

Assessment of Quality of Life in Patients with Chronic Oral Mucosal Diseases: A Questionnaire-Based Study

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Abstract

Context: A validated discipline-specific questionnaire has been developed recently to assess the quality of life (QOL) in patients with chronic oral mucosal diseases.

Objective: Use the Chronic Oral Mucosal Diseases Questionnaire for evaluating a diverse group of patients with chronic oral mucosal disease after therapy.

Design: Prospective convenience sample.

Main Outcome Measure: Quality of life.

Methods: Seventy patients seen in the Department of Oral Medicine and Radiology with oral lichen planus, recurrent aphthous ulcers, pemphigus, and other chronic oral mucosal diseases were included in the study. Patients completed the questionnaire after undergoing treatment of their oral mucosal disease to assess their QOL.

Results: Patients older than age 35 years reported significantly lower QOL ($p = 0.015$) in the domain of social and emotional status. Significant age-related differences in QOL were not observed in other domains. Older individuals also reported a significantly lower overall QOL. Men reported significantly better oral health-related QOL than women did in pain and functional limitation: 16.14 ± 8.94 vs 21.44 ± 7.696 , respectively ($p = 0.010$). Significant differences were not observed between sexes for other domains. Significant differences were observed between the disease groups only for recurrent aphthous ulcers and pemphigus ($p = 0.005$). Patients with pemphigus had the worst overall QOL (73.6 ± 5.6).

Conclusion: Even after treatment, chronic oral mucosal diseases negatively affect patients' QOL. Use of the Chronic Oral Mucosal Diseases Questionnaire may allow physicians to more effectively care for their patients with these diseases.

Introduction

Chronic oral mucosal diseases (COMD) are a diverse group of autoimmune, inflammatory, and infectious conditions that can affect the soft tissues of the mouth. These conditions, like other diseases of the mouth, can result in considerable morbidity with physical, social, and psychological consequences for patients.¹ Some of the most commonly encountered COMD in dental practice include recurrent aphthous ulcers, oral lichen planus, and

pemphigus. Both the clinical manifestations and the treatment options available in the management of these can affect quality of life (QOL).² Although most COMD are currently managed symptomatically, not much importance has been given to QOL.

According to the World Health Organization, QOL is defined as an individual's perception of his/her position in life in the context of the culture and value system in which s/he lives and in relation to his/her goals, expectations, standards, and concerns.³ A number of patient-centered oral health status measurement instruments have been developed over the last decade to assess the physical, social, and psychological consequences of oral health and the impact of oral health status on QOL. The QOL measurement instruments can be divided into generic, disease-specific, and discipline-specific questionnaires.⁴ Generic QOL questionnaires cannot detect small but clinically important changes associated with a particular disease, but they allow comparisons to be made across different diseases.⁵ Disease-specific questionnaires accurately predict clinical changes associated with a particular disease but do not allow comparison to be made across diseases.⁶ Discipline-specific questionnaires combine the increased accuracy and sensitivity to disease-specific changes with the ability to compare the QOL of patients with related diseases.⁷

The 2 most commonly used QOL measures in oral medicine are the Oral Health Impact Profile-14 and the 36-Item Short Form Health Survey.^{8,9} They have certain disadvantages, such as poor responsiveness and lack of suitability for certain patients.^{10,11} The Chronic Oral Mucosal Diseases Questionnaire (COMDQ) is a discipline-specific questionnaire developed for the field of oral medicine and radiology.¹² The questionnaire was developed on a patient-centered approach and has demonstrated acceptable validity and reliability to support its use.^{4,13}

QOL questionnaires can provide an important role in therapy, because they can help patients communicate with their physicians in an objective fashion about the subjective conditions associated with their illness. Clinicians may be considered experts at observation of disease activity, and with effective QOL questionnaires, patients can help make decisions about their treatment.⁵

The aim of the study was to measure the QOL after therapy in patients with COMD using the COMDQ. We sought to assess the role of pain and functional limitation, efficacy of the medication

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Chronic Oral Mucosal Diseases Questionnaire**Pain and functional limitation**

