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**Quality of life and oral potentially malignant disorders: Critical appraisal and prospects**

Gondivkar SM *et al*. Quality of life and oral potentially malignant disorders

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**Abstract**

Quality of life (QoL) is a vital and often required health outcome measure that is relevant to patient care. A healthy and functional oral cavity allows an individual to perform daily activities without any limitations. However, any disturbance may result in impaired QoL. The oral health-related quality of life (OHRQoL) is an integral aspect of general health and well-being. In recent years, the tradition of clinical practice and research has been changed by incorporating QoL assessment, as it helps in evaluating the oral health needs of patients and monitoring treatment responses. Oral potentially malignant disorders (OPMDs) are a group of chronic disorders including oral leukoplakia (OL), oral lichen planus and oral submucous fibrosis (OSF) that have an increased potential for malignant transformation. It is evident that patients with OPMDs experience significant health-related symptoms, functional limitations and psycho-social impairment because they are always worried about the possibility of developing cancer, compromising their QoL. Moreover, the worsening of QoL has been associated with advanced stages of OPMDs. Although OPMDs are relatively common and potentially debilitating, there is a scarcity of literature on QoL assessment in these patients. In spite of the higher prevalence of habit-related OPMDs, particularly OSF and OL in Southern Asian countries, only a few studies have been performed in these populations. Moreover, these studies administered generic QoL instruments, which offer less sensitivity to clinical changes than disease-specific tools and, thus, may not be completely appropriate for a particular disease. As the impacts of different conditions on OHRQoL may vary, the development and validation of a QoL instrument specific to each clinical entity of OPMDs is currently needed.

**Key words:** Quality of life; Oral potentially malignant disorders; Oral submucous fibrosis; Oral lichen planus; Oral leukoplakia

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**Core tip:** The quality of life (QoL) assessment has become an essential tool in clinical practice to better understand patient reported outcomes in recent years. It definitely helps to better understand the impact of oral health on the lives of patients with oral potentially malignant disorders (OPMDs) and their families and to monitor the outcomes of treatments. It is a foremost pre-requisite to employ the best available QoL instrument when treating OPMDs. In view of the scarcity of research on QoL assessments in OPMDs, the development and application of condition-specific QoL instruments can allow them to become tools to better understand and shape the state of clinical practice, dental research and dental education.

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**INTRODUCTION**

The World Health Organization (WHO) has defined quality of life (QoL) as “an individual’s perception of his position in life in the context of the culture and value system in which he lives and in relation to his goals, expectations and standards and concerns”[1]. QoL is a vital and often required health outcome measure that is relevant to patient care. Oral health-related QoL (OHRQoL) is a multidimensional construct that includes a subjective evaluation of the individual’s oral health, functional wellness, emotional wellness, expectations and satisfaction with respect to oral health and self-esteem[2]. A healthy oral cavity empowers an individual to perform routine daily activities without any physical and psycho-social limitations. However, any disturbance associated with the oral cavity may cause pain, difficulties in eating and speaking and altered appearance. Persistent discomfort and a functionally impaired oral cavity may subsequently result in decreased self-confidence and social communication of the individual, compromising his or her QoL. It is well-known that OHRQoL reflects an integral aspect of general health and well-being of patients and has become an essential tool in evaluating their oral health needs and treatment plans[3,4]. Although the effects of oral mucosal diseases have traditionally been measured using thorough clinical examination, there is a blooming trend of utilizing patients’ perspectives to better evaluate objective signs and subjective cognizance of affected aspects of patients’ lives. Therefore, the new era demands QoL assessment using patient reported outcomes (PROs) and experiences (PREs) as a part of day-to-day practice along with a thorough clinical examination[5]. Moreover, deciding proper treatment protocols and measuring treatment outcomes based on PROs and PREs is definitely helpful and has changed the tradition of clinical practice, surveys and research in recent years.

Oral potentially malignant disorders (OPMDs) are a group of chronic disorders that has an increased potential for malignant transformation[6]. Per recent literature, the values of the malignant potential of oral leukoplakia (OL), oral lichen planus (OLP) and oral submucous fibrosis (OSF) are 3.5% (range, 0.13-34.0%)[7], 1.1%[8] and 7%-13%[9], respectively. Careful monitoring of these lesions by an experienced specialist is highly recommended to identify any malignant changes in the early stages to reduce the cancer burden. It has been documented that patients with OPMDs experience significant health-related symptoms affecting their QoL[10]. Moreover, OPMD patients suffer psychological discomfort because they are always worried about the possibility of developing cancer[11]. The emotional and social wellness of these patients is also disturbed due to various dysfunctions. Although oral cancer (OC) and OPMDs show comparable health-related symptoms affecting the QoL of patients[12], the available OHRQoL instruments are OC/head and neck cancer specific, and thus, the OHRQoL of patients suffering from OPMDs is seldom assessed. Moreover, the literature on QoL assessment in patients with OPMDs is scanty in contrast to the plentiful literature on QoL in OC/head and neck cancer patients[13,14].

