

# A Survey of Consultants and Specialists in Restorative Dentistry on their use of Health-Related Quality of Life questionnaires.

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**Abstract** - A national survey of 178 consultants and specialists in restorative dentistry was undertaken to assess their use of health-related quality of life questionnaires in patients having oral rehabilitation following treatment for oral cancer. The response rate was 74% (132). 42% treated patients following oral cancer, 25% forming part of the head and neck multidisciplinary team. Only 19% had ever used questionnaires. Main barriers to their use were lack of experience with evaluation (27%), lack of staff to administer questionnaires (21%) and insufficient time (18%). Few clinicians thought that questionnaires were not clinically relevant or that no suitable instrument existed. In order to facilitate the use of an oral rehabilitation-specific questionnaire in clinical practice there needs to be greater awareness of the potential benefits, training in the process and the means of reducing the administrative burden.

KEY WORDS: Oral rehabilitation, oral cancer, questionnaire, survey

## INTRODUCTION

The transfer of information between healthcare professionals and their patients is critical to diagnosis, management and patient support<sup>1</sup>. Important to this are patient-derived outcome measures assessing the impact of disease and treatment on patient quality of life (QOL) and more specifically on patient health-related quality of life (HRQOL). In patients with head and neck cancer, HRQOL helps promote best patient care. 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 this aspect as a routine outcome measure in clinical practice. Kanatas *et al.*, (2004)<sup>2</sup> surveyed UK consultant clinicians of the British Association of Head and Neck Oncologists in 2002 and found that only 29% of those managing head and neck cancer patients relied on HRQOL data for successful evaluation of their practices. More recently, Mehanna & Morton (2006)<sup>3</sup> surveyed members of the Australian and New Zealand Head and Neck Society (ANZHNS) and found that the vast majority of clinicians did not use QOL as a clinical outcome measure, though most indicated a readiness to use a short consensus QOL questionnaire for routine clinical practice and for research, if one was available.

There are few studies reporting health-related quality of life for patients undergoing oral rehabilitation following treatment for oral and oro-pharyngeal cancer. Those assessing patient-derived outcomes used ad hoc non-validated instruments solely for the purpose of the studies<sup>4, 5, 6 & 7</sup>. Some of these questionnaires only assessed one or two domains of interest e.g. masticatory efficiency<sup>7</sup> or were restricted to particular patients e.g. maxillary defects<sup>8</sup>. There are questionnaires that assess the impact of oral health on HRQOL, such as the Oral Health Impact Profile (OHIP)<sup>9</sup>, and these have been used in implant-based oral rehabilitation of non-cancer patients<sup>10, 11, 12 & 13</sup>. However these measures are not that appropriate for use with patients undergoing oral rehabilitation following treatment for head and neck cancer as patient concerns and priorities are different. The conventional head and neck specific questionnaires are unlikely to be specific or sensitive enough to assess the success or failure of rehabilitation or oral function due to the limited number of items pertaining to issues such as chewing. The absence of validated questionnaires to assess the impact of oral rehabilitation on HRQOL led to the more recent development of the Liverpool Oral Rehabilitation Questionnaire (LORQ) for use in patients undergoing oral rehabilitation following treatment for oral and oropharyngeal cancer<sup>14 & 15</sup>.

This paper summarises a survey of consultants and specialists in restorative dentistry, affiliated with the Association of Consultants and Specialists in Restorative Dentistry (ACSRD). The main aim was to assess the use of HRQOL questionnaires by consultants and specialists affiliated with the ACSRD involved in the rehabilitation following treatment for head and neck cancer and to identify the commonly used questionnaires and the perceived barriers to their utilisation.

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## METHODS

A mailing list of members of the Association of Consultants and Specialists in Restorative Dentistry (ACSRD) was obtained from its chairman. Survey questionnaires (n=197), together with a short covering letter and a return stamped addressed envelope were sent in July 2005. A reminder letter, with the questionnaire, was mailed to non-respondents in the first week of September 2005. Other data collected of all members included: (i) date of qualification; (ii) number of years post-qualification; (iii) work setting; and (iv) region in the UK where clinicians practiced.

