

ORIGINAL RESEARCH–HEAD AND NECK SURGERY

Spanish validation of the University of Washington Quality of Life questionnaire for head and neck cancer patients

Gonzalo Nazar, MD, María Luisa Garmendia, MD, PhD, Michel Royer, MD, Jennifer A. McDowell, MS, Ernest A. Weymuller, Jr., MD, and Bevan Yueh, MD, MPH, Santiago, Chile; Seattle, WA; and Minneapolis, MN

Sponsorships or competing interests that may be relevant to content are disclosed at the end of this article.

ABSTRACT

OBJECTIVE: The University of Washington Quality of Life (UW-QOL) questionnaire is one of the most widely used instruments to evaluate the quality of life of head and neck cancer patients. The aim of this study was to perform a Spanish translation and validation of the UW-QOL questionnaire.

STUDY DESIGN: A cross-sectional study.

SETTING: Three tertiary-care hospitals and a laryngectomy rehabilitation center.

SUBJECTS AND METHODS: The translation and cultural adaptation of the questionnaire were performed following accepted international guidelines. The psychometric validation was performed on a consecutive series of patients treated for squamous cell carcinoma of the upper aerodigestive tract with no signs of relapse, recruited from May 2007 to December 2008. Eligible subjects were invited to complete the Spanish version of the UW-QOL questionnaire during routine clinical consultation, and complete it again within 15 days. Subjects also completed a validated Spanish version of the Goldberg Mental Health Survey and were evaluated by the use of the Karnofsky Index.

RESULTS: A Spanish version of the questionnaire was developed in iterative fashion. In the psychometric validation process, a total of 76 patients were analyzed. Reliability was excellent, including both internal consistency (Cronbach's alpha of 0.84) and test-retest reliability (intraclass correlation coefficient between 0.91 and 0.97 with a confidence interval of 95%). Construct validity was supported by statistically significant relationships between the Karnofsky Index, the Goldberg Mental Health Survey, and the translated UW-QOL questionnaire.

CONCLUSION: The Spanish version of the UW-QOL questionnaire appears to be culturally appropriate and psychometrically valid.

© 2010 American Academy of Otolaryngology–Head and Neck Surgery Foundation. All rights reserved.

Head and neck cancer is a devastating disease, with poor overall survival rates regardless of the recent advances in chemotherapy, radiation therapy, and surgical techniques. The symptoms and sequelae of treatment associated with advanced head and neck cancer have a deep impact on quality of life (QOL), affecting multiple aspects of daily functioning. Patients may experience chronic pain and sensory impairment, including visual, hearing, smell, and taste deficits, depending on the tumor location and the type of therapy. Usually there is some degree of difficulty in chewing, swallowing, breathing, and speaking, in many cases associated with facial disfigurement and social isolation. Furthermore, at present there are several therapeutic strategies for head and neck cancer, with similar oncologic efficiency. In this context, outcome evaluation with the classic oncologic parameters of local control and survival is clearly insufficient in head and neck cancer, and QOL assessment has become essential in these patients. QOL evaluation assists the clinician in understanding the effect of head and neck cancer and its treatment on the patient's life, and it could also become an important tool for treatment planning.¹⁻⁴

Health-related QOL cannot be measured by objective parameters and is usually evaluated by the application of specific surveys. There are many instruments designed to assess QOL in patients with head and neck cancer, including List's Performance Status Scale, the European Organization for Research and Treatment of Cancer Core QOL questionnaire with the H&N35 appendix,⁵ and the University of Washington Quality of Life (UW-QOL) questionnaire.⁶⁻⁸ The UW-QOL has several advantages: it is well validated, concise, practical, and easy to complete and interpret; in addition, it correlates well with more thorough instruments like EORTC.⁹ This questionnaire has reference data available from noncancer patients, which allows its comparison with "normal" values.¹⁰

The UW-QOL survey has been extensively and successfully used in the United States and other English-speaking populations. To use it in other cultures and countries, it needs

Received February 11 2010; revised July 11, 2010; accepted August 10, 2010.

to be carefully translated, culturally adapted, and validated in the new language, which guarantees its accuracy in the new population.¹¹ To date, there is no validated Spanish version of this instrument. Thus, this study was undertaken to perform a Spanish translation and validation of the UW-QOL questionnaire in a Spanish-speaking population.

Patients and Methods

The study protocol and the informed consent form were approved by the Ethics Committee of the University of Chile Hospital.

