

Discriminant validity of the University of Washington quality of life questionnaire in the Brazilian context

Validade discriminante do questionário de qualidade de vida da Universidade de Washington no contexto brasileiro

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Abstract

Objective: To assess discriminant validity of the University of Washington quality of life questionnaire for patients with head and neck cancer, and to identify socio-demographic factors that may modify its results. **Methods:** We interviewed 47 patients with oral and oropharyngeal cancer in pre-surgical stage in a hospital located in the South region of the city of São Paulo, in 2007, and 141 patients without cancer, matched by sex and age in a ratio of three to one, who were attending outpatient clinics of the same hospital in 2008. The results for the two groups were compared by the Student t test. Poisson regression models to evaluate factors that may modify quality of life scores among patients without cancer. **Results:** The overall quality of life score was significantly higher ($p < 0.001$) for patients without cancer (91.1) than for patients with cancer (80.6). Similar observations were made for eight of the twelve quality of life domains included in the questionnaire (pain, appearance, swallowing, chewing, speech, shoulder, taste, and anxiety). As factors that may modify the quality of life scores, we identified family income (which impacted in recreation, $p = 0.017$, and shoulder function, $p = 0.049$), schooling (in anxiety, $p = 0.003$), sex (in shoulder function, $p = 0.038$) and toothache (in chewing, $p = 0.015$). **Conclusions:** The questionnaire has discriminant validity, because its scores are specifically more reduced among cancer patients. The use of the questionnaire for monitoring the treatment of cancer patients is reinforced, and the assessment of factors that may impact in its results is recommended.

Keywords: Quality of life. UW-QOL. Validity. Head and neck neoplasms. Mouth neoplasms. Pharyngeal neoplasms. Laryngeal neoplasms.

Resumo

Objetivo: Avaliar a validade discriminante do questionário de qualidade de vida da Universidade de Washington para pacientes com câncer de cabeça e pescoço e identificar possíveis fatores sociodemográficos que modifiquem seus resultados. **Métodos:** Foram entrevistados 47 pacientes com câncer de boca e orofaringe em estágio pré-cirúrgico em um hospital no sul do município de São Paulo em 2007, e 141 pacientes sem câncer, pareados por sexo e idade em uma proporção de três para um, que foram atendidos em ambulatórios do mesmo hospital em 2008. Os resultados obtidos para os dois grupos foram comparados pelo teste t de Student. Para os pacientes sem câncer utilizou-se análise de regressão de Poisson para avaliar possíveis fatores de modificação da qualidade de vida. **Resultados:** O escore geral de qualidade de vida foi significativamente mais elevado ($p < 0,001$) para os pacientes sem câncer (91,1) do que para os pacientes com câncer (80,6). Observações análogas foram efetuadas para oito dos doze domínios de qualidade de vida compreendidos no questionário (dor, aparência, deglutição, mastigação, fala, ombros, paladar e ansiedade). Como possíveis fatores de modificação dos escores de qualidade de vida foram identificados renda familiar (com impacto nos domínios de recreação, $p = 0,017$, e função dos ombros, $p = 0,049$), escolaridade (em ansiedade, $p = 0,003$), sexo (em função dos ombros, $p = 0,038$) e dor de dente (em mastigação, $p = 0,015$). **Conclusões:** O questionário tem validade discriminante, pois seus escores são especificamente mais afetados para pacientes com câncer. Reforça-se a indicação do questionário para monitorar o tratamento e recomenda-se avaliar os fatores que podem causar impacto nesses indicadores.

Palavras-Chave: Qualidade de vida. UW-QOL. Validade. Neoplasias de cabeça e pescoço. Neoplasias bucais. Neoplasias faríngeas. Neoplasias laríngeas.

Introduction

“Quality of life” is an increasingly employed concept in the assessment of health status of individuals and population groups, and of the impact of therapeutic applications associated with different diseases¹. Information on the quality of life can be obtained in a systematic way by semi structured interviews and qualitative assessments, but questionnaires have been consolidated as the most used resource, as they are easier operationally in relation to costs and analysis of results^{2,3}.

There are two questionnaires of quality of life specifically directed toward patients with head and neck cancer, that have already been translated into and validated for Portuguese: the EORTC QLQ H&N C-35 (totaling 65 questions), developed by the European Organization for Research and Treatment of Cancer (www.eortc.be); and the UW-QOL (12 questions), developed by the University of Washington. For studies held in Brazil, the UW-QOL may be an advantage from the operational point of view, because it has fewer questions, and because its translation and validation considered the Portuguese spoken in Brazil, while the EORTC QLQ H&N C-35 was translated and validated for use in Portugal.