The survey questionnaire was piloted with 12 clinicians at the Liverpool University Dental Hospital. The final questionnaire asked if clinicians undertook oral rehabilitation for head and neck cancer patients, if they were part of the head and neck multi-disciplinary team (MDT), about their current and future use of HRQOL questionnaires in clinical practice and about barriers to using them. Those having used HRQOL questionnaire were asked which ones they had used, which patients they targeted and how they administered questionnaires. Those undertaking oral rehabilitation after treatment for oral cancer were asked which questionnaires they used and when they used them.

The Chi-squared test was used to compare use of HRQOL questionnaires between subgroups based on region, years since qualification and workplace. Fisher's Exact test was used to compare use of HRQOL questionnaires by whether respondents treated patients for oral rehabilitation and by whether they were part of a head and neck MDT. Statistical significance was set at  $P < 0.05$ .

## RESULTS

Of 197 consultants and specialists identified on 'the ACSRd register', 15 had either retired or had no clinical contact with patients, 3 had no contact address and 1 lived in Hong Kong. Of the remaining 178, questionnaires were returned by 132 giving a response of 74%. The response rate was higher from those working outside of England (91% 42/46 Vs 68% 90/132) and from those more recently qualified (81% if up to 20 years ago, 75% for 21-30 years, 73% for 31-40 years and 62% for >40 years)

Of the 132 responders, 42% (56) treated patients following head and neck cancer, and 25% (33) formed part of the head & neck cancer MDT. Only 19% (25) had ever used HRQOL questionnaires for any of their patients, and use was higher for those who had treated patients for oral

**Table 1.** Use of HRQOL questionnaires in the past, or in the future

|                                                             |                   | Ever used HRQOL Questionnaire for your patients? |    |    | P Value           | Intend using any HRQOL questionnaire in the future? |    |          |     |    |    | P value * (Yes Vs No/ Not sure) |
|-------------------------------------------------------------|-------------------|--------------------------------------------------|----|----|-------------------|-----------------------------------------------------|----|----------|-----|----|----|---------------------------------|
|                                                             |                   | ALL                                              | %  | N  |                   | YES                                                 |    | Not Sure |     | NO |    |                                 |
|                                                             |                   |                                                  |    |    |                   | %                                                   | N  | %        | N   | %  | N  |                                 |
| Treat patients for Oral Rehabilitation after Head & Neck Ca | Yes               | 56                                               | 27 | 15 | 0.07              | 34                                                  | 19 | 50       | 28  | 16 | 9  | 0.006                           |
|                                                             | No                | 76                                               | 13 | 10 |                   | 13                                                  | 10 | 32       | 24  | 55 | 42 |                                 |
| Part of a Head & Neck MDT                                   | Yes               | 33                                               | 21 | 7  | 0.80              | 33                                                  | 11 | 55       | 18  | 12 | 4  | 0.09                            |
|                                                             | No                | 99                                               | 18 | 18 |                   | 18                                                  | 18 | 34       | 34  | 47 | 47 |                                 |
| Region                                                      | London            | 32                                               | 25 | 8  | 0.002             | 22                                                  | 7  | 25       | 8   | 53 | 17 | 0.001                           |
|                                                             | South (East/West) | 10                                               | 10 | 1  |                   | 30                                                  | 3  | 60       | 6   | 10 | 1  |                                 |
|                                                             | Midlands/East     | 11                                               | 18 | 2  |                   | 27                                                  | 3  | 36       | 4   | 36 | 4  |                                 |
|                                                             | North(East/West)  | 25                                               | 44 | 11 |                   | 48                                                  | 12 | 24       | 6   | 28 | 7  |                                 |
|                                                             | Yorkshire         | 12                                               | 17 | 2  |                   | 25                                                  | 3  | 33       | 4   | 42 | 5  |                                 |
|                                                             | Ireland           | 10                                               | 10 | 1  |                   | 0                                                   | 0  | 80       | 8   | 20 | 2  |                                 |
|                                                             | Scotland          | 24                                               | 0  | 0  |                   | 4                                                   | 1  | 54       | 13  | 42 | 10 |                                 |
|                                                             | Wales             | 7                                                | 0  | 0  |                   | 0                                                   | 0  | 43       | 3   | 57 | 4  |                                 |
| Jersey                                                      | 1                 | 0                                                | 0  |    | 0                 | 0                                                   | 0  | 0        | 100 | 1  |    |                                 |
| Years since Qualification                                   | 11-20             | 25                                               | 20 | 5  | 0.60 linear assoc | 36                                                  | 9  | 28       | 7   | 36 | 9  | 0.03 linear as-<br>sociation    |
|                                                             | 21-30             | 64                                               | 20 | 13 |                   | 22                                                  | 14 | 45       | 29  | 33 | 21 |                                 |
|                                                             | 31-40             | 35                                               | 17 | 6  |                   | 17                                                  | 6  | 40       | 14  | 43 | 15 |                                 |
|                                                             | >40               | 8                                                | 13 | 1  |                   | 0                                                   | 0  | 25       | 2   | 75 | 6  |                                 |
| Workplace                                                   | Dental Hospital   | 81                                               | 25 | 20 | 0.10              | 26                                                  | 21 | 37       | 30  | 37 | 30 | 0.28                            |
|                                                             | Practice          | 13                                               | 8  | 1  |                   | 8                                                   | 1  | 31       | 4   | 62 | 8  |                                 |
|                                                             | OMFU              | 6                                                | 33 | 2  |                   | 50                                                  | 3  | 50       | 3   | 0  | 0  |                                 |
|                                                             | DGH               | 7                                                | 0  | 0  |                   | 14                                                  | 1  | 57       | 4   | 29 | 2  |                                 |
|                                                             | Univ Hospital     | 11                                               | 9  | 1  |                   | 9                                                   | 1  | 64       | 7   | 27 | 3  |                                 |
|                                                             | PG Dental Inst    | 10                                               | 10 | 1  |                   | 20                                                  | 2  | 20       | 2   | 60 | 6  |                                 |
|                                                             | Other             | 4                                                | 0  | 0  |                   | 0                                                   | 0  | 50       | 2   | 50 | 2  |                                 |