Translation and Adaptation Process

Two Spanish translations of the original English version of the UW-QOL questionnaire were performed by two independent bilingual otolaryngologists, following internationally accepted guidelines.¹¹ A bicultural expert compared the two translations, and a consensus version was obtained. A professional translator back-translated the resulting consensus Spanish version to English and sent it to one of the original authors of the instrument (B.Y.), who compared it with the original English-language version to ensure that it was suitable. At this point, the Spanish translation of the UW-QOL was approved in its format and content. Then, the Spanish version of the questionnaire was tested in a pilot study on five subjects with the same characteristics of the intended study population. This testing allowed for final corrections to be made in the questionnaire to make it easier for the patients to read, understand, and answer.

Psychometric Validation

The Spanish version of the UW-QOL was tested on a consecutive series of patients seen at four different Cancer Centers in Santiago, Chile, between May 2007 and September 2008. The participating institutions were the Otolaryngology Department of the University of Chile Hospital, the Oncologic Institute of Clínica Las Condes, the Arturo López Pérez Cancer Foundation, and the National Corporation of Chilean Laryngectomees. Inclusion criteria were as follows: adult patients (18 years or older) who had received complete treatment for a squamous cell carcinoma of the upper aerodigestive tract with curative purposes. Patients with evidence of recurrent disease were excluded from the study, as well as patients with primary malignancies of the thyroid gland and the skin. Eligible subjects were invited to participate in the study, and participants were asked to sign an informed consent form approved by the Institutional Ethics Committee.

All participating patients were invited to complete a set of self-administered questionnaires that included the UW-QOL, the Goldberg Mental Health Survey-12 (GHQ-12), and a sociodemographic form. Patients were interviewed by a nurse or speech pathologist, who assessed the patients for Karnofsky status, gathered rele-

vant clinical information (tumor characteristics, comorbidities, and therapies received), determined the patients' levels of education, and addressed patients' concerns or doubts about the questionnaires. When possible, the charts of the enrolled subjects were reviewed for completion of the clinical data collection. After two weeks, subjects were asked to answer a second UW-QOL, either in person or by mail. The two applications of the UW-QOL with a two-week interval allowed for the determination of test-retest reliability. No treatment was given to the study patients during this two-week interim period.

The UW-QOL is a questionnaire specifically designed to assess the QOL of patients with head and neck malignancies. It was first described in 1993 by Hassan and Weymuller⁶ and has been updated since with the latest version (UW-QOL v4), which was published in 2002.⁸ It has three domains: a symptom scoring area; a priority symptom selection area; and a global health-related QOL area. In the symptom scoring area, 12 symptoms are assessed with multiple-choice questions that are scored from 0 (worst QOL) to 100 (best QOL). The symptom scores can be averaged to obtain a composite QOL score, with 100 being the maximum achievable result. Some of the symptom domains have been evaluated separately and have been found to have very good correlations with more specific and detailed surveys.¹²⁻¹⁴ At the end of the UW-QOL questionnaire, patients are invited to offer open-ended comments, which allow them to raise concerns about additional issues not included in the other domains.¹⁵

The GHQ-12 is a 12-item questionnaire designed with the purpose of identifying minor psychiatric disturbances; thus, it is considered to assess the state of mental health. It is used to evaluate four fundamental psychiatric areas: depression, anxiety, socially inappropriate behaviors, and hypochondria. It is composed of a series of proposals that are presented to the patients in a Likert scale (0 to the first two, 1 to the third and fourth), with a greater score meaning a worse level of mental health. The total score is obtained by adding the scores of every item, and the result is an estimation of the severity of the mental disturbance. The maximum possible score is 12, and the minimum score is 0. Our hypothesis is that greater scores in the GHQ-12 would result in a worse UW-QOL score.

The Karnofsky scale was developed by David Karnofsky and Joseph Burchenal in the 1940s as a method to measure the performance status of cancer patients. A health professional assesses the patient and assigns a score which ranges from 100 percent (normal health) to 0 percent (death). Although it is not strictly a QOL instrument, its score strongly correlates with the result of many QOL questionnaires.

Statistical Analysis

Descriptive data included mean values and standard deviation for continuous variables and percentages for categorical variables. The statistical analysis was performed

Table 1
Epidemiological characteristics of the study population

Age, yrs	
<40	2.8
40-49.9	13.9
50-59.9	15.3
60-69.9	25.0
≥70	43.1
Sex	
Male	77.6
Female	22.4
Total years of education	
≤8	31.3
9-12	53.7
>12	14.9
Comorbidity	
Hypertension	19.2
Diabetes	19.2
Hypothyroidism	3.8

Values are expressed as percentages.

by the use of STATA 10.0 software (StataCorp LP, College Station, TX).

Reliability. Internal consistency was estimated by interim correlation matrix testing (Cronbach's alpha). Test-retest reliability was calculated through the intraclass correlation coefficient (ICC) and 95% confidence intervals (95% CIs). Internal consistency is considered good if Cronbach's alpha approximates 0.70 but does not exceed 0.90, which implies the presence of redundant items. Test-retest reliability was measured with the ICC, which is more rigorous for this purpose than Pearson's correlation coefficient because it considers the strength of the correlation together with systematic variations.¹⁶

Construct validity. The correlation between the UW-QOL first application, Karnofsky scale, and GHQ-12 was assessed through Pearson's correlation coefficient *r*.