The UW-QOL was originally proposed in 1993, aimed at recording the quality of life of patients with head and neck cancer in different stages of disease and of treatment. Following, the questionnaire was improved, with changes in how items were addressed and with the introduction of new questions⁴. Two literature revisions appointed this instrument as one of the most used internationally to monitor the treatment of patients with mouth, pharyngeal and laryngeal cancer^{3,5}.

Studies to validate the UW-QOL questionnaire consider that the instrument has internal consistency (assessed by the alpha Cronbach coefficient)⁴ and that there is a high correlation between answers for the different domains of quality of life and the measures obtained by applying other

questionnaires previously validated⁶. The original version of the UW-QOL, developed in the United States was used in patients with head and neck cancer in Britain⁶ and in India⁷; both studies considered the instrument as appropriate for international comparisons. The Spanish version⁸ was considered valid for use in Argentina, after being tested in a group of patients with head and neck cancer. The questionnaire was translated into Chinese⁹ and, after using it in patients with laryngeal cancer, it was considered valid for use in that country.

Its most recent version (fourth edition) was also translated into Portuguese and validated for use in Brazil¹⁰, in a study that included the following stages of validation: translation, cultural adaptation, test/retest and external validity (comparison of results with those of other questionnaires already considered validated). However, no discriminant validity studies of this questionnaire were done in the country. The concept of discriminant validity is an important part of the validation process of the questionnaire construct and refers to the ability of the measurement proposed not being changed by processes that in theory are not related to the object of the questionnaire¹¹.

The impact on quality of life is expected, as it is measured by the questionnaire, to be specifically attributable to the disease. Discriminant validity studies¹² aim to assess if measurement instruments measure their objects in a specific fashion, or if they can reflect the loss of quality of life related to physiological processes, like aging, or other conditions different from head and neck cancer. Discriminant validity studies could also provide reference parameters (related to individuals without head and neck cancer), for comparison to quality of life scores of people affected by the disease.

The objective of this study was to assess the discriminant validity of the UW-QOL through its application to people without cancer and the comparison of its results with information obtained for patients affected by disease. The present study also aimed to assess the effect of possible factors

of change in quality of life on reference values obtained for patients without cancer.

Methods

Participants

The present study complied with domestic and international guidelines for health research in humans. All participants signed the consent form after explanations on the objective of the study and their freedom to withdraw consent, including data collecting. The research Project was approved by the Ethics in Research Committee of the São Paulo University School of Dentistry (N. 03/07).

Two groups of patients from the same hospital in the South region of the city of São Paulo were set up.

The first group had 47 patients from the Department of Head and Neck Surgery, which were the total number of patients with a histological diagnosis of epidermoid carcinoma of the mouth or oropharyngeal carcinoma, and who were submitted to primary surgery for tumor resection in 2007. Two patients with mouth cancer died in the post-operative period and were not included among our cases. Nine patients had already been diagnosed with large tumors (size T3 or T4), nine already had regional metastases and eight had both conditions. Still, all patients were diagnosed a few days before and the questionnaire was used in the pre surgical phase, right after their admission for tumor resection. This information is relevant, because patients at different stages of disease and treatment have different quality of life status. More detailed information on the development of quality of life of this cohort has been reported elsewhere^{13,14}.

The second group had 141 patients without cancer, seen during 2008 at the internal medicine and dermatology outpatient clinics of the same hospital. The selection obeyed individual pairing by gender and age (plus or minus five years) in relation to patients with mouth and oropharyngeal

cancer, at a three to one ratio. A previous or current diagnosis of cancer and seeking health care for oral cavity disease were considered exclusion factors for participating in this group. Patients were selected using a convenience sample, using an operationally easy criterion for selecting pairs. Patients filled out the questionnaire at the external care units of the hospital immediately after their medical appointment.

Data collecting

All patients filled out the UW-QOL questionnaire (4th edition), in the Portuguese validated version for use in Brazil¹⁰. The questionnaire has twelve multiple choice questions comprising the following quality of life domains: pain, appearance, activity, leisure, swallowing, chewing, speech, shoulders, taste, saliva, mood and anxiety. The questionnaire also has additional open and closed questions for patients to express their general quality of life status, taking into account not only functional aspects, but their family, social and spiritual setting. However, as a function of its more comprehensive aspect, the answers to these questions were not been described and analyzed in the present study.