\* Chi-squared test (>2 groups) or Fishers Exact test (2 groups): Region (6 groups, with non-England as one group), Years (4 groups excluding unknown), workplace (3 groups- dental Hospital, practice and other)

rehabilitation and for those based in the North East/North West of England (Table 1). Use of HRQOL questionnaire was lowest for those outside England and there was little difference in regard to whether being part of a Head and Neck MDT. Only 22% (29) said they intended to use HRQOL questionnaires in future and 19 of these 29 had used them before. There were 39% (52) who said they were 'not sure' about their future use of HRQOL instruments whilst 39% (51) said 'no' to future use. Those most intent on using questionnaires in future were treating patients for oral rehabilitation, were part of an MDT, were based in England and more recently qualified (Table 1).

The main barriers to using HRQOL questionnaires for the 132 responders were lack of experience with HRQOL evaluation (27%, n=35), lack of staff to administer questionnaires (21%, n=28) and insufficient time (18%, n=24). Lesser barriers were split-site working (n=11), no suitable questionnaire (10), lack of clinical relevance (6) and difficult to get baseline data (5). Other barriers (17) included unfamiliarity with HRQOL, unreliability of questionnaires, relevance of questionnaires, unaware of existence of questionnaires, clinic time, opens up problems unable to deal with. For one quarter (34) no barrier was stated.

Various HRQOL questionnaires had been used (Table 2) with oncology, atrophy and hypodontia patients. More than half (56%) had used them for other conditions - treatment with implant supported prosthesis (4), periodontal treatment (3), cleft palate (2), edentate patients (2), dental caries and sequelae (1), toothwear (1), temporomandibular disorders and the impact of ageing, nutrition and diabetes on HRQOL (1). The distribution and collection of questionnaires was done mainly by consultants, specialist registrars, nurses and researchers. Questionnaires were also distributed by researchers (7), research coordinators (2) data entry clerks (2), dental students (1), lecturers (1) and secretaries (1). The main method of distribution was by hand at clinic.

