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Health-Related Quality of Life among Patients with Oral Potentially Malignant Disorder and Oral Cancer in Malaysia

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ABSTRACT

Presently there is a lack of health-related quality of life (HRQOL) measure and its corresponding utility values for oral cancer and oral potentially malignant disorders (OPMD). This limits patient-centered outcomes for cost-effectiveness evaluations. The study aimed to determine post-treatment HRQOL of patients and ascertained differences between OPMD, early and late-stage oral cancer. A cross-sectional survey was conducted among patients in oral maxillofacial specialist clinics in two public tertiary hospitals. Consented participants were required to complete the EQ-5D-5L questionnaire with the EQ Visual Analogue System (VAS). Kruskal-Wallis test was used to explore differences in values between stages. Multiple linear regression was used to explore factors that influenced the HRQOL.

A total of 50 OPMD and 52 oral cancer patients were surveyed. The mean EQ-5D-5L health utility values was 0.842 (n = 50, SD = 0.139), 0.822 (n = 10, SD = 0.150) and 0.626 (n = 42, SD = 0.310) for OPMD, early- and late-stage cancer, respectively. The mean values of the EQ-5D-5L index and EQ-VAS scale showed significant differences between groups and between early- and late-stage cancer with good discriminative properties. Results of the multiple linear regression indicated that ethnicity, income, residency, diagnosis, and treatment modality were able to significantly account for 25% of EQ-5D-5L utility values, F(10,91) = 3.83, p < 0.001, R2 = 0.360. Indian ethnicity, rural location, income less than RM4,360, late-stage cancer, and multi-modal therapies were all predictors of poorer HRQOL. This study evidenced disease severity and treatment modality to greatly impact the HRQOL of patients, in addition to socio-demographic factors such as ethnicity and income.

Keywords: *Inequality; oral cancer; oral potentially malignant disorders; precancer; quality of life*

INTRODUCTION

Oral cancer is a major public health problem due to its substantial impact on morbidity and mortality. Incidences are anticipated to continue on an increasing trajectory across all age groups. Worldwide figures are projected to increase by 46.5% in 2020, affecting more than 553,481 people (Ferlay *et al.*, 2020). The impact of such an upward trend will be further compounded by a high mortality rate and a relatively unchanged 5-year survival among patients, especially in the Asian region (Sung *et al.*, 2021). In Malaysia, oral cavity cancer remains among the top 20 most common cancers with an age-standardised rate of 3.0 for incidence and 1.0 for mortality per 100,000 population, respectively (Cheong *et al.*, 2017; Azizah *et al.*, 2019). These incidences are worryingly projected to almost double in the next two decades, leading towards a greater socioeconomic burden to both society and the healthcare service (Ferlay *et al.*, 2020).

Notably, patients who survive oral cancer face a myriad of physical and psychosocial sequelae from both the disease and the intensive treatment regimens. Relative to cancers in other anatomical sites such as breast and colon, oral cancer patients experience one of the highest distress levels (Carlson *et al.*, 2004). The distress occurs partly because oral cancer affects regions that are critical for the basic function and social interaction of an individual (Martino & Ringash, 2008; Gomes *et al.*, 2020). Thus treatment modalities like surgery and radiotherapy, while being vital for the survival of patients, often also adversely affect their quality of life (QOL). Furthermore, disfigurement and aesthetic appearances continue to cause anguish and hamper their ability to integrate into the community, even after a long post-treatment period (Ojo *et al.*, 2012). Consequently, clinicians and policymakers are increasingly incorporating health-related quality of life (HRQOL) measures in planning treatment options and evaluation of health services to take into account patient experiences.