The score for multiple choice questions was previously determined by the developers of the UW-QOL and already come printed in the form. Score alternatives vary between 0 (minimum) and 100 (maximum), obeying the organization of the scale of answers, respectively indicating higher or lower impact. The reference period is the current moment and the questionnaire was developed using the present tense. All questions followed the same score- high scores represent desirable conditions, while lower values refer to a greater harmful impact on quality of life, and there are no questions with a reverse score. The scale thus obtained allows assessing each domain of quality of life using specific scores. It also allows integration of all measurements in a general synthetic score for each patient.

An additional form with questions on

gender, age, family income and schooling was included to collect information on socio-demographic factors that could be associated with changes in quality of life. Family income was classified into "less than four" and "four or more" (using the median without decimal fractions of family income) minimum wages (R\$ 415.00 in 2008, time of data collecting) depending on figures informed. Schooling was informed as number of years of formal schooling, and classified in complete or incomplete elementary (eight or more years of schooling). For comparison, 60 years (median) was considered as the cutoff to classify age bracket. This additional form also had a question on having had toothache, with the assumption that this relatively common problem throughout life, may also impact some quality of life domains included in the questionnaire. The question on toothache referred specifically to the 30 day period preceding data collecting.

Data analysis

Data were compiled separately into two groups, with and without cancer. Scores reached for each quality of life domain and the total score, which was the sum of values for each question, were the dependent variables of the study. The Kolmogorov-Smirnov test was used to assess the assumption of normal distribution of scores obtained. Statistical parametric analysis was used for describing and analyzing scores. General and specific mean scores per domain and their standard deviations and confidence intervals were calculated. The Student t test was used to compare the scores of the two groups¹⁵.

Specifically for the group of patients without cancer, the assessment of the association between each score (general and specific per quality of life domain) and the quality of life modification factors was sought. Toward that end, Poisson regression models were developed, as they are appropriate analytical resources both for studying dichotomous outcomes and for comparing counts or rates^{12,16}. The association measurement resulting from

the Poisson regression analysis is the ratio between the mean scores obtained for both groups of comparison. Values equal to one indicate equal mean scores attributed to both groups; values above or below one indicate, respectively, a higher or lower mean score for the comparison group in relation to the reference group.

Taking into account the small sample, multivariate analysis of quality of life scores was not performed. The association between these data and possible quality of life modification factors was studied only using bivariate analysis. The Stata 11.0 (Stata Corporation, College Station, Texas, USA, 2009) program was used for statistical analysis.

Results

Both groups were paired by gender and age and had an analogous distribution in regard to the following variables: 12.8% were women and 51.1% were 55 years old and over. In the group of patients without cancer, 40.4% had a family income of four or more minimum wages; 11.3% had had toothache in the previous month; and 44.7% had completed elementary school.

The general quality of life score reached a mean of 91.1 in the group of patients without cancer. This value was significantly higher ($p < 0.001$) than the mean of the group of patients with mouth and oropharyngeal cancer in the pre-operative stage: 80.6. The Kolmogorov-Smirnov test showed that the distribution of the total quality of life score and of the twelve question-specific scores in both study groups did not differ significantly ($p > 0.05$) from the normal distribution. This observation indicates that it complied with one criterion for the comparison of the two groups (with and without cancer) using parametric analysis (Table 1).

Table 1 presents mean scores and confidence intervals for each quality of life domain in both patient groups, and their pertaining indicators (p values) in the comparative analysis. Pain, swallowing and taste were the least affected domains (highest

score) in the group of patients without cancer. Anxiety was the lowest score domain (65.1) in this group; however, this score was even lower for the group of patients with cancer (39.0), with a statistically significant difference ($p < 0.001$).

The mean scores for patients without cancer were significantly higher ($p < 0.05$) than those of patients with cancer in eight of the twelve quality of life domains evaluated: pain, appearance, swallowing, chewing, speech, shoulders, taste and anxiety. For the remaining domains (activity, leisure, saliva and mood) no statistically significant difference was observed for the scores obtained for both groups.