1. How much do certain types of food/drink cause you discomfort (spicy food, acidic food)?
2. How much does your oral condition cause you to limit the types of food/drinks you consume?
3. How much do certain food textures cause you discomfort (rough food, crusty food)?
4. How much does your oral condition cause you to limit the textures of the food you consume?
5. How much does the temperatures of certain foods/drinks cause you discomfort?
6. How much does your oral condition cause you to limit the temperature of the foods/drinks you consume?
7. How much does your oral condition lead to discomfort when carrying out your daily oral hygiene routine (brushing, flossing, mouthwash usage)?
8. How much does your oral condition cause you to limit your daily oral hygiene routine (brushing, flossing, mouthwash usage)?
9. How much does your oral condition lead to discomfort when wearing a denture (false teeth)?

Medication and treatment (including mouthwashes, gels, creams, ointments, injections, tablets, infusions)

1. How much do you feel you need medication to help you with activities of daily life (talking, eating, etc)?
2. How satisfied are you with the medication being used to treat your oral condition?^a
3. How concerned are you about the possible side effects of the medications used to treat your oral condition?
4. How much does it frustrate you that there is no single standard medication to be used in your oral condition?
5. How much does the use of the medication limit you in your everyday life (routine/the way you apply or take your medications)?
6. How much does it bother you that there is no cure for your oral condition?

Social and emotional

1. How much does your oral condition get you down?
2. How much does your oral condition cause you anxiety?
3. How much does your oral condition cause you stress?
4. How much does the unpredictability of your oral condition bother you?
5. How much does your oral condition cause you to worry about the future (spread of the condition, possible cancer risk)?
6. How much does your oral condition make you pessimistic about the future?
7. How much does your oral condition disrupt social activities in your life (social gatherings, eating out, parties)?

Patient support

1. How satisfactory do you consider the information available to you regarding your oral condition?^a
2. How satisfied are you with the level of support and understanding shown to you by family regarding this oral condition?^a
3. How satisfied are you with the level of support and understanding shown to you by friends/work colleagues regarding your oral condition?^a
4. How isolated do you feel as a result of this oral condition?

Response options and scale rating code

Not at all = 0
Slightly = 1
Moderately = 2
Considerably = 3
Extremely = 4

^a Questions in which the response scale was reversed: Not at all = 4; Slightly = 3; Moderately = 2; Considerably = 1; Extremely = 0.

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and treatment, social and emotional status, and patient support in determining subjects' overall QOL.

Methods

After approval from the institutional ethics committee, eligible patients who signed written informed consent were enrolled from November 15, 2011, to February 7, 2012. The study sample consisted of 70 patients receiving treatment in the Department of Oral Medicine and Radiology who had a clinical diagnosis of chronic oral mucosal disease.

Study subjects had to be older than age 18 years. In addition to recurrent aphthous ulcers, oral lichen planus, and pemphigus, the following other chronic oral mucosal diseases were seen in study participants: oral submucous fibrosis, radiation-induced mucositis, speckled leukoplakia, and Stevens-Johnson syndrome. Diagnoses were based on history, clinical examination findings, laboratory test results, and histopathologic findings where appropriate. Individuals with chronic oral mucosal disease who did not undergo any treatment, patients who found it difficult to understand the questions, and mentally disabled patients were excluded from the study. An explanation of the rationale behind the study was given to patients in writing before they gave their consent to become involved. They were given a self-administered COMDQ to complete (see Sidebar: Chronic Oral Mucosal Diseases Questionnaire).

The COMDQ is an oral health-related QOL instrument containing 26 items. The items are grouped according to clinical judgment into 4 domains: pain and functional limitation, medication and treatment, social and emotional status, and patient support. For each questionnaire, patients answered by using a Likert-type response scale coded (see Sidebar: Chronic Oral Mucosal Diseases Questionnaire for response ratings). Responses were added to give a total potential score of 104. Raw scores were then converted to percentages. A score of 0% to 25% was considered an excellent QOL; 26% to 50%, a good QOL; 51% to 75%, a moderate QOL; and 76% to 100%, a poor QOL. The data were entered and proofread by 2 independent researchers. The numerically coded responses were entered into a computer spreadsheet (Microsoft Excel 2010, Microsoft, Redmond, WA)