Results

The translation process of the UW-QOL to Spanish was successful, with only minor manageable difficulties. The terms "narcotics" and "non-narcotic medication" (in the question regarding pain) are used almost exclusively by health care professionals in Chile and in many Spanish-speaking countries. We decided to add explanations of these concepts in the questionnaire: "morphine and derivatives" and "anti-inflammatory drugs and acetaminophen," respectively. The final Spanish version is shown in the Appendix (available online at www.otojournal.org).

A total of 76 patients with previously treated head and neck cancer were enrolled in the psychometric validation process. All patients lived in Santiago de Chile and had received oncological therapy (radiation, chemotherapy, surgery, or combined therapy) in one of the public or private health institutions in the city. The study popula-

tion was composed of mainly male patients (77.6%), with ages ranging from 28 to 87 years (median, 64.4 years, SD 12.7 years). The time spent in formal education ranged from nine to 12 years in 54 percent of the subjects. The most common primary tumor site was the glottic larynx (56%), and T1 (35.1%) was the most frequent tumor stage. Most (47.2%) patients were treated with surgery and radiotherapy, 27.8% had surgery alone, 11.1% had radiotherapy alone, 4.2% had chemoradiation, and 9.7% had a combination of surgery, radiation, and chemotherapy (Tables 1 and 2).

The mean composite score obtained at the first administration of the UW-QOL was 79.4 (SD 16.1), and the most affected domains were speech (*n* = 37), swallowing (*n* = 30), activity (*n* = 17), and saliva (*n* = 15). Neither the composite score nor the symptom scores demonstrated a significant variation between the two administrations of the UW-QOL (Fig 1). The Karnofsky scale had a mean score of 87.8 (SD 10.4) for the whole study group, whereas the mean GHQ-12 score was 2.6 (SD 3.2).

The mean time required to complete the form was 9.5 minutes (SD 4.6 minutes), with marked variations depending on the educational level of the patients (Table 3). Although 63 percent of patients answered the questionnaire by themselves, 25 percent needed some help, and 12 percent of patients required assistance during the completion of the entire survey. There was a clear correlation between the educational level of the patients and their ability to answer the UW-QOL (Fig 2). Most subjects (59.1%) who needed assis-

Table 2
Oncological characteristics of the study population

Tumor site	
Oral cavity	21.1
Oropharynx	6.1
Hypopharynx	1.5
Glottic larynx	56.1
Supraglottic larynx	6.1
Nasal/sinusal	4.6
Others	4.6
Clinical stage	
T stage	
T1	35.1
T2	18.9
T3	18.9
T4	27
N stage	
N0	72.2
N1	8.3
N2	19.5
N3	0
Treatment modality	
Surgery and radiotherapy	47.2
Surgery alone	27.8
Radiation therapy alone	11.1
Chemoradiation	4.2
Surgery and radiation and chemotherapy	9.7

Values are expressed as percentages.

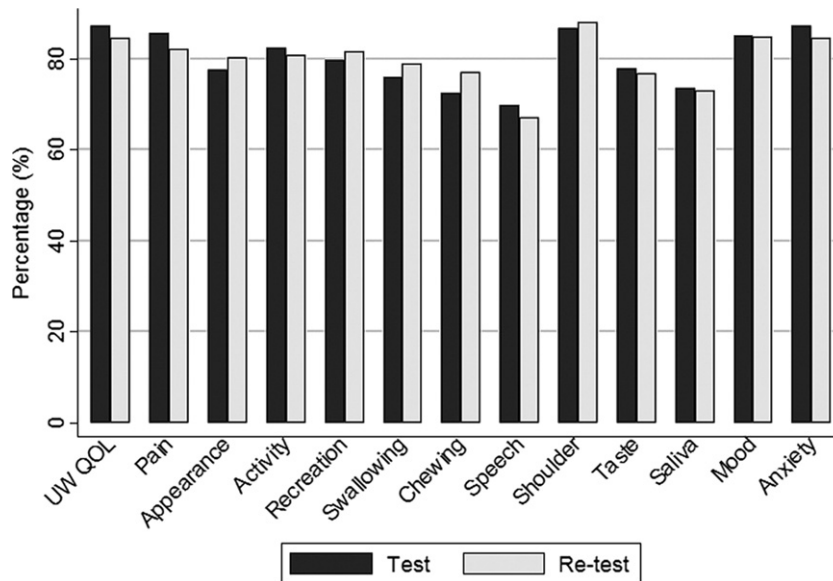


Figure 1 Graphic representation of the average UW-QOL composite scores and single UW-QOL symptom scores obtained for both administrations of the instrument.

tance had attended eight or fewer years of school, whereas the percentage of patients with low-level education was much smaller (8%) among patients who were able to read and answer the questionnaire by themselves; this difference was statistically significant (χ^2 test with a $P < 0.001$).

