

# Quality of Life and Maxillary Defects: A Cross-Sectional Study

Calidad de Vida y Defectos Maxilares: Un Estudio Transversal

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**ABSTRACT:** There has been little discussion about the quality of life of patients with maxillary defects. This article evaluates the issues related to the condition. We performed a cross-sectional study of patients with maxillary defects from referral centers in Brazil. To avoid subject burden, a questionnaire was developed, based on questions from seven instruments, which dealt with domains and conclusions that were similar to those from other studies. The predictor variable was the patients' score for each question. The outcome measure was the presence of the best-ranked items on the questionnaire as the impact factor. Six experts assessed these items and suggested which questions to include or exclude. Patients scored each item according to its occurrence and importance. Descriptive statistics and the items' rank according to the impact factor were computed to determine whether there is a comprehensive instrument available. Thirteen patients and six professionals were included in this study. The patients' age ranged from 24 to 72 years (mean (standard deviation, SD), 50.41 (14.46) years). We obtained a 60-item instrument from the selected questionnaires and subject interviews. Only 12 (37.5 %) out of the 32 best-rated items were verified by the existing instruments, two (6.25 %) were suggested by professionals and 18 (56.25 %) were conclusions from other studies. To the best of our knowledge, this is the first study to provide many features related to the quality of life in patients with maxillary defects.

**KEY WORDS:** maxillofacial prosthesis, quality of life, maxillary diseases, maxillary neoplasms, palatal obturators.

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## INTRODUCTION

Maxillary defects can be caused by more than 40 different etiologies (Grange *et al.*, 1992), including infections, opioid inhalation, cancer resection, trauma, and congenital diseases. This deformity may destroy soft tissue and establish communication between the oral cavity and the maxillary sinus, nasal cavity, nasopharynx, and/or orbital cavity (Rezende, 1997). Some studies show disorders of mastication, phonation, deglutition, and nutrition, which can affect patients' social life and emotional status (Kornblith *et al.*, 1996; Brown *et al.*, 2000; Sloan *et al.*, 2001; Genden *et al.*, 2003; Rieger *et al.*, 2003; Rogers *et al.*, 2003; Goiato *et al.*, 2009; Irish *et al.*, 2009; Depprich *et al.*, 2011; Kumar *et al.*, 2013). Several questionnaires cover these different domains, but choosing the most appropriate questionnaire is challenging because none of them seem to be sufficiently comprehensive. Additionally, they usually have items that are not related to the maxillary defect.

The purpose of this study was to assess the existing instruments to determine if there is an appropriate evaluative questionnaire for this condition. The investigators hypothesized that such an instrument does not yet exist. The specific aim of this study was to verify the presence of relevant issues reported by patients in these instruments.

## MATERIAL AND METHOD

**Study Design and Sample Description.** The investigators designed and implemented a cross-sectional study, and study participants were derived from patients with maxillary defects who were treated at two referral centers in Brazil from November 1, 2012 to October 31, 2013. Eligible patients with acquired

maxillary defects had to be at least 18 years old and understand Brazilian Portuguese. People with cognitive problems and/or having difficulty in following the scoring system and/or with other deformities beyond the maxillary defect were excluded.

A new instrument was developed based on results reported in other articles and items from existing questionnaires. The items were selected by experts and patients (Aday & Cornelius, 2006a). This instrument eliminates the use of multiple questionnaires and reduces patient and researcher burden because some questions were similar among the instruments and the questionnaires had different scoring systems.

Items related to permanent conditions during treatment (i.e. smell perception) were removed from the evaluative instrument. The instrument was obtained based on questionnaire development guidelines and methodologies (Kirshner & Guyatt, 1985; Creswell, 1994; Aday & Cornelius, 2006b; Terwee *et al.*, 2007; Francis *et al.*, 2010).

A literature review was conducted to collect and examine all relevant studies in the area using PubMed, a tool for a structured literature searches. The terms used were: “quality of life” combined with “maxillary defect” and/or “maxillary resection” and/or “oropalatal communication” and/or “oropalatal perforation” and/or “oroantral communication” and/or “oroantral communication”. Only studies in English, Portuguese, or Spanish that assessed changes in the quality of life with clinical and/or interview outcomes were included. Articles dealing with patients with impairments other than acquired maxillary defects, such as eye loss, external communication of the maxillary defect, or larynx damage were excluded. To increase the number of the studies in this phase, articles in the reference list from the studies identified via the PubMed search that fulfilled the inclusion criteria were also included.