Table 1. Patient demographics by disease group

Sex	Number	Mean age (SD), years	Mean disease duration (SD), months
Oral lichen planus			
Women	18	46.33 (13.53)	17.11 (9.4)
Men	14	44.8 (15.03)	16.3 (5.39)
Recurrent aphthous ulcers			
Women	4	27.0 (7.87)	10.25 (2.75)
Men	9	38.78 (17.58)	13.5556 (5.39)
Pemphigus			
Women	5	44.80 (13.39)	9.40 (8.35)
Men	4	39.25 (6.50)	4.5 (2.08)
Others ^a			
Women	7	57.71 (16.78)	10.2857 (10.48)
Men	9	35.33 (12.75)	11.7778 (9.78)

^a Included candidiasis, Stevens-Johnson syndrome, oral submucous fibrosis, leukoplakia, radiation-induced mucositis, and bullous pemphigoid.
SD = standard deviation.

before being imported into the data editor of analytics software (SPSS version 15.0, SPSS Inc, Chicago, IL) for analysis.

Results

Patient demographics are displayed in Table 1. Patients were divided into 4 disease categories: oral lichen planus, recurrent aphthous ulcers, pemphigus, and others. The latter category included candidiasis, Stevens-Johnson syndrome, oral submucous fibrosis, leukoplakia, radiation-induced mucositis, and bullous pemphigoid. We observed that chronic oral mucosal diseases affected a wide range of ages. The 2 decades with the most study subjects were those age 31 to 40 years and those age 51 to 60 years, which consisted of 26% and 20% of subjects, respectively. There were equal numbers of men and women in our study.

The overall COMDQ scores by domain are displayed in Table 2. Patients had a moderate overall QOL when physical disability, medications and side effects, and social and emotional status were considered. However, patients had a good QOL when support from family members and friends was considered. We observed a significant correlation between medication and treatment and social and emotional status with pain and functional limitation using Pearson correlation (Table 3). Social and emotional status also correlated with patient support, indicating that all four variables affected the patients' QOL. Improvement in any or all of these variables could positively affect the QOL.

Disease group-specific scores on the COMDQ are reported in Tables 4 and 5. Recurrent aphthous ulcers and pemphigus adversely affected the QOL more than the other COMD subgroups did. Among different disease groups, patients with pemphigus had the worst QOL: 73.67 ± 5.68 .

Age- and sex-related questionnaire scores are reported in Tables 6 and 7, respectively. Older patients—those older than age 35 years—reported significantly lower QOL ($p = 0.015$). There was also a significantly lower overall QOL in older individuals (Table 6). Further comparison of age with different domains revealed a significantly lower QOL in the domain of social and emotional status (Table 8). Significant age-related differences in QOL were not observed in the other domains. Men reported significantly better oral health-related QOL than women in pain and functional limitation: mean (standard deviation) 16.14 ± 8.94 vs 21.44 ± 7.70 ($p = 0.010$; Table 8). Significant differences were not observed between the sexes for the other domains. Significant differences in QOL were not observed between the disease groups apart from recurrent aphthous ulcers and pemphigus ($p = 0.005$).

Discussion

In this study, we found that COMD significantly affected the patients' QOL, which was influenced by pain and functional limitation, medication and treatment, social and emotional status of the patient, and patient support. Llewellyn and Warnakulasuriya¹⁴ evaluated oral diseases such as recurrent aphthous ulcers, oral lichen planus, oral candidiasis, dry mouth, burning mouth, and other temporomandibular joint disorders using the Oral Health Impact Profile-14 and observed that COMD can have a serious impact on patients' oral health-related QOL.

Mumcu et al¹⁵ evaluated the effect of disease activity in Behçet's disease and recurrent aphthous ulcers using an oral health-related QOL. Those patients with active oral ulcers reported poorer oral health-related QOL compared with ulcer-free patients.