Reliability analysis showed a high internal consistency in the UW-QOL for the 12 domains of the scale (Cronbach’s alpha 0.84). The retest was applied to 76 percent of the study population after two weeks, and a slightly greater score was recorded than in the first application (mean 80.4, SD 15.5). The ICC coefficient obtained between the two applications of the questionnaire was excellent (ICC 0.95, 95% CI 0.91–0.97, $P < 0.001$) (Fig 3). Concurrent validity in relation to the Karnofsky scale was excellent as well (Pearson’s correlation coefficient of 0.443, $P < 0.001$), and also with the GHQ-12 (Pearson’s correlation coefficient was -0.602 , $P < 0.001$). We also assessed the relationship between the UW-QOL mental health domains and the GHQ-12: whereas mood (question 11) correlated very well with the mental health survey (Pearson’s coefficient of -0.45 , $P < 0.001$), anxiety (question 12) showed a nonsignificant correlation with GHQ-12 (Pearson’s coefficient of -0.34 , $P = 0.07$).

Table 3
Time required to answer University of Washington Quality of Life questionnaire in relation to educational level

School, yrs	Mean time, min	SD
8 or less	13.5	6.9
9-12	11.5	5.0
More than 12	8.1	3.8

Discussion

QOL evaluation has increasingly become an important supplement for interpreting outcome information in head and neck cancer treatment during the past two decades.^{4,6,17} This relevance is stressed by the severe impact of such tumors and their treatment on multiple spheres of daily functioning, social interaction, and life enjoyment.^{18,19}

As it refers to the subjective perception of their well-being, QOL has to be measured by the application of specific questionnaires to the affected patients. Most instruments have been developed in English-speaking countries, initially limiting their use worldwide.^{6,20,21} To be used in other countries and cultures, these surveys require rigorous translation and revalidation.¹¹ The UW-QOL questionnaire

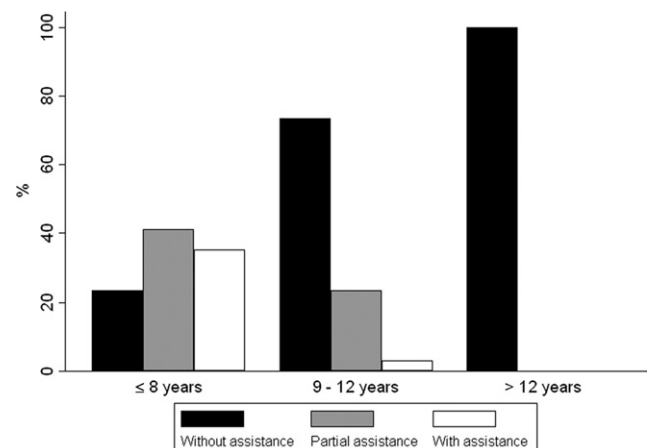


Figure 2 Comparison of the need for assistance when answering the UW-QOL and the educational level of patients (expressed in number of school years).

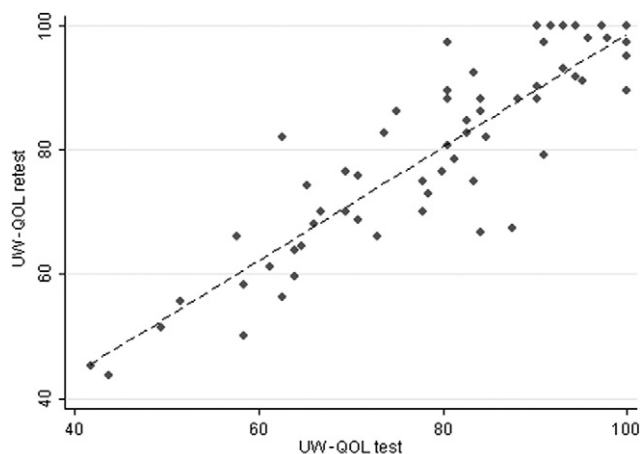


Figure 3 Test-retest data of UW-QOL (ICC = 0.95).

is a well-validated, concise, and practical scale⁶ that has already been validated in Brazilian-Portuguese,²² Chinese, Swahili, and Hindi.²³ In the present study, a validated Spanish version of the instrument was obtained by following accepted international guidelines, and it showed excellent reliability and construct validity.