There were 15 responders who had used HRQOL questionnaires and who undertook oral rehabilitation of patients. Five of these had not used questionnaires in oncology oral rehabilitation (Table 3), and one respondent did not answer. Of the 9 who had used questionnaires in oral rehabilitation, 5 had used both the Oral Health Impact profile (OHIP)<sup>9</sup> and the University of Washington QOL (UWQOL) questionnaire<sup>16</sup>. Seven had administered questionnaires before treatment and 9 after treatment. Seven had targeted all patients and 2 had targeted some patients though the selection criteria for patients were not stated. Two felt there was a need for another questionnaire for patients undergoing oral rehabilitation and two were unsure about this.

One-quarter (33/132) of respondents used the free-text question at the end of the questionnaire to express their opinions and views regarding the use of HRQOL instruments. A selection of comments is included as Table 4.

## DISCUSSION

There is a drive to develop reliable and valid questionnaires that measure the impact of health and intervention on subjective well-being and then to apply them in treatment evaluation. This is also the trend in dentistry<sup>17</sup>.

**Table 2.** Use of HRQOL questionnaires by those (n=25) who have used them

|                                                                | %  | N  |
|----------------------------------------------------------------|----|----|
| <i>Which patient groups were included?</i>                     |    |    |
| Oncology                                                       | 36 | 9  |
| Atrophy                                                        | 28 | 7  |
| Hypodontia                                                     | 12 | 3  |
| Other                                                          | 56 | 14 |
| <i>Which questionnaires were used?</i>                         |    |    |
| Oral Health Impact Profile                                     | 48 | 12 |
| Oral Health QoL Questionnaire (UK)                             | 28 | 7  |
| University of Washington QOL Questionnaire                     | 20 | 5  |
| EORTC H&N C35 Questionnaire                                    | 4  | 1  |
| Liverpool Oral Rehabilitation Questionnaire (LORQ)             | 8  | 2  |
| Other questionnaire*                                           | 32 | 8  |
| Not sure                                                       | 4  | 1  |
| <i>Who helped distribute &amp; collect the questionnaires?</i> |    |    |
| Consultants                                                    | 36 | 9  |
| SHOs                                                           | 12 | 3  |
| Nurse Specialist                                               | 8  | 2  |
| Medical students                                               | 4  | 1  |
| SpRs                                                           | 24 | 6  |
| Nurses                                                         | 24 | 6  |
| SLT                                                            | 0  | 0  |
| Other                                                          | 52 | 13 |
| <i>How were questionnaires distributed?</i>                    |    |    |
| At Clinic                                                      | 84 | 21 |
| By telephone                                                   | 8  | 2  |
| By Post                                                        | 36 | 9  |
| Computer Input by patients                                     | 8  | 2  |
| By other means                                                 | 0  | 0  |

Multiple answers were possible for each section

\* Ad hoc (5), GHQ-12 (1), Eysenck Personality Inventory (1) GOHAI & OIDP (1)

**Table 3.** Which HRQOL questionnaires were used in oncology oral rehabilitation by those (n=15) who have used them

| <i>Which questionnaires were used?</i>             | %  | N |
|----------------------------------------------------|----|---|
| Oral Health Impact Profile                         | 40 | 6 |
| Oral Health QoL Questionnaire (UK)                 | 20 | 3 |
| University of Washington QOL Questionnaire         | 33 | 5 |
| EORTC H&N C35 Questionnaire                        | 7  | 1 |
| Liverpool Oral Rehabilitation Questionnaire (LORQ) | 13 | 2 |
| Other questionnaire*                               | 7  | 1 |
| None                                               | 33 | 5 |

Multiple answers were possible for each section

\* Own questionnaire

One of the aims of this study was to assess the use of HRQOL instruments by consultants and specialists in restorative dentistry affiliated with the ACSRD. Whilst only 19% of respondents country-wide had ever used HRQOL questionnaires, this low rate most likely reflects use either as a research tool or when a substantial impact on HRQOL is expected, such as with complex dental implant treatment. Crucially, the target group of clinicians providing

