Title of measure
The Head and Neck Symptom Scale of the University of Washington Quality of Life Scale (UWHNSS)

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Brief overview:
Hassan and Wymuller of the University of Washington, Seattle, developed the University of Washington Quality of Life Questionnaire. This questionnaire was designed specifically to address problems incurred by head and neck cancer patients. The first scale consists of 20 questions on head and neck cancer symptoms that generate scores for 4 domains or dimensions of quality of life; communication, eating, pain, and emotional well-being. Global symptoms, disability attributable to head and neck cancer, and response to treatment are also assessed (4).

Validated (yes/no):
Yes, see below.

Psychometric properties and references:
In the original UWHNSS four relevant domains were identified: Eating (6 items), Communication (4 items), Pain (4 items), and Emotion (6 items). Each had an internal consistency (Cronbach α value) of greater than 0.80. Construct validity was demonstrated by moderate correlations with SF-12 Physical and Mental component scores (r=0.43-0.60). Test-retest reliability for each domain demonstrated strong reliability between the 2 time points. Correlations were strong for each individual question, ranging from 0.53 to 0.93 (5).

The questionnaire was tested on 75 head and neck cancer patients and was compared to two established tools, the Karnofsky Performance Scale (KPS) and the Sickness Impact Profile (SIP), for validity, acceptability, reliability and responsiveness. The overall results demonstrated that the University of Washington and SIP for reliability and responsiveness; it was the preferred test format for 97% of the tested patients. The scores of the UWHNSS correlated well with the KPS and SIP, indicating validity. The test-retest reliability coefficient was 0.95 (1).

Normative data:
Normative data have previously been published (3, 5).

Clinically significant changes:
The University of Washington Quality of Life (UW-QOL) questionnaire has undergone several recent improvements. The current Version 3, has 10 domain-specific questions. The domains focus on physical symptoms, physical functioning, and social function. Specifically, the items address pain, appearance, activity level, recreation, swallowing, chewing, speech, shoulder function, taste, and
saliva production. They are now testing a Version 4, that includes two additional questions about emotional function. The remainder of the scale will be unchanged. The two specific questions will address depression and anxiety. The addition of emotional items will make the UW-QOL a more well-rounded QOL instrument. Both versions ask the patient to rate the domain items of greatest importance to them. In addition to domain-specific items, both versions also include 4 generic QOL questions: What is your overall quality of life (‘Global QOL’)?; What is your health-related quality of life (“Global HR-QOL”)? How has your health-related quality of life changed (“Transitional HR-QOL”, “Incremental HR-QOL”)? Free text response to describe quality of life (“Open-ended QOL”). Our patients have used this question as an opportunity to describe their QOL in their own words or drawings. Both versions remain brief and are simple for patients to complete. Either scale is completed in 5 minutes. Version 3 is fully validated in terms of reliability, construct validity, and responsiveness, but does not offer an emotional domain. Version 4 has the advantage of having emotional questions, but formal prospective validation is ongoing.

Scoring version 3 and 4. Each of the domain-specific items is scored from 0 (worst QOL) to 100 (best QOL). The ‘composite’ score is created by averaging the scores from the 10 (Version 3) or 12 (Version 4) items. They do not include the four generic questions in the composite scoring, because these represent very different constructs. The University of Washington have found that the global QOL, global HR-QOL and transitional HR-QOL items provide different and useful perspectives from the composite score. They recommend that these questions be used independently. They are developing methodology to ‘score’ the open-ended QOL questions. (http://depts.washington.edu/soar/projects/dxcat/hnca/qol_uw.htm)

Website or how to register to use:

List any fees for usage:
None

Languages available:
English

Instructions for CRAs and/or credentialing of administration:
The Symptom Scale Questionnaires needs to be completed by the patient at the time intervals specified by the protocol; therefore, it is crucial that the patient is followed in your department, at least for the visits, during which the QOL forms are due.

Please note that the questionnaire is a separate pre-therapy Symptom Scale questionnaire and a post treatment version. Be sure to use the appropriate form for each evaluation. The pretreatment version is used prior to all therapy.

If for some reason, the patients cannot complete the questionnaire while in the department, s/he should be requested to complete them within the next day or so. The following procedure should be used: arrangement must be made to call the patient, at which time the interviewer (research associate/nurse) goes through questionnaire with patient while on the telephone. The patient supplies each response to the interviewer who completes the form and submits it to Headquarters. The patient may have completed the questions in advance of the call. Before hanging up the phone, re-check to be sure all items were covered.

Be sure to give the patient a blank set of questionnaires to keep so these will be available for completion at home if a follow-up visit is missed.
If the patient misses a scheduled appointment, s/he should be contacted without delay by telephone or mail and arrangements made to complete the questionnaires by telephone interview as described above. (Quality of Life Head and Neck – RTOG 9901. Instructions: http://www.rtog.org/members/forms/9901/qolinstr.pdf)

**Time required to administer instrument:**
No specific reference found.

**Quality assurance for administration (if needed)**
The patient questionnaire must be submitted if any items were completed. All questions should be checked they are received from the patients for completeness and readability, making certain that all items are coded with only one response when required. All pages of the questionnaires must contain the study and case number.

A cover sheet that represents the first page of the Symptom Scale is completed by the investigator / data manager / nurse. This page should not be given to the patient but added before submitting the questionnaire. If the patient completes no items on the patient questionnaire, or the evaluation was missed, only the cover sheet with the applicable questions completed by the investigator / data manager / nurse is submitted. All patients’ questionnaire without the completed cover sheet will be returned to the institution. A calendar-listed questionnaire will not be suppressed with a request memo. The completed cover sheet must be submitted.

The initial pre-study questionnaire must be completed prior to treatment start for the case to be considered eligible for inclusion in analysis of these components. If the patient refuses to participate or completes none of the pre-study items, only the cover is submitted and subsequent QOL evaluations are omitted. These questionnaires are an important part of this study and necessary for the case to be completely analyzable.

Carefully check the questionnaires completed by the patient. Missed items on the assessments, especially on the pretreatment evaluation (missed baseline) will adversely affect the ability to analyze the missed parameters on subsequent questionnaires.

If assistance is required by the patient to complete the questionnaires, the staff and not the patient's spouse or family member should provide the assistance. Use care not to influence the patient’s responses.

A videotape for patients participating in QOL studies is available from RTOG Headquarters. (Quality of Life Head and Neck – RTOG 9901. Instructions: http://www.rtog.org/members/forms/9901/qolinstr.pdf)

**Scoring of instrument:**
The scale consists of ten symptom-specific categories, each of which describes important daily living function/limitations of head and neck cancer patients. Each category has five possible item choices. The highest level or “normal” is scored 10 points while the lowest (or greatest dysfunction) is scored 50 points. The options between are in multiples of 10. The patient is asked to circle the statements which best describe their current status. The scores are totaled and then adjusted to obtain the final range from 0 to 100. The lower the score, the greater the QOL, and conversely, the higher the score, the lower the QOL.

**References:****