Because it is the official language of Spain and most Latin American countries, with the exception of Brazil and French-speaking Caribbean territories, Spanish is spoken by approximately 500 million people around the world. Furthermore, Spanish also is spoken in many other countries in Europe, North America, Africa, and Asia. In the United States, there are more than 48 million Hispanics (15% of the total population of the country). It is expected that by year 2030, the Hispanic population in the United States will increase to 66 million (23% of the estimated total population).²⁴ Therefore, it became of utmost importance to obtain a validated Spanish version of the UW-QOL. We have successfully translated and adapted this scale for the Chilean population. This instrument should become the basis for validations of Spanish versions of the UW-QOL in Spain and in different Latin American countries, as there may be significant local variations in the use of the language.

To determine construct validity, we evaluated the correlation among the UW-QOL, Karnofsky scale, and GHQ-12. The Karnofsky scale is one of the most widespread instruments used to evaluate functional impairment in oncologic patients, and, although not designed as an AOL survey, it has been used together with QOL questionnaires in many studies.²⁵⁻²⁷ In the original work describing the UW-QOL,⁶ the questionnaire was compared to the Karnofsky scale to assess construct validity: the correlation was very good. GHQ-12 also has been used in QOL research, specifically in head and neck oncology.²⁸ In the Brazilian-Portuguese validation of the UW-QOL, Vartanian²² compared this questionnaire to a mental health survey (the Hospital Anxiety and Depression Scale [HADS]) to support construct validity. We preferred GHQ-12 because it has been previously validated in our country, and because it is widely used in public health research.

We found a statistically significant correlation between the Karnofsky score and the translated UW-QOL scale (Pearson's correlation coefficient: 0.443), providing further evidence of validity. However, its relatively low value confirms that these two measures reflect differing constructs, and that a comprehensive evaluation of QOL in patients with head and neck cancer should include both general and disease-specific measures.

Mental health domains (mood and anxiety) were added to the UW-QOL in 2002.⁸ We evaluated the effectiveness of this psychological assessment by comparing the UW-QOL overall score and the specific scores of these domains to a mental health survey, the GHQ-12. There was a very good correlation between the GHQ-12 and both the UW-QOL composite score and the mood item. However, there was a nonsignificant correlation between the anxiety domain and the GHQ-12.

We assessed the time required by the patients to complete the Spanish version of the UW-QOL in an attempt to demonstrate its ease of use. Our results, with a mean answering time of less than 10 minutes, reaffirm that the UW-QOL is among the most practical and cost-effective surveys available for the evaluation of QOL in head and neck cancer patients. Although the rate of illiteracy in Chile is 4.3 percent according to the last census (year 2002),²⁹ it is remarkable that more than one third of the study patients required at least some help in the completion of the questionnaire. We demonstrated that a lack of formal education strongly correlated with poorer understanding of the instrument, and therefore patients needed help to answer it. This may be of paramount importance in Latin American countries (including Chile), where the average educational level, at least in the low-income groups, may be considerably lower than in the U.S. and European countries. Thus, the need for assistance from a health care professional (nurse or speech and language pathologist) should be considered during the completion of the survey.

It should be emphasized that the objective of this work was to translate and then validate the UW-QOL for a Chilean Spanish culture. Performing cross-cultural comparisons with populations previously evaluated with the original UW-QOL was beyond the scope of this study. This type of comparison would have required additional data and analyses, as well as a larger number of patients to make statistical comparisons possible. This work, through the Spanish validation of the UW-QOL, will enable head and neck oncology groups throughout Spain and Latin America to assess QOL in their patients and compare their results with those obtained with the English version of the instrument.

In conclusion, the Spanish version of the UW-QOL questionnaire appears to be culturally appropriate and psychometrically valid. This version is a valuable tool to accurately evaluate the QOL of Chilean patients with head and neck cancer.

Acknowledgments

We thank Mrs. Inés Stagno, RN, and speech and language pathologists Mrs. Yolanda Aybar and Mr. César Casanova for their help in collecting patient data; Mrs. María Gatica for her contribution to the development of the database; and Mr. Faustino Alonso for designing the graphic representation of the data. We also thank Luis Cabezas, MD, Carlos Celedón, MD, Luis Marín, MD, and Gustavo Vial, MD, for their advice and assistance with the development of the study in their own health care institutions.

Author Information

From the Department of Otolaryngology, Clínica Las Condes (Dr. Nazar), Santiago, Chile; School of Public Health, Universidad de Chile (Dr. Garmendia), Santiago, Chile; Department of Otolaryngology, Hospital Clínico Universidad de Chile (Dr. Royer), Santiago, Chile; Veterans Affairs Puget Sound Healthcare System (Ms. McDowell), Seattle, WA; Department of Otolaryngology–Head and Neck Surgery, University of Washington (Dr. Weymuller), Seattle, WA; and Department of Otolaryngology–Head and Neck Surgery, University of Minnesota (Dr. Yueh), Minneapolis, MN.