**Table 4.** *Some of the opinions and views expressed on the use of HRQOL instruments.*

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|                                                                                                                                                                                                                                                                        |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| A vital part of our understanding of patient care - outcome. Much under-rated                                                                                                                                                                                          |
| An excellent idea                                                                                                                                                                                                                                                      |
| Extremely important as a measuring tool especially when trying to commission services                                                                                                                                                                                  |
| Fully supportive of their use to define the importance of various forms of dental treatment to those who require it particularly in relation to those with neoplastic conditions                                                                                       |
| Happy to use a validated and concise questionnaire - if such an animal exists.                                                                                                                                                                                         |
| HRQOLQs are valuable but care must be taken to devise the appropriate one for the area being studied                                                                                                                                                                   |
| I consider HRQOL Qs can play a valuable role in oral rehabilitation of maxillofacial patients and would wish to develop this process with colleagues                                                                                                                   |
| This would be a useful addition to the management of this deserving and complex patient group                                                                                                                                                                          |
| I think the use of HRQOL is essential in the correct management of HN oncology patients                                                                                                                                                                                |
| It may open up problems that we as an institution have no resources to treat. For instance - person may say they have depression due to yellow teeth or suicidal because they can't wear F/F - What do we do then? Patients who have had HNC are obviously unfortunate |
| None have ever been validated or are of proven reliability                                                                                                                                                                                                             |
| Poor patients - so many questionnaires at such a difficult time.                                                                                                                                                                                                       |
| QOL may be relevant to any number of dental treatments                                                                                                                                                                                                                 |
| Sometimes difficult to be sure that the pt is interpreting statements / questions as intended. Specific relevance and responsiveness can be a problem                                                                                                                  |
| Useful research tool. Never thought of using them in clinical care.                                                                                                                                                                                                    |
| Why don't we just apply previous findings and make it part of "good practice"? Why keep repeating what has been done?                                                                                                                                                  |
| Would use them if required to support research in my areas of clinical interest                                                                                                                                                                                        |

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oral rehabilitation for patients following treatment of head and neck cancer were more likely to have used HRQOL questionnaires and were more intent on using them in the future.

There was generally little in the responses received to indicate that available questionnaires were perceived to be clinically irrelevant or unsuitable, despite only a few using them. This could suggest no need for further questionnaires in that clinicians do see them as relevant but face barriers preventing their use. As expected both use and intended use was higher for more recently qualified clinicians. Consultants in restorative dentistry, working closely with oral and maxillofacial units, also reported higher rates.

The main barriers to the use of questionnaires were lack of experience with HRQOL evaluation (27%), lack of staff (21%) and insufficient time (18%) to administer questionnaires. Other reasons given were the lack of clinical relevance of HRQOL and a perceived lack of need for use in clinical practice. Free text comments although generally supportive of having HRQOL assessments also raise issues indicative of resistance. For example, one clinician raised concerns about identifying functional and psychological problems outside the remit of the speciality of restorative dentistry thus raising the issue of resources as well

as clinical management of such patients. These practical, methodological and attitudinal barriers to the use of patient-based measures of health in routine practice have been reviewed by Greenhalgh & Meadows<sup>19</sup>.

If the role of questionnaires in clinical practice is to be realized then these barriers and attitudes need to be addressed. Greenhalgh et al., (2005)<sup>20</sup>, in a review of the literature, stated that educational methods alone were not enough to bring about changes in clinician behavior in implementing changes in clinical practice whereas provision of specific management guidelines, using disease specific instruments and linking provision of information to patient visits, may 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<sup>1</sup>.

There is growing evidence that computer based methods of survey administration are robust, acceptable to patients and feasible to run in oncology clinics<sup>21,22</sup>. Computer-based approaches enable patient responses to be collected, scored and transcribed in an instant, so that the information is available to guide the consultation. Detmar & Aaronson<sup>23</sup> looked at the feasibility of introducing individual QOL 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 QOL issues for discussion. Millsopp et al., (2006)<sup>22</sup> reported on a feasibility study using Touch Screen Technology (TST) in review clinics using the UWQOL version 4 and although 76% of these 41 patients had never used a computer, their feedback was broadly positive and patients found the task relatively easy to complete.

## CONCLUSION

Data from this study suggest that the determining factors for whether clinicians use HRQOL questionnaires is not the questionnaires themselves but rather the clinical setting, the training they receive and their general appreciation of the HRQOL concept. Computer technology allows for questionnaire responses to be immediately available in consultations and might improve acceptance of this valuable outcome measure.

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