Items from the Obturator Functional Scale (OFS) (Kornblith *et al.*), Voice Handicap Index (Fukazawa *et al.*, 1988), Oral Health Impact Profile-49 (Pires *et al.*, 2006), Geriatric Oral Health Assessment Index (GOHAI) (de Souza *et al.*, 2012), European Organization for Research and Treatment of Cancer – H&N35 (EORTC Head and Neck) (Bjordal *et al.*, 1999), EORTC Quality of Life Questionnaire Core-30 (EORTC QLQ – C30) (Aaronson *et al.*, 1993), and Swallow Quality-of-Life Questionnaire (McHorney *et al.*, 2002) were included in the study’s questionnaire. Questions specifically related

to other conditions, such as cancer therapy, were excluded and similar items were grouped together.

The selected items were submitted for further analysis by experts, who suggested including or excluding items. The question was deleted or added when over 70 % of the clinicians agreed with it. Finally, they answered a semi-structured questionnaire to validate the information obtained based on the literature review.

**Data collection.** Patients scored the items from “0” to “10”, according to the importance of the experiences. At the end of the interview, they suggested other questions, reworded items, and pointed out if any question made them feel uncomfortable. The sample size was estimated after ten interviews, using the method of impact. The stopping criteria of three interviews without new information was applied (Francis *et al.*).

The method of impact was conducted to rank the questions according to their impact factor (importance mean  $\times$  frequency of items with relevance that are different from “0”) (Guyatt *et al.*, 1986; Juniper *et al.*, 1997).

**Study Variables.** The predictor variable was the patients’ mean impact factor score for each question. The outcome measure was the presence of all items from an existing questionnaire among the best-ranked items according to the impact factor.

**Data analyses.** Cronbach’s alpha was used to calculate the internal consistency (Streiner, 2003). Descriptive statistics and the rank of the items according to the impact factor were computed to determine whether there was a comprehensive instrument available. All study variables were generated using commercial statistical software SPSS v17 (IBM, Chicago, IL, USA).

**Ethics.** The validation study design was approved by the Ethics Committee at the University of São Paulo, Faculty of Dentistry, São Paulo, Brazil. (Approval No. 179.697). All participants signed an informed consent form.

## RESULTS

There were 109 studies identified in the literature review, and 12 of these studies were included in our research, according to the inclusion criteria. There were

Table I. Questions with a lower impact factor.

Question	Freq	IM	IF
Worsened digestion	0.54	7.43	4.00
Avoid going out because of my condition	0.54	7.29	3.92
Sex life is worse than before	0.46	8.17	3.77
Loneliness	0.46	8.00	3.69
Work performance	0.46	8.00	3.69
Voice sounding creaky and dry	0.54	6.71	3.62
Affected concentration	0.54	6.71	3.62
Irritable with the precautions	0.38	9.20	3.54
Trouble getting along with other people	0.46	7.50	3.46
Tendency to avoid people because of voice	0.54	6.14	3.31
Avoid social contact because of the condition	0.46	7.17	3.31
Family absence	0.38	8.20	3.15
Feeling uncomfortable about the mouth appearance	0.38	8.00	3.08
Distress	0.38	7.80	3.00
Having trouble falling asleep	0.38	7.80	3.00
Feeling tired	0.46	6.00	2.77
Running out of air when talking	0.46	5.83	2.69
Fear of suddenly choking	0.46	5.83	2.69
People asking what happened	0.77	3.40	2.62
Coughing	0.46	5.57	2.57
Having trouble staying asleep	0.38	6.00	2.31
Trouble going out in public	0.38	5.80	2.23
Difficulty finding tasty and edible food	0.38	5.40	2.08
Feeling tense	0.31	6.75	2.08
Voice worsening in the evening	0.38	5.20	2.00
I miss my teeth	0.31	6.50	2.00
Feeling tense	0.23	5.00	1.15
Somewhat irritable with other people because of the ...	0.15	1.50	0.23

Freq, frequency; IM, importance; IF, impact factor  
Abbreviated questions are sorted in descending order of the impact factor.

Table II. Social domain items with higher scores .

Social relationship domain	Freq	IM
Talking to other people	0.92	8.17
Eating in public	0.85	8.82
Speaking on the telephone	0.92	7.67
Difficulty speaking in a quiet situation	0.85	8.18
Difficulty speaking in public	0.85	8.00
People ask to repeat words during a conversation	0.92	7.25
Avoid smiling	0.85	7.45
Food sticking in the mouth	0.69	7.22
Difficulty speaking in a noisy situation	0.85	5.82

Freq, frequency; IM, importance; IF, impact factor  
Abbreviated questions are sorted in descending order of the impact factor.