Corresponding author: Gonzalo Nazar, Department of Otolaryngology, Clínica Las Condes, Lo Fontecilla 441, Las Condes, Santiago, Chile.

Email address: gnazar@clc.cl.

This article was presented at the LXV Chilean Meeting of Otolaryngology, Pucón, December 3–6, 2008.

Author Contributions

Gonzalo Nazar, study conception and design; leading role and coordinator with the coauthors (both Chilean and American); performed the Spanish translation of the UW-QOL; performed data acquisition, analysis, and interpretation; drafted most of the article; final approval of the version to be published; **María Luisa Garmendia**, study design, performed statistical analysis and interpretation of the data, drafted part of the article and critically revised the rest of it, final approval of the version to be published; **Michel Royer**, study design; performed data acquisition, analysis, and interpretation; revised the draft article; final approval of the version to be published; **Jennifer A. McDowell**, study design, revised the draft article, final approval of the version to be published; **Ernest A. Weymuller, Jr.**, original author of the UW-QOL, study conception and design, revised the draft article, final approval of the version to be published; **Bevan Yueh**, study conception and design, reviewed the retranslated version of the UW-QOL (English to Spanish and then back), performed data analysis and interpretation, revised of the draft article, final approval of the version to be published.

Disclosures

Competing interests: None.

Sponsorships: This study was financially supported by the Chilean Society of Otolaryngology, Head and Neck Surgery. The funding organization had no influence in study design, data analysis, or manuscript writing. The Chilean Society of Otolaryngology only demands that the paper resulting from the funded research must be published in a medical journal.

References

- Deleyiannis FW, Weymuller EA Jr, Coltrera MD, et al. Quality of life after laryngectomy: are functional disabilities important? *Head Neck* 1999;21:319–24.
- Allal AS, Nicoucar K, Mach N, et al. Quality of life in patients with oropharynx carcinomas: assessment after accelerated radiotherapy with or without chemotherapy versus radical surgery and postoperative radiotherapy. *Head Neck* 2003;25:833–4.
- Hanna E, Sherman A, Cash D, et al. Quality of life for patients following total laryngectomy vs chemoradiation for laryngeal preservation. *Arch Otolaryngol Head Neck Surg* 2004;130:875–9.
- Vartanian JG, Carvalho AL, Yueh B, et al. Long-term quality of life evaluation after head and neck cancer treatment in a developing country. *Arch Otolaryngol Head Neck Surg* 2004;130:1209–13.
- Bjordal K, Ahler-Elmqvist M, Hammerlid E, et al. A prospective study of quality of life in head and neck cancer patients. Part II: longitudinal data. *Laryngoscope* 2001;111:1440–52.
- Hassan SJ, Weymuller EA Jr. Assessment of quality of life in head and neck cancer patients. *Head Neck* 1993;15:485–96.
- Weymuller EA, Alsarraf R, Yueh B, et al. Analysis of the performance characteristics of the University of Washington quality of life instrument and its modification (UW-QOL-R). *Arch Otolaryngol Head Neck Surg* 2001;127:489–93.
- Rogers SN, Gwanne S, Lowe D, et al. The addition of mood and anxiety domains to the University of Washington Quality of Life scale. *Head Neck* 2002;24:521–9.
- Rogers SN, Lowe D, Brown JS, et al. A comparison between the University of Washington head and neck disease-specific measure and the medical short form 36, EORTC QOQ-C33 and EORTC head and neck 35. *Oral Oncol* 1998;34:361–72.
- Rogers SN, O'Donnell JP, Williams-Hewitt S, et al. Health-related quality of life measured by the UW-QOL—reference values from a general dental practice. *Oral Oncol* 2006;42:281–7.
- Guillemin F, Bombardier C, Beaton D. Cross-cultural adaptation of health-related quality of life measures: literature review and proposed guidelines. *J Clin Epidemiol* 1993;46:1417–32.
- Rogers SN, Scott B, Lowe D. An evaluation of the shoulder domain of the University of Washington quality of life scale. *Br J Oral Maxillofac Surg* 2007;45:5–10.
- Thomas L, Jones TM, Tandon S, et al. An evaluation of the University of Washington quality of life swallowing domain following oropharyngeal cancer. *Eur Arch Otorhinolaryngol* 2008;265:S29–S37.
- Thomas L, Jones TM, Tandon S, et al. Speech and voice outcomes in oropharyngeal cancer and evaluation of the University of Washington quality of life speech domain. *Clin Otolaryngol* 2009;34:34–42.
- Millsopp L, Humphris G, Lowe D, et al. Patient's response using freetext in the University of Washington quality of life scale. *Head Neck* 2003;25:1042–50.
- Deyo RA, Diehr P, Patrick DL. Reproducibility and responsiveness of health status measures. Statistics and strategies for evaluation. *Control Clin Trials* 1991;12(suppl):142S–58S.
- Murphy BA. Advances in quality of life and symptom management for head and neck cancer patients. *Curr Opin Oncol* 2009;21:242–7.
- Taylor JC, Terrell JE, Ronis DL, et al. Disability in patients with head and neck cancer. *Arch Otolaryngol Head Neck Surg* 2004;130:764–9.
- Vartanian JG, Carvalho AL, Toyota J, et al. Socioeconomic effects and risk factors for disability in long-term survivors of head and neck cancer. *Arch Otolaryngol Head Neck Surg* 2006;132:32–5.
- List MA, D'Antonio LL, Cella DF, et al. The Performance Status Scale for head and neck cancer patients and the Functional Assessment of Cancer Therapy-Head and Neck Scale: a study of utility and validity. *Cancer* 1996;77:2294–301.
- Bjordal K, Hammerlid E, Ahlner-Elmqvist M, et al. Quality of life in head and neck cancer patients: validation of the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-H&N35. *J Clin Oncol* 1999;17:1008–19.
- Vartanian JG, Carvalho AL, Yueh B, et al. Brazilian-Portuguese validation of the University of Washington Quality of Life Questionnaire for patients with head and neck cancer. *Head Neck* 2006;28:1115–21.
- D'cruz AK, Yueh B, Das AK, et al. Validation of the University of Washington quality of life questionnaires for head and neck cancer patients in India. *Indian J Cancer* 2007;44:147–54.