Many oral cancers are preceded by precursor lesions, termed as oral potentially malignant disorders (OPMD). OPMD consists of a range of oral conditions such as lichen planus, leukoplakia and submucous fibrosis which are associated with a propensity to progress to become oral cancer (Warnakulasuriya *et al.*, 2007). Patients with OPMD also experience varying degrees of discomfort and continuously live in fear of their lesions progressing into malignancy (Kumar *et al.*, 2021). However, a recent systematic review revealed an overall lack of evaluation on HRQOL among such patients, especially in Asia, which coincidently reports the highest prevalence of OPMD worldwide (Tadakamadla *et al.*, 2015). Examining the impact of OPMD on QOL is important in understanding the willingness of these patients to seek treatment or participate in early screening.

The HRQOL concept is broadly based on quantifications of the subjective health status of patients through either profile-based or preference-based instruments. The commonly applied EuroQol 5-dimension scale (EQ-5D) converts generic patient-reported values to a utility index score using country-specific algorithms to reflect population preferences (Herdman *et al.*, 2011). Presently there is still a void in utility values of OPMD and oral cancer patients in this region (Kularatna *et al.*, 2016). These measures are crucial as they form the basis for cost-utility analysis to guide the assessment of newer health treatments and initiatives. In the presence of the recently available Malaysian EQ-5D-5L population value set, it is timely to evaluate the current HRQOL of OPMD and oral cancer patients. Hence, this study aims to determine the HRQOL and ascertain differences in utility values between OPMD, early- and late-stage oral cancer post-treatment in Malaysia. We also sought to explore factors influencing this QOL. Our findings are imperative for future evaluations of national oral health policies and to address the unmet needs of patients.

MATERIALS AND METHODS

Study Design and Sampling

A cross-sectional study was conducted from August 2019 to January 2020. Data was collected from OPMD and oral cancer patients who are receiving treatment at the oral maxillofacial specialist clinics in Hospital Tengku Ampuan Rahimah (HTAR), Klang and Hospital Umum Sarawak (HUS), Kuching, Malaysia. These public tertiary care facilities were selected as they were the main referral centres in East and West Malaysia. This study was approved by the Ministry of Health Medical Research Ethics Committee (NMRR-18-3842-45321) and the Universiti Sains Malaysia Human Research Ethics Committee (USM/JEPeM/18120789).

A stage-stratified convenience sampling was implemented in recruiting adult patients attending their clinic reviews. The sample size was calculated based on detecting a minimal clinically important difference in the health utility value of 0.04 with an estimated standard deviation (SD) of 0.06 between OPMD and oral cancer (McClure *et al.*, 2017). Based on the level of confidence of 95% and power of 80%, the calculated sample size per group was 40.

Only adult patients diagnosed histologically with either dysplasia or oral squamous cell carcinoma and on treatment were recruited. International Classifications of Diseases 10th Revision was applied to the identification of oral cancer, comprising of ICD00 to ICD06 (World Health Organization, 2004). OPMD on the other hand was defined according to WHO Collaborating Centre for Oral Cancer and Precancer (Warnakulasuriya *et al.*, 2007). Cases were included regardless of their treatment duration as long as a minimum of a single treatment was completed. This entailed at least completion of any surgical or oncologic interventions in oral cancer. For patients with OPMD, they must have either underwent excisional surgery or been treated with oral or topical medications.

All participants were briefed about the study and were required to provide written informed consent before data collection. A standard proforma was used to capture sociodemographic data, comorbidities, clinical history and lesion or tumour status from medical records. The participant's residency was categorised as "rural" or "urban" based on their postcode and township details as per local government apportionment. Patient and family income was categorised according to the national median monthly household revenue threshold. This consists of below poverty line index of RM1,000 (USD625); Bottom 40% (B40) with income between RM1,000–RM4,360 (USD635–USD2,722); Middle 40% (M40) with income between RM4,360–RM9,619 (USD2,722–USD6,004); and

Top 20% (T20) for income above RM9,619 (USD6,004) (Mahdin, 2017; Ng *et al.*, 2018). Subsequently, participants were required to complete the interviewer-administered EQ-5D-5L questionnaire with the EQ Visual Analogue System (VAS).