Table III. Speech and voice domain items with higher scores.

Speech and Voice domain	Freq	IM	IF
Nasal speech	0.92	6.92	6.38
Trouble pronouncing some words	0.85	7.36	6.23
Great effort to speak	0.62	7.63	4.69
Too much effort to speak	0.54	7.71	4.15

Freq, frequency; IM, importance; IF, impact factor  
Abbreviated questions are sorted in descending order of the impact factor

58 items from existing instruments and other research.

Two items were suggested by clinicians. The six interviewed experts verified the questionnaire generated in this study and reported that it was comprehensive. Sample saturation was achieved by 13 patients. The patients ranged in age from 23 to 72 years (mean, 50.41 [standard deviation (SD), 14.46] years).

In this study, the authors established that an impact factor greater than 4.0 determined the best-scored items. Thirty-two (53.33 %) questions achieved this requirement.

The frequency, importance means, and impact factor for each abbreviated question with a lower impact factor are shown in Table I.

The data from the best-ranked items are sorted by domains and shown in Table II (social relationship), Table III (speech and voice), Table IV (feeding), Table V (emotional), and Table VI (non-grouped).

The number of items, questions with high scores from each questionnaire assessed, and the percentage of these questions among the best-ranked items are presented in Table VII.

The Cronbach's alpha coefficient of the preliminary instrument was 0.92. Despite this value indicating excellent internal consistency, our questionnaire has more than 20 items, which increases the coefficient<sup>6</sup>. Thus, internal consistency was not confirmed in this study.

Table IV. Feeding domain items with higher scores.

Feeding domain	Freq	IM	IF
Food coming out of nose	0.85	8.09	6.85
Mastication ability	0.69	8.56	5.92
Unsatisfactory diet	0.69	8.22	5.69
Food restriction	0.69	8.22	5.69
Effort to swallow	0.77	7.30	5.62
Choking	0.77	7.00	5.38
Worsening sense of taste	0.54	9.57	5.15
Food sticking in mouth	0.69	7.22	5.00
Food sticking in throat	0.69	6.89	4.77

Freq, frequency; IM, importance; IF, impact factor. Abbreviated questions are sorted in descending order of the impact factor.

Table V. Emotional domain items with higher scores.

Emotional domain	Freq	IM	IF
Fear of choking when eating food	0.77	7.70	5.92
Upset with condition	0.69	8.33	5.77
Irritability	0.69	7.56	5.23
Feeling that life is less satisfactory	0.54	8.14	4.38
Daily activity performance	0.54	7.86	4.23
Fear of choking when drinking liquids	0.54	7.71	4.15

Freq, frequency; IM, importance; IF, impact factor. Abbreviated questions are sorted in descending order of the impact factor.

Table VI. Other items with higher scores.

Non grouped items	Freq	IM	IF
Financial difficulties	0.92	8.08	7.46
Dissatisfaction with appearance	0.85	8.00	6.77
Upper lip feeling numb	0.69	7.11	4.92
Halitosis	0.54	8.29	4.46
Pain in mouth	0.62	7.13	4.38

Freq, frequency; IM, importance; IF, impact factor. Abbreviated questions are sorted in descending order of the impact factor.

Table VII. Number of items, items with high impact factor (IF) scores from the instrument, and percentage of these items among the 32 best-ranked items according to IF.

Instrument	Number of items	Items with high Impact factor score (%)	Among best items
Geriatric Oral Health Assessment Index	13	7 (53.85)	25 %
Obturator Functional Scale	15	8 (53.33)	28.12 %
Voice Handicap Index	30	9 (30)	12.5 %
Swallow Quality-of-Life Questionnaire	44	4 (9.09)	21.87 %
EORTC QLQ – H&N35*	45	4 (8.89)	3.12 %
Oral Health Impact Profile-49	49	4 (8.16)	12.5 %
EORTC QLQ – C30 †	30	1 (3.3)	12.5 %

\* EORTC QLQ – H&N35, European Organization for Research and Treatment of Cancer – Head and neck; †EORTC QLQ-C30, European Organization for Research and Treatment of Cancer – Quality of Life Questionnaire Core-30.

## DISCUSSION

Health-related quality of life (HRQoL) is increasingly used as an outcome in clinical trials, effectiveness research, and research on the quality of care (Wilson & Cleary, 1995). Although some instruments deal with similar domains, none of them seems to be appropriate to assess the quality of life in patients with a maxillary defect. Thus, the purpose of our study was to assess whether an instrument is available that can measure the quality of life for this condition, using a cross-sectional study based on the literature review and interviews with patients.