24. U.S. Census Bureau. 2008 National Population Projections (August 2008). Available at: <http://www.census.gov/population/projections/nation/summary/np-t4-f.pdf>. Accessed January 17, 2010.
25. Alicikus ZA, Akman F, Ataman OU, et al. Importance of patient, tumour and treatment related factors on quality of life in head and neck cancer patients after definitive treatment. *Eur Arch Otorhinolaryngol* 2009;266:1461–8.
26. Gourin CG, McAfee WJ, Neyman KM, et al. Effect of comorbidity on quality of life and treatment selection in patients with squamous cell carcinoma of the head and neck. *Laryngoscope* 2005;115:1371–5.
27. Schaafsma J, Osoba D. The Karnofsky Performance Status Scale re-examined: a cross-validation with the EORTC-C30. *Qual Life Res* 1994;3:413–24.
28. Watkinson JC, Owen C, Thompson S, et al. Conservation surgery in the management of T1 and T2 oropharyngeal squamous cell carcinoma: the Birmingham UK experience. *Clin Otolaryngol Allied Sci* 2002;27:541–8.
29. Ministry of Education, Chile. Statistics on illiteracy from the 2002 census (June 2005). Available at: <http://www.mineduc.cl/usuarios/adultos/doc/200507151621370.Analfabetismo%20en%20Chile.doc>. Accessed January 17, 2010.

Appendix: Spanish Version of the UW-QOL Questionnaire

Cuestionario de la Universidad de Washington sobre Calidad de Vida (UW-QOL)

Este cuestionario contiene preguntas acerca de su salud y calidad de vida **en los últimos siete días**. Por favor conteste todas las preguntas marcando una alternativa para cada pregunta.

