



## QUALITY OF LIFE AND PERFORMANCE IN ORAL SUBMUCOUS FIBROSIS PATIENTS: A QUESTIONNAIRE BASED STUDY

### Dental Science

<b>Dr.Himani Tyagi</b>	B.D.S, M.D.S. oral medicine and Radiology Senior lecturer, Department of Oral medicine and Radiology, Inderprastha Dental College and Hospital, Ghaziabad, U.P., India
<b>Professor Suma G.n.</b>	JB.D.S, M.D.S. oral medicine and Radiology Head of the department of Oral medicine and Radiology, Faculty of dental sciences, SGTunior resident
<b>Professor Manisha Lakhanpal</b>	B.D.S, M.D.S. oral medicine and Radiology Head of the department of Oral medicine and Radiology, I.T.S. dental college and Research Centre, Greater Noida, U.P., India
<b>Dr. Anchal Goel</b>	B.D.S, M.D.S. oral medicine and Radiology Senior lecturer, Department of Oral medicine and Radiology, Inderprastha Dental College and Hospital, Ghaziabad, U.P., India
<b>Dr. Rashi Jaiswal</b>	BDS Post graduate student in the department of Oral medicine and Radiology, D.J College of dental sciences and Research Centre, U.P., India
<b>Dr.Riddhi Chawla*</b>	BDS, MDS Orthodontics and Dentofacial orthopedics Lecturer, Department of Orthodontics, Penang International Dental College, NB Tower, Jalan Bagan Luar, Penang, Butterworth, Malaysia 12000 *Corresponding Author

### ABSTRACT

**Aim:** To assess the quality of life and performance in Oral submucous fibrosis (OSMF) patients who are undergoing a treatment regime and being followed up for 3 months using validated specific questionnaire.

**Material and methods:** 30 patients receiving treatment in the department of oral medicine and radiology who had a clinical and established histopathological diagnosis of oral submucous fibrosis were enrolled for the study and were assessed by using standardized measures of quality of life (QOL).

**Result:** Older patients—those older than age 35 years—reported significantly lower QOL ( $p = 0.015$ ). Further comparison of age with different domains revealed a significantly lower QOL in the domain of social and emotional status. 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.

**Conclusion:** Clinical evaluation of COMDQ, by including dentists and physicians, may give information about the cause, can aid in determining potential treatments, and can also provide clues about the prognosis but may not directly reflect the resulting level of impairment.

### KEYWORDS

QOL, OSF, COMDQ

### INTRODUCTION

“Technology and competence have to be infused with compassion and benevolence; life is not just a matter of length but of depth and quality as well.”<sup>1</sup>

Oral submucous fibrosis (OSMF) is a chronic, insidious disease caused by areca nut use, and is associated with both considerable morbidity (including pain and reduced mouth opening) and potential risk for malignancy. The basis for embarking on the study was based on the “need-to-know” about the effects and efficiencies of clinical interventions. Effectiveness was to be calculated by a ratio of services or treatments provided to services or treatment enviable. To a certain extent it does not rely on direct measurement of oral disease(s) alone, the symptomatic alleviation of disease could be a sign of the oral health needs.

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. QOL encompasses the social, physical & psychological aspects of the oral health. The QOL measurement instruments can be divided into: Generic, Disease-specific, Discipline-specific questionnaires.<sup>2</sup>

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.<sup>3</sup> Disease-specific questionnaires accurately predict clinical changes associated with a particular disease but do not allow comparison to be made across diseases.<sup>6</sup> 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.<sup>7</sup>

Study questionnaires devised to assess the existing quality of life are

many including the EORTC QLQ – Head and neck (bjordal et al, 2000), International classification of functioning, disability and health (icf) questionnaire for patients with head and neck cancer (tschiesner et al, 2010) and performance status scale (list et al, 1996).<sup>3</sup> The Chronic Oral Mucosal Diseases Questionnaire (COMDQ) however is a discipline-specific questionnaire developed for the field of oral medicine and radiology.<sup>8</sup> The questionnaire completely has a patient-centered approach and has established validity and reliability to make use of. This study included questionnaires designed specifically to evaluate quality of life post treatment of OSMF.

### MATERIALS AND METHODS

Study involved 30 patients diagnosed with OSMF clinically as well as histologically between April 2014 to June 2014. The study was approved by the institutional ethical committee. All patients provided written informed consent for the management of personal data before participating in the study. Inclusion criteria was defined as : 1) age >18 years 2) Biopsy graded and then the treatment was advised to alleviate the symptoms, treatment modalities includes habit intervention, medical treatments (i.e. systemic, intralesional injection, physical therapy. Exclusion criteria were defined as patient who did not undergo any treatment, patient who found it difficult to understand the questionnaire, mentally disabled patients.

