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# Health-related quality of life measured by the UW-QoL—reference values from a general dental practice \*\*

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#### **KEYWORDS**

Health-related quality of life; Oral cancer; Oropharyngeal cancer; Reference values; UW-QoL

The objective of this study was to obtain age and sex-specific reference values for the University of Washington head and neck cancer questionnaire version 4 (UW-QoLv4) and to compare this with patients with oral and oropharyngeal cancer. Cross-sectional reference data was collected from 372 patients in six local general dental practices, 349 of whom presented for routine appointments. Quota sampling was used to collect data for similar numbers of patients by gender by four age bands (40-49, 50-59, 60-69, 70-79 yr). The longitudinal sample consisted of 450 consecutive patients undergoing primary surgery for previously untreated oral and oropharyngeal squamous cell carcinoma presenting to the Regional Maxillofacial Unit Liverpool, between the years 1995 and 2002. At baseline the key differences were anxiety, pain, swallowing, chewing, and mood. At 1 yr there were big differences in all domains with deterioration in the oral cancer group. The difference was least notable in pain, shoulder, mood and anxiety. Reference data from a non-cancer population is very important when considering UW-QoL domains as an outcome parameter in clinical trials and also when discussing health-related quality of life outcomes with patients and their families. © 2005 Elsevier Ltd. All rights reserved.

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## Introduction

Patient self-completed questionnaires have an important role in the assessment of disease states and their treatment. There are several health-related quality of life (HRQoL) questionnaires

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suitable in head and neck cancer. <sup>1,2</sup> Questionnaire validation takes many years and one aspect is the comparison with groups who do not have the disease. Comparison with 'normative' data allows a point of reference and the opportunity to put the patients experience of their illness into a wider perspective. It is useful when interpreting changes in HRQoL in clinical trials. Population based reference data exists for some of the more commonly used general questionnaires such as the SF36<sup>3</sup> and questionnaires that do not have a direct application in head neck cancer, such as the oral health-related quality of life (OHR-QoL).<sup>4</sup>

Of the commonly reported head and neck cancer specific questionnaires only the functional assessment of chronic illness therapy (FACIT)<sup>5</sup> and the European Organization for Research and Treatment of Cancer (EORTC) Core 30 quality of life questionnaire<sup>6–9</sup> have published reference data in peer review journals. The findings show that age and sex differences must be taken into consideration when different groups of cancer patients are compared.

The University of Washington Quality of Life Scale (UW-QoL) and is one of the most popular in UK head and neck oncology practice.<sup>10</sup> The questionnaire is part of a national dataset (DAHNO).<sup>11</sup> Although the questionnaire has been widely published, there has been to date no reference in a non-cancer cohort.

The aim of this project was to collect data on the UW-QoL in a non-cancer 'reference' cohort and to compare responses with those obtained from an oral and oropharyngeal cancer patient population followed since 1995. Patients attending general dental practice are suitable group for two reasons. Firstly, domains such as chewing, swallowing and speech are pertinent to patients attending both the dentist and those with oral cancer. Secondly, oral cancer patients present to and are referred from dental practitioners.

### Materials and methods

The University of Washington (UW-QoLv4) is a patient self-completed questionnaire and currently tests 12 specific areas relating to the head and neck cancer patient. These are pain, appearance, activity, recreation, swallowing, chewing, speech, shoulder function, taste, saliva, mood and anxiety. For use with a non-cancer population the UW-QoL had any reference to 'cancer' removed. The UW-QoL was printed for optical recognition to assist in efficient and accurate data entry.

General Dental Practitioners from Liverpool attending a local postgraduate teaching course were asked to contribute to the project. Six practices participated and three dental students visited these practices over the summer of 2003 as part of their elective period. To obtain a 'normative' sample reflecting the age distribution of patients with oral cancer, only patients between 40 and 79 were recruited. They used appointment lists to identify patients and quota sampling to collect UW-QoL data for similar numbers of patients in four age bands (40-49, 50-59, 60-69, 70-79 yr) for men and women separately. Students approached patients and asked them to complete the UW-QoL whilst they were waiting to see the dentist or hygienist. Although no formal record of refusals was made the students reported that few of the patients they approached declined to participate.

The sample of cancer patients comprised consecutive patients aged 40—79 undergoing primary surgery for previously untreated oral and oropharyngeal squamous cell carcinoma at the Regional Maxillofacial Unit Liverpool, between 1995 and 2002. Follow-up was to May 2003.

#### Statistical method

The UW-QoL domain scales have 3, 4 or 5 ordered tick box categories which are scaled evenly for analysis to produce scores from 0 (worst score) to 100 (best score) for each domain. Results were tabulated for reference purposes by gender and age groups. Summary statistics comprised domain mean scores, percentages of patients giving the best possible response and percentages stating the domain as important to them. Differences in domain scores between types of appointment, and between males and females were tested using the Mann-Whitney test. Differences in importance were assessed with Fisher's exact or chi-squared test as appropriate. Spearman correlation was used to assess correlation between age group and the UW-QoL scales. All analyses used SPSS Version 11.

# **Results**

# Non-cancer patients

Six general dental practices participated and 372 patients completed UW-QoL questionnaires, of whom 349 attended routine appointments and 23 were emergencies (Table 1). Patient numbers for each practice were 110, 94, 69, 66, 19 and 14

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