1. **Dolor.** (Marque un recuadro:)
 - No tengo dolor.
 - Tengo un dolor leve que no requiere medicamentos.
 - Tengo un dolor moderado - requiero medicamentos regularmente: codeína o analgésicos no-narcóticos (antiinflamatorios o paracetamol).
 - Tengo un dolor severo que sólo se controla con analgésicos narcóticos (morfina o derivados).
 - Tengo un dolor severo que no se controla con medicamentos.
2. **Apariencia.** (Marque un recuadro:)
 - No hay ningún cambio en mi apariencia.
 - Hay un leve cambio en mi apariencia.
 - Mi apariencia me molesta, pero mantengo mis actividades habituales.
 - Me siento desfigurado(a) y limito mis actividades debido a mi apariencia.
 - No puedo estar con otras personas debido a mi apariencia.
3. **Actividad.** (Marque un recuadro:)
 - Estoy tan activo(a) como siempre.
 - Hay ocasiones en las que no puedo mantener mi antiguo ritmo, pero no es lo habitual.
 - A menudo estoy cansado(a) y he disminuido mis actividades, pero aún salgo de casa.
 - No salgo de casa porque no me siento capaz.
 - Habitualmente estoy en cama o en una silla y no salgo de casa.
4. **Recreación.** (Marque un recuadro:)
 - No tengo limitaciones para divertirme en casa o fuera de casa.
 - Hay algunas cosas que no puedo hacer, pero aún salgo y disfruto de la vida.
 - Muchas veces quisiera salir más, pero no me siento capaz.
 - Hay grandes limitaciones a lo que puedo hacer, generalmente me quedo en casa y veo televisión.
 - No puedo hacer nada que me entretenga.
5. **Deglución (tragar).** (Marque un recuadro:)
 - Puedo tragar igual que siempre.
 - No puedo tragar algunas comidas sólidas.
 - Sólo puedo tragar comidas líquidas.
- No puedo tragar porque la comida “se va por el camino equivocado” y me atraganto.
6. **Masticación.** (Marque un recuadro:)
 - Puedo masticar igual que siempre.
 - Puedo comer alimentos blandos, pero hay algunas comidas que no puedo masticar.
 - No puedo masticar ni siquiera alimentos blandos.
7. **Habla.** (Marque un recuadro:)
 - Hablo igual que siempre.
 - Tengo dificultades para decir algunas palabras, pero me entienden cuando hablo por teléfono.
 - Sólo mi familia y amigos me entienden cuando hablo.
 - Nadie me entiende cuando hablo.
8. **Hombro.** (Marque un recuadro:)
 - No tengo problemas con mi hombro.
 - Mi hombro está rígido, pero no ha afectado mi actividad ni mi fuerza.
 - Me he cambiado de trabajo debido al dolor o debilidad en mi hombro.
 - No puedo trabajar debido a los problemas en mi hombro.
9. **Gusto.** (Marque un recuadro:)
 - Siento el sabor de la comida igual que siempre.
 - Puedo sentir el sabor de la mayoría de las comidas.
 - Puedo sentir el sabor de algunas comidas.
 - No siento el sabor de ninguna comida.
10. **Saliva.** (Marque un recuadro:)
 - Mi saliva es de consistencia normal.
 - Tengo menos saliva de lo normal, pero es suficiente.
 - Tengo muy poca saliva.
 - No tengo saliva.
11. **Ánimo.** (Marque un recuadro:)
 - Mi ánimo es excelente y no ha sido afectado por mi cáncer.
 - Mi ánimo es generalmente bueno y sólo a veces es afectado por mi cáncer.
 - No estoy ni de buen ánimo ni deprimido debido a mi cáncer.
 - Estoy algo deprimido(a) debido a mi cáncer.
 - Estoy muy deprimido(a) debido a mi cáncer.
12. **Ansiedad.** (Marque un recuadro:)
 - No estoy ansioso(a) debido a mi cáncer.
 - Estoy un poco ansioso(a) debido a mi cáncer.
 - Estoy ansioso(a) debido a mi cáncer.
 - Estoy muy ansioso(a) debido a mi cáncer.

¿Cuáles aspectos han sido los más importantes para usted durante los últimos 7 días?

Marque hasta 3 recuadros.

- | | | |
|-------------------------------------|---|---------------------------------|
| <input type="checkbox"/> Dolor | <input type="checkbox"/> Deglución (tragar) | <input type="checkbox"/> Gusto |
| <input type="checkbox"/> Apariencia | <input type="checkbox"/> Masticación | <input type="checkbox"/> Saliva |

- | | | | |
|-------------------------------------|---------------------------------|-----------------------------------|-----------------------------------|
| <input type="checkbox"/> Actividad | <input type="checkbox"/> Habla | <input type="checkbox"/> Ánimo | <input type="checkbox"/> Regular |
| <input type="checkbox"/> Recreación | <input type="checkbox"/> Hombro | <input type="checkbox"/> Ansiedad | <input type="checkbox"/> Mala |
| | | | <input type="checkbox"/> Muy mala |
-

Preguntas Generales

En comparación con el mes previo a que usted desarrollara su cáncer, ¿cómo calificaría su calidad de vida actual en relación a su salud? (marque un recuadro:)

- Mucho mejor
- Algo mejor
- Igual o casi igual
- Algo peor
- Mucho peor

En general, usted diría que su **calidad de vida en relación a su salud** durante los últimos 7 días ha sido: (marque un recuadro:)

- Excelente
- Muy buena
- Buena

La calidad de vida global incluye no sólo la salud física y mental, sino que muchos otros aspectos, como la familia, los amigos, la espiritualidad y las actividades recreativas que son importantes para que usted disfrute la vida. Considerando todos los aspectos de su vida que contribuyen a su bienestar personal, califique su **calidad de vida global** durante los últimos 7 días. (marque un recuadro:)

- Excelente
- Muy buena
- Buena
- Regular
- Mala
- Muy mala

Por favor, describa cualquier otro aspecto (médico o no-médico) que sea importante para su calidad de vida y que no haya sido abordado adecuadamente por nuestras preguntas (puede adjuntar hojas adicionales si las necesita).