In order to study the association among the thirteen quality of life scores (one general and twelve domain-specific) and five possible modification factors in reporting quality of life (gender, age, family income, schooling and toothache) 65 regression models (bivariate analysis) had to be developed. Of the total, 60 indicated absence of a statistically significant association among the factors and scores involved in the analysis, indicating that the factors tested did not change the quality of life scores. For the five remaining models, the bivariate regression analysis indicated a significant association ($p < 0.05$) between the scores and quality of life modification factors (Table 2).

In the group of participants without cancer, individuals with higher family income reported a significantly more favorable condition for the quality of life domains related to leisure and to shoulders. Women had significantly more complaints related to shoulders than men; and those who reported toothache in the previous month reported a significant compromise to chewing. Schooling was associated with anxiety, in that patients with lower schooling (incomplete elementary school) reported significantly higher levels of anxiety.

Discussion

Favorable indicators were presented for the discriminant validity of the UW-QOL

Table 1 - Reference values for the UW-QOL questionnaire: average scores and 95% confidence intervals in 141 patients without cancer and 47 patients with oral and oropharyngeal cancer.

Tabela 1 - Valores de referência do questionário UW-QOL: escores médios e intervalo de confiança (95%) em 141 pacientes sem câncer e 47 pacientes com câncer de boca e orofaringe.

Quality of life domains	Patients without cancer Mean score (95%Conf. Int.)	Patients with oral cancer Mean score (95%Conf. Int.)	p value ⁽¹⁾
pain	98.8 (97.9–99.7)	72.9 (65.2–80.6)	<0.001
Appearance	93.4 (91.1–95.7)	78.7 (70.4–87.0)	<0.001
Activity	89.5 (86.5–92.5)	88.8 (82.2–95.5)	0.830
Leisure	93.1 (90.5–95.7)	88.3 (80.9–95.7)	0.534
Swallowing	98.3 (96.8–99.9)	87.9 (80.6–95.2)	<0.001
Chewing	95.7 (93.4–98.1)	72.3 (62.5–82.1)	<0.001
Speech	96.7 (94.8–98.6)	86.6 (81.1–92.1)	<0.001
Shoulders	87.7 (84.2–91.3)	95.7 (91.5–100.0)	0.020
Taste	97.2 (95.0–99.3)	84.4 (76.7–92.1)	<0.001
Saliva	96.5 (94.5–98.4)	93.6 (88.5–98.7)	0.211
Mood	81.2 (77.7–84.7)	78.7 (70.7–86.7)	0.109
Anxiety	65.1 (60.3–69.9)	39.0 (27.2–50.8)	<0.001
Total score	91.1 (89.9–92.3)	80.6 (77.2–83.9)	<0.001

⁽¹⁾ Teste t de Student / ⁽¹⁾ Student t test

questionnaire, which is the most important result of the present study. Functional changes with a higher or lower degree of limitation in quality of life can be added throughout life, as shown by the 8.9% reduction in the maximum possible total score measured. This value is significantly not as high as the 19.4% reduction registered for patients with pre-operative stage cancer. This value is also not as high as the 44.4% reduction for patients recently submitted

to tumor resection surgery¹³, or than the 31.5% reduction identified in the longitudinal follow-up of one year after surgery for patients with câncer¹⁴. These observations are compatible with the assumption that the questionnaire has discriminant validity, and that greater variations in its scores occur only as a specific manifestation of cancer and of its consequences.

In order to acknowledge the validity of the measurement instrument per

Table 2 - Identification of factors that modify quality of life and comparative analysis of domain-specific quality of life average scores in 141 patients without cancer.

Tabela 2 - Identificação dos fatores de modificação da qualidade de vida e análise comparativa dos escores médios nos domínios da qualidade de vida em 141 pacientes sem câncer.

Domains	Modifying Factors	Categories	N	Mean Score	Scores Ratio	95% Conf. Int.	p Value ⁽¹⁾
Leisure	Family income	4 MW or more	57	96.5	1.06	1.01–1.12	0.017
		Up to 4 MW	84	90.8			
Chewing	Toothache	Yes	16	81.3	0.83	0.73–0.97	0.015
		No	125	97.6			
Shoulders	Gender	Female	18	76.0	0.85	0.73–0.99	0.038
		Male	123	89.5			
	Family income	4 MW or more	57	91.8	1.08	1.00–1.17	0.049
Up to 4 WM		84	85.0				
Anxiety	Schooling years	8 or more	63	86.9	1.13	1.04–1.23	0.003
		0 to 7	78	76.6			

⁽¹⁾ Análise de regressão de Poisson / ⁽¹⁾ Poisson regression analysis.

especificity¹² its scores cannot suffer a substantial reduction in the absence of head and neck cancer. In fact, the present study observed that, in the absence of disease, the difference between the total quality of life score and the maximum possible to be measured was relatively reduced. Moreover, for eight of the twelve specific scores and for the total quality of life score, patients without cancer had significantly higher values than patients with cancer.