Table 2. Overall scores on Chronic Oral Mucosal Diseases Questionnaire

Domain	Mean	SD	Mean percentage of total score	Range of score obtained	Maximum possible score	Level
Pain and functional limitation	18.71	8.71	51.98	1 - 36	36	Moderate
Medication and treatment	14.57	4.91	60.71	2 - 22	24	Moderate
Social and emotional	16.04	7.53	57.30	0 - 28	28	Moderate
Patient support	7.93	3.20	49.55	1 - 14	16	Good
Overall QOL	57.26	19.73	55.05	13 - 85	104	Moderate

QOL = quality of life; SD = standard deviation.

Table 3. Karl Pearson correlation between different domains of Chronic Oral Mucosal Diseases Questionnaire

Karl Pearson correlation coefficient		Pain and functional limitation	Medication and treatment	Social and emotional	Patient support	Overall
Pain and functional limitation	r value		0.604 ^a	0.693 ^a	0.176	0.885 ^a
	p value		0.000	0.000	0.146	0.000
Medication and treatment	r value	0.604 ^a		0.667 ^a	0.180	0.800 ^a
	p value	0.000		0.000	0.135	0.000
Social and emotional	r value	0.693 ^a	0.667 ^a		0.308 ^a	0.904 ^a
	p value	0.000	0.000		0.010	0.000
Patient support	r value	0.176	0.180	0.308 ^a		0.402 ^a
	p value	0.146	0.135	0.010		0.001
Overall	r value	0.885 ^a	0.800 ^a	0.904 ^a	0.402 ^a	
	p value	0.000	0.000	0.000	0.001	

^a Correlation is significant at the 0.01 level (2-tailed).

Table 4. Disease group-specific scores on Chronic Oral Mucosal Diseases Questionnaire

Disease group	Number	Mean	SD	ANOVA F	p value
Pain and functional limitation					
Oral lichen planus	32	17.78	8.35	3.497	0.020 ^a
Recurrent aphthous ulcers	13	14.54	8.41		
Pemphigus	9	25.67	5.96		
Others	16	20.06	9.04		
Total	70	18.71	8.72		
Medication and treatment					
Oral lichen planus	32	15.03	5.13	2.844	0.044 ^a
Recurrent aphthous ulcers	13	11.77	5.04		
Pemphigus	9	17.56	1.88		
Others	16	14.25	4.66		
Total	70	14.57	4.91		
Social and emotional					
Oral lichen planus	32	16.44	6.64	3.905	0.012 ^a
Recurrent aphthous ulcers	13	11.69	8.21		
Pemphigus	9	22.11	3.37		
Others	16	15.38	8.38		
Total	70	16.04	7.53		
Patient support					
Oral lichen planus	32	7.72	3.51	0.187	0.905
Recurrent aphthous ulcers	13	7.69	2.90		
Pemphigus	9	8.33	2.87		
Others	16	8.31	3.20		
Total	70	7.93	3.21		
Overall					
Oral lichen planus	32	56.97	18.62	4.046	0.011 ^a
Recurrent aphthous ulcers	13	45.69	20.18		
Pemphigus	9	73.67	5.68		
Others	16	58.00	21.30		
Total	70	57.26	19.73		

^a Statistically significant.
ANOVA = analysis of variance; SD = standard deviation.

Hegarty et al¹⁶ found that increase in pain evaluated by a visual analog scale score was associated with poor oral health-related QOL in patients with oral lichen planus. In our study looking at the specific domains of the COMDQ, we observed that pain, physical status, and patient's psychological status were equally affected in patients with oral lichen planus.¹⁶

With increasing age, we observed a worse QOL that was attributed mainly to the worsening social and emotional status that included the patient's own perception of his/her disease. However, in our opinion, giving proper education about COMD, patient counseling, and assurance about the success of available treatment modalities may help prevent worsening of QOL in patients with a poor social and emotional status.

The existing literature shows that oral health problems can result in pain and discomfort and can lead to problems in eating, interpersonal relationships, appearance, and self-image.^{17,18} Therefore, pain and functional limitation secondary to disease should be properly evaluated and treated when possible to help improve the patient's QOL.