OSF is an OPMD that is highly prevalent in South Asian countries, affecting 5 million people in India alone[9]. Its etiology is multifactorial but arecoline in the areca nut is the main causative agent in initiating the disease process. OSF is characterized by a burning sensation in the oral cavity, oral ulceration, vesiculation, and blanching of the oral mucosa. This subsequently leads to increasing stiffening of the tissues, marked rigidity and an eventual inability to open the mouth, significantly compromising the patient’s QoL. The published literature in the past demonstrated a definite significant impact of OSF on the OHRQoL of many patients, and the worsening of QoL has been associated with advanced stages of OSF[15].

OLP is a chronic inflammatory disorder with etiopathogenesis that is still poorly understood. OLP affects approximately 1%-2% of the population worldwide[16] and is more prevalent in middle-aged females. It is characterized by outbreaks or flares of different types of clinical presentations, which has been categorized by Eisen[17] into three subtypes: (1) reticular form; (2) erosive/atrophic form; and (3) ulcerative form. Even though the reticular form is asymptomatic, erosive and ulcerative forms are often painful and disabling and are variants with burning sensations of the oral mucosa. The persistent painful symptoms can have a significant negative impact on daily life activities including eating, swallowing or speaking. Moreover, OLP has been linked with impaired psychosocial morbidity and QoL[4,18].

The prevalence of OL is approximately 1%, with a greater number of cases seen in adults. The etiology of OL includes chewing or smoking of tobacco and related products. Clinically, OL can be classified into homogenous and non-homogenous subtypes, with the highest malignant potential reported in proliferative verrucous leukoplakia and speckled leukoplakia. OHRQoL of patients with OL was evaluated in a few past studies[19,20].

Our recent systematic review demonstrated that the QoL of patients affected by different OPMDs has been studied and successfully assessed by various authors using different QoL instruments in European countries. However, most of these studies have focused on QoL in patients with OLP, which is not at all applicable to all OPMDs[21]. Despite the fact that habit-related OPMDs, such as OSF and OL are predominantly seen in people in Southern Asian countries[22] or Southern Asian immigrants in other parts of the world, surprisingly, only a few studies have assessed QoL in patients with OSF and OL in this population to our knowledge. Moreover, all these studies administered QoL instruments, namely the Oral Health Impact Profile (OHIP), University of Washington Quality of Life Questionnaire (UW-QOL), Chronic Oral Mucosal Disease Questionnaire (COMDQ) and Oral Health Related Quality of Life-UK (OHQoL-UK). However, these instruments are generic to a range of chronic oral mucosal diseases and are not condition-specific. The generic questionnaires offer less sensitivity to clinical changes than disease-specific tools[23], as they are applicable to a wide variety of population and disease states. In contrast, it is well-known that condition-specific instruments allow for better measurement of QoL than generic questionnaires, as they assess the impact of a particular condition on daily activities and the life quality of a diseased person. A disease-specific QoL instrument for OPMD, *i.e.,* the OPMDQoL questionnaire study, observed a significant impact of OLP and OSF compared to OL on the QoL of affected patients particularly in the domains of “physical impairment and functional limitations”[24]. Recently, we developed an instrument called “OHRQoL-OSF” specifically for OSF patients, which was found to be valid and reliable in QoL assessment in an Indian population[25].

We believe that QoL assessment has become a necessity to determine the feelings and perceptions of patients as well as to increase effective communication between health care professionals and patients. This definitely provides clues not only to better understand the influence of oral health on the lives of the patients and their families but also to monitor the outcomes of the treatments provided. The current scenario of rapidly increasing the number of OPMD cases, specifically OSF and OL in South Asian countries, is an alarming situation as far as oral cancer is concerned. This might be due to the increased popularity of commercially available areca nut and tobacco preparations, especially in India. In addition, an increasing number of young people are becoming addicted to this ancient, socially acceptable habit due to easy access, effective price changes and marketing strategies. In view of the scarcity of research on QoL assessment in OPMDs, there is a dire need for more studies to better understand this situation. It is evident that researchers have been continuously focusing on improving the QoL of affected individuals. Therefore, it is a foremost pre-requisite to employ the best available QoL instrument in OPMDs. Furthermore, due to differences in their pathogenesis and clinical presentations and thus, differing impacts on OHRQoL, the development and validation of a QoL instrument specific to each clinical entity of OPMD separately is needed. Such condition-specific instruments can become tools to understand and shape not only the state of clinical practice, dental research and dental education but also that of the community at large.

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