Head and neck cancer is known to have a higher incidence in individuals over 45 years¹⁷. However, adults with more advanced age are expected not to keep 100% of their physical, mental and social capabilities, even in the absence of disease. As the quality of life questionnaire aims to specifically assess the reduction of the capabilities that are attributable to the disease, it is important to check if the measurement instrument has discriminant validity, given the reference term related to quality of life in the absence of disease should not refer to younger individuals.

Not all the reduction in quality of life scores measured by the questionnaire is related to the impact of the cancer or of therapy such as surgery, radiation therapy and chemotherapy. However, this study showed that the reduction in the quality of life scores measured by the UW-QOL is low and little relevant to individuals without cancer, when compared with patients with head and neck cancer^{13,14}. Moreover, individuals without cancer had significantly higher indicators than individuals affected by the disease, both for the general score, and for two thirds of the domain-specific quality of life scores.

The specific scores that were significantly higher in patients without cancer indicate the domains most affected by disease (pain, appearance, swallowing, chewing, speech, shoulders, taste and anxiety), which corroborates assessments done previously in the domestic scenario^{18,19}. This observation also suggests that these were the quality of life domains that contributed most to the discriminant validity of the questionnaire.

The present study identified sociodemographic factors that associate to changes in

quality of life even in the absence of disease; this finding is also an important result of the study. Worse scores for some quality of life domains were associated with differentials of gender, schooling, family income and age. Analogous observations were made by studies that used the EORTC-C30 (another specific questionnaire for patients with cancer whose use is quite widespread internationally) for individuals not affected by cancer^{20,21}.

The mean chewing score was significantly not as high for patients without cancer that had had toothache in the thirty day period preceding data collecting. This observation is not surprising, but has to be taken into account when one seeks to focus on functional limitations of the chewing capacity that may have been induced by cancer or by its treatment, and not due to widely prevalent problems such as dental caries. The scores attributed to anxiety were observed to be significantly lower for the group with lower schooling, suggesting that patients with higher schooling have more hope to solve their health problem at medical hospital care services.

The item anxiety had the lower mean of all domains (65.1), which possibly reflects the concern of patients with the health problem that motivated their demand for outpatient care. This observation is indicated as a limitation of the present study, that derives from the option in performing a hospital based study. Although representing operational ease for inclusion of participants, this option involves uncontrolled aspects related to the different reasons for the hospital visit.

The option to perform a hospital based study is acknowledged as the main limitation of the study. However, the option to include only outpatients is believed to have prevented or at least reduced substantially the inclusion of severe patients, thus bringing the reference group closer to the ideal comparison represented by healthy individuals.

Another study performed with the same objective²² tried to overcome this difficulty

using a convenience sample of patients of the dental clinic of a graduate course. This option, however, has even greater limitations, given that all individuals sought care for oral problems, which, as appointed in the present study, also influences scores of at least one of the domains of quality of life.

All patients without cancer were interviewed at the dermatology and internal medicine outpatient clinics, and did not have a past or current history of cancer. Although 11.3% of study participants had reported toothache in the thirty day period before data collecting (a compatible proportion with the prevalence of this condition in the general population²³), seeking health care was not due to toothache.

Quality of life scores measured in the present study cannot be stated as a reference for the population as a whole, because the sample was not probabilistic. However, the present study is able to infer that not all the reduction observed in the quality of life scores of patients with head and neck cancer

should be immediately related to the disease or its treatments. The study also drew attention to the sociodemographic factors that modify some quality of life indicators even in the absence of disease.

Conclusions

The results reported in the present study strengthen the assumption that the questionnaire has discriminant validity. Patients without cancer had quality of life scores a little below the maximum value and significantly higher than patients with cancer. Most of the scores were not modified by sociodemographic factors. Using quality of life questionnaires for patients with head and neck cancer is an important element to assess progression of disease and the effectiveness of treatments, and the conclusion of the present study strengthens the recommendation for its use in our setting.

Conflict of interest: None.

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