Tabolli et al¹⁹ found that administration of specific and generic questionnaires provided a detailed picture of the impact of oral diseases on patients, which adds information that may be useful in clinical practice. The COMDQ, being a single discipline-specific questionnaire, could help in the analysis of both physical and psychological evaluation of QOL. The use of this questionnaire for the evaluation of QOL may help give a greater focus to the limited time available at follow-up appointments. These outpatient visits have often concentrated on the symptomatic exacerbation of COMD to the exclusion of other aspects of a patient's health. The COMDQ may allow the patient to assist in the evaluation and assessment of treatment effectiveness. It could supply valuable information regarding the patient's perspective on his/her COMD, which helps the clinician to modify the treatment provided following this in-depth evaluation.²⁰

Conclusion

The clinical evaluation of COMD, by including dentists and physicians, may give information about the cause, can aid in determining potential treatments, and can also provide clues about

Table 5. Post hoc analysis showing the subgroups with difference

Multiple comparisons		Dependent variable, p value				
		Pain and functional limitation	Medication and treatment	Social and emotional	Patient support	Overall
OLP	RAU	1.000	0.238	0.276	1.000	0.414
	Pemphigus	0.084	0.970	0.227	1.000	0.119
	Other	1.000	1.000	1.000	1.000	1.000
RAU	OLP	1.000	0.238	0.276	1.000	0.414
	Pemphigus	0.017 ^a	0.038 ^a	0.007 ^a	1.000	0.005 ^a
	Other	0.471	0.987	1.000	1.000	0.480
Pemphigus	OLP	0.084	0.970	0.227	1.000	0.119
	RAU	0.017 ^a	0.038 ^a	0.007 ^a	1.000	0.005 ^a
	Other	0.654	0.588	0.155	1.000	0.280
Other	OLP	1.000	1.000	1.000	1.000	1.000
	RAU	0.471	0.987	1.000	1.000	0.480
	Pemphigus	0.654	0.588	0.155	1.000	0.280

^a The mean difference is significant at the 0.05 level.
OLP = oral lichen planus; RAU = recurrent aphthous ulcers.

the prognosis but may not directly reflect the resulting level of impairment. This is where QOL measurements can play a key role by helping evaluate the more subjective dimensions of the disease and its treatment. These measurements must be simple and practical enough for the clinician and patient to use and interpret, but at the same time include all the factors that can affect the disease burden. The COMDQ was found to be reliable, simple to use, and sensitive to clinical parameters and treatment modalities. A limitation to this report was that it was based on a sample of convenience and had no control group. The COMDQ can be successfully administered to assess the oral health-related QOL as a part of the routine management of COMD. The COMDQ may be useful in future clinical trials. ❖

Table 6. Correlation between age and scores on Chronic Oral Mucosal Diseases Questionnaire

Age group	n	Mean score	SD	t value	df	Significance (2-tailed p value)
≤ 35 years	25	48.62	21.48	-2.17	68	0.033
> 35 years	45	58.63	16.62			

df = degrees of freedom; SD = standard deviation.

Table 7. Sex correlation with scores on Chronic Oral Mucosal Diseases Questionnaire

Sex breakdown by questionnaire domain	Mean	SD	t value	p value
Pain and functional limitation				
Men	16.14	8.94	2.65	0.010 ^a
Women	21.44	7.70		
Medication and treatment				
Men	14.17	4.98	0.71	0.482
Women	15.0	4.88		
Social and emotional				
Men	14.47	8.28	1.83	0.072
Women	17.71	6.34		
Patient support				
Men	8.22	3.23	0.79	0.434
Women	7.62	3.20		
Overall				
Men	53.0	21.33	1.89	0.063
Women	61.76	17.05		

^a Statistically significant.
SD = standard deviation.

Table 8. Correlation between age and scores in different domains of chronic oral mucosal disease questionnaire

Karl Pearson correlation coefficient: Age with	r value	p value
Pain and functional limitation	0.231	0.054
Medication and treatment	0.104	0.392
Social and emotional	0.290	0.015 ^a
Patient support	0.227	0.058
Overall	0.275	0.021 ^a

^a Statistically significant.

Disclosure Statement

The author(s) have no conflicts of interest to disclose.

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