senior lecturer
NHS consultant

Specialist registrar or university equivalent
Other (please state) _____

3. Have you/your unit ever used a HRQOL questionnaire?

Yes No (if no, please go to Question 11)

4. What do/did you use the questionnaires for? (you may mark more than one choice)

Routine clinical follow-up of patients
Outcome measure as part of a clinical trial

Quality of life research
Other (please state) _____

5. Who distributes and collect the questionnaires?

Consultants
Specialist registrars
Clinic/ward nurses

Speech and language therapist
Medical students
Clinical nurse specialist

Research staff

Other (please state) _____

6. Do you still use a HRQOL questionnaire?

Yes (if yes, please go to Question 7) No

7. Why did you stop using the questionnaires? (you may mark more than one choice)

Did not add value to clinical management of patient
Too time consuming or intrusive in a clinic setting
Not wanted by patients

Current questionnaires do not fulfil my needs
Did not know what to do with the information
Other (please state) _____

8. Which questionnaire(s) have you used (you may mark more than one)?

EORTC ☐ FACT ☐ UW-QOL ☐
Other ☐ (please state) _____

(continued)

9. When have you used questionnaire(s)?

Pre-treatment No ☐ Yes ☐
 Post-treatment No ☐ Yes ☐ (if yes, when/how often?) _____

10. Which group of patients?

Used for ALL patients ☐ Selected patients ☐ Which groups _____

11. Are there any group of patients where HRQOL data are more clinically relevant?

No – no patients Yes – but all patients

Some groups determined by (you may mark more than one choice)

Patient characteristics such as age	No ☐	Yes ☐
Tumour characteristics such as site (<i>e.g.</i> base of tongue)	No ☐	Yes ☐
Tumour characteristics such as advanced disease	No ☐	Yes ☐
Likely prognosis (<i>e.g.</i> when cure is not possible)	No ☐	Yes ☐
Enrolment in a clinical trial	No ☐	Yes ☐

12. Please list any benefits in using HRQOL questionnaire(s)?

1. _____
2. _____
3. _____

13. Will the NICE guidelines and the Improving Outcomes Guidance (IOG) documents make you more likely to measure HRQOL in clinical practice?

No ☐ Yes ☐ Not sure ☐

14. If you do not use HRQOL questionnaire(s), please indicate the reasons? (you may mark more than one choice)

- a. Did not add value to clinical management of patient
- b. Too time consuming or intrusive in a clinic setting
- c. Not wanted by patients
- d. Current questionnaires do not fulfil my needs
- e. Did not know what to do with the information
- f. Do not have resource to do and process it
- f. Other (please state) _____

15. If you do not use HRQOL questionnaire(s), what factors would encourage you to use them? (you may mark more than one choice)

- a. Nothing would encourage me to use questionnaires
- b. Short validated consensus HRQOL questionnaire
- c. Ability to use in research activities
- d. More detailed/comprehensive questionnaire
- e. Questionnaire specific to primary site
- f. Database manager to collate and input data
- g. Computerised data collection (*e.g.* touch screen)
- h. Other (please state) _____