During the development of the questionnaire for this study, questions related to “flavor of the food” were not excluded because, in addition to maintaining the ability to taste during treatment, the patient could enjoy eating the food after or during treatment (i.e. removal of the nasogastric tube feeding and use of prosthesis).

The items related to “nasal speech”, “feeling tense”, and “halitosis” were not understandable to all. These questions were reworded at the time of the interview and no problems were reported. The participants answered all the questions, and nobody reported embarrassment caused by any question. Some professionals and patients were impressed by the comprehensiveness of the questions and indicated the importance of the questionnaires during the treatment.

The maxillary defect can remain unnoticed if the patient does not talk nor eat, and thus, according to Kornblith *et al.* (1994), this shift between visible and invisible could cause an emotional impairment that

affects the quality of life. Our study confirms these findings and suggests that items related to social life (i.e. eating in public) tend to show higher scores than similar ones from the functional domain (i.e. masticatory skills). The same authors found an impact on patients' sex life, but our study showed that this item had a score of 3.77, which was slightly lower than the cut-off impact factor of 4.0. This could be explained by non-sexually active patients, who would decrease the frequency rates and the impact factor, because the mean age of our patients ranged from 23 to 72 years (mean, 50.41 [SD, 14.46] years).

Among the 32 (53.33 %) best-rated items on our questionnaire, two (6.25 %) were suggested by professionals, 12 (37.5 %) were collected from the existing questionnaires, and 18 (56.25 %) were conclusions from other studies.

Even though the GOHAI and OFS questionnaires had the best performance among the instruments studied, more than 30 % percent of their items were not among the highest-rated questions.

The most striking result from the data is that there was not a comprehensive evaluative instrument for the condition. This outcome may be because it affects multiple domains and several items are not in the existing questionnaires.

Thus, an evaluative instrument to assess HRQoL in adults with acquired maxillary defects is required. This is the first study, to the best of our knowledge, that provides many features that affects quality of life in patients with a maxillary defect. A limitation of this study is the small number of patients during the scoring step. A future study should, therefore, include a longitudinal study with a larger number of patients and more variables (such as interventions, the extent of loss, etiology, age, sex, and marital status) to develop and validate a specific instrument.

Despite the limitations, these findings support the importance of the development and validation of a questionnaire that is specific to maxillary defects. Such an instrument will help professionals to measure the clinical benefits of health-care interventions and to improve patients' quality of life.

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**NAKAMURA, D. M.; PIMENTEL, M. L.; COTO, N. P. & DIAS, R. B.** Calidad de vida y defectos maxilares: Un estudio transversal. *Int. J. Odontostomat.*, 14(1):67-72, 2020.

**RESUMEN:** Existe escasa discusión en la literatura sobre la calidad de vida de los pacientes con defectos maxilares. Este artículo evalúa los problemas relacionados con esta condición. Realizamos un estudio transversal de pacientes con defectos maxilares de centros de referencia en Brasil. Se desarrolló un cuestionario basado en preguntas de siete instrumentos, que trataba sobre dominios y conclusiones similares a las de otros estudios. La variable de estimación fue la puntuación de los pacientes para cada pregunta. La medida de resultado fue la presencia de los elementos mejor clasificados en el cuestionario como factor de impacto. Seis expertos evaluaron estos ítems y sugirieron qué preguntas incluir o excluir. Los pacientes puntuaron cada ítem según su ocurrencia e importancia. Se calcularon las estadísticas descriptivas y la clasificación de los ítems según el factor de impacto, para determinar si existe un instrumento completo. Trece pacientes y seis profesionales fueron incluidos en este estudio. La edad de los pacientes osciló entre 24 y 72 años [media (desviación estándar), 50,41 (14,46) años]. Obtuvimos un instrumento de 60 ítems de los cuestionarios y entrevistas de temas seleccionados. Solo 12 (37,5 %) de los 32 ítems mejor calificados se verificaron de acuerdo a los instrumentos existentes, dos (6,25 %) fueron sugeridos por profesionales y 18 (56,25 %) fueron conclusiones de otros estudios. De acuerdo a nuestro conocimiento, este es el primer estudio que proporciona características relacionadas con la calidad de vida en pacientes con defectos maxilares.

**PALABRAS CLAVE:** prótesis maxilofacial, calidad de vida, enfermedades maxilares, neoplasias maxilares, obturadores palatales.

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