The primary outcomes explored were the

- (I) Maximal jaw opening, measured as the inter-incisal distance,
- (ii) Maximal tongue protrusion
- (iii) Mucosal burning sensation using visual analogue scale,
- (iv) Cheek flexibility
- (v) Pain while opening mouth
- (vi) Salivation

### Evaluation procedure-

QOL and performance status evaluations were incorporated into the

treatment protocol and treatment consent form. Self-administered questionnaires were given to the patients to complete. Disease and treatment data were retrieved from patients' history records. Patients were assessed before treatment (baseline), during treatment, and 3 months after completion of treatment.

The Chronic Oral Mucosal Diseases Questionnaire (COMDQ) was used as an assessment tool. 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 wherein responses were added to give a total potential score of 104.

**Response options and scale rating code:**

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

**Questions in which the response scale was reversed:**

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

Raw scores were then converted to percentages.

- ❖ 0% to 25% : Excellent;
- ❖ 26% to 50% : Good
- ❖ 51% to 75% , : Moderate
- ❖ 76% to 100% : Poor .

**I. Pain and functional limitation**

1. How much do certain types of food/drink cause discomfort to you (spicy food, acidic food)?
2. How much does your oral condition cause you to limit the types of food/drinks you consume? Does loss of taste sensation leave you hungry?
3. How much do certain food textures cause discomfort to you (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 discomfort to you?
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. Do you feel discomfort while and after blowing in a balloon?
10. How much difficulty you experience while chewing or swallowing food due to lack of salivation?

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

1. How much medication you need 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 conditions?
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?

**III. Social and emotional**

1. How much does your oral condition get you down?
2. How much anxiety does your oral condition cause?
3. How much stress does your oral condition cause?
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)?
8. Are you afraid of smiling in front of people due to the appearance?

**IV. Patient support**

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

**RESULTS**

Data were entered by investigator. The numerically coded responses were entered into a computer spreadsheet (Microsoft Excel 2007) before being imported into the data editor of analytics software (SPSS version) for analysis

Sex	Number	Mean age (SD) ,years	Mean disease duration(SD), months
male	23	35	17
female	7	32	16

Descriptive Statistics					
variables	N	Minimum	Maximum	Mean	Std. Deviation
Pain and functional limitation	30	25	31	27.53	1.833
Medications and treatment	30	15	20	17.37	1.326
Social and emotional	30	21	25	22.50	1.280
Patient support	30	10	14	12.20	1.095
Overall score	30	72	91	79.63	4.038

DOMAIN	RANGE OF SCORE OBTAINED	MAXIMUM POSSIBLE SCORE	RANGE
PAIN AND FUNCTIONAL LIMITATION	05 - 36	36	MODERATE
MEDICATION AND TREATMENT	2-21	24	MODERATE
SOCIAL AND EMOTIONAL	8-28	28	MODERATE
PATIENT SUPPORT	5-14	16	GOOD
OVERALL QOL	20-85	104	MODERATE

Chronic oral mucosal diseases affected a wide range of ages. Older patients—those older than age 35 years—reported significantly lower QOL (p= 0.015).

Further comparison of age with different domains revealed a significantly lower QOL in the domain of social and emotional status. 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

**DISCUSSION**

QOL questionnaire has been found to be effective in evaluating the OSMF patients. These questionnaires help in comparing the pre-treatment and post-treatment QOL, hence bringing the awareness regarding the range of treatment options available for patients. Though OSMF is a debilitating and depressing disease, there is no such questionnaire based assessment with this background hence creating the need for this study.

Treating the oral cavity has great impact on the physical, emotional and

functional state of patients. COMDQ has the holistic approach, providing evidence for the acceptability, validity, and reliability of Questionnaire in measuring the quality of life of people with OSMF at all phases of the disease trajectory. COMDQ considerably affected the patient QOL, which was prejudiced by pain and functional limitation, medication and treatment, social and emotional status of the patient and patient support.

Llewellyn and Warnakulasuriya evaluated oral diseases such as RAU, OLP, oral candidiasis, dry mouth, burning mouth, and other temporomandibular joint disorders using the Oral Health Impact Profile-14 and observed that COMDQ can have a serious impact on patients' oral health-related QOL.<sup>10</sup> Mumcu et al. evaluated the effect of disease activity in Behçet's disease and RAU using an oral health-related QOL.<sup>11</sup> Those patients with active oral ulcers reported poorer oral health-related QOL compared with ulcer-free patients.

However, giving proper education about COMDQ, patient counselling, 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 COMDQ, being a single discipline-specific questionnaire, could help in the analysis of both physical and psychological evaluation of QOL. Use of this questionnaire for evaluation of QOL may help give a greater focus to the limited time available at follow-up appointments. COMDQ may allow the patient to assist in the evaluation and assessment of treatment effectiveness.

## CONCLUSION

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 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.

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