EQ-5D-5L and VAS

The EQ-5D-5L questionnaire covers five dimensions consisting of mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension has five levels: no problems, slight problems, moderate problems, severe problems and extreme problems. The participants were required to indicate their health state based on the most appropriate statement in each dimension. This decision results in a 1-digit number expressing the level selected for that dimension. The scores on the five dimensions were then converted into a single summary utility value by applying a Malaysian social tariff (Shafie *et al.*, 2019). The state of full health (11111) was given the utility value of one and that of death was assigned a value of zero. Utility values can be less than zero for health states regarded as worse than death. This was followed by requesting participants to record their self-rated health on a vertical visual scale, which ranges from zero to 100, with 100 reflecting the "best imaginable health state". EQ-VAS acts as a quantitative measure of health outcomes based on the patient's judgement.

Statistical Analysis

Cancer staging was based on the American Joint Committee on Cancer (AJCC) TNM system. These stages were further categorised as early (Stages I and II) or late (Stages III and IV) for analysis. Sociodemographic and clinical characteristics were recorded as frequencies and percentages of the total. Association between categorical variables and disease stages was assessed using Fisher's exact test. All HRQOL scores were reported as mean and SD by respective disease stages with a Kruskal-Wallis test applied to explore differences between groups. Kruskal-Wallis test was also used to explore the differences in levels reported in EQ-5D-5L dimensions due to the ordinal nature of responses.

The ability of EQ-5D-5L to discriminate between different severities was examined by calculating their effect size. The effect size was generated by dividing the mean difference of two adjacent groups by the SD of the milder stage (Rowen *et al.*, 2012). A larger effect size reflects a better discriminating ability of the instruments used. Cohen's effect size guide was used to categorise them into small (0.2–0.5), medium (0.5–0.8), and large (>0.8) (Cohen, 1992). Multiple linear regression was used to investigate factors that influenced the HRQOL of patients. Potential variables with a p-value <0.1 in univariate analysis were explored further for multicollinearity and included in a multivariate model. In our analysis, the explanatory regression model was used to control independent variables rather than be applied for prediction. All statistical analyses were performed using Stata version 14.0 (StataCorp, College Station, Texas 77845 USA) with a statistical significance set at $p < 0.05$.

RESULTS

A total of 102 patients completed the survey, consisting of 50 with OPMD and 52 with oral cancer. The mean treatment follow-up period for the patients was 34.3 (SD = 41.6) months. The average age was 59.8 (SD = 12.4) years old, with no significant difference among patients diagnosed with OPMD, early- or late-stage cancer (p = 0.307). Table 1 shows the sociodemographic and clinical characteristics of patients. Based on TNM staging, patients with oral cancer were in Stage I (n = 2, 3.8%); Stage II (n = 8, 15.4%); Stage III (n = 13, 25.0%) and Stage IV (n = 29, 55.8%), respectively. Lichen planus consisted of 58.0% of cases of OPMD, followed by 16.0% of leukoplakia. Buccal mucosa remained the most common primary site of lesions. Table 1 showed a significant

disparity in location among the groups, with a larger proportion of patients diagnosed with late-stage cancer being from the rural area while the urban population predominated the OPMD and early cancer groups. Although there was no difference in income category between groups, a subgroup analysis showed there was a significant difference in the annual mean income of patients diagnosed with OPMD and oral cancer, at RM29,508 and RM23,969 respectively, $\chi^2(1, n = 102) = 5.9, p = 0.015$.

The mean values of the EQ-5D-5L utility scores and EQ-VAS scale are shown in Table 2. Significant differences in values

Table 1 Sociodemographic and clinical characteristics

Characteristic		OPMD *n* = 50 (%)	Early cancer *n* = 10 (%)	Late cancer *n* = 42 (%)	*p*-value[a]	
					All group	Cancer
Gender	Male	16 (32.0)	6 (60.0)	18 (42.9)	0.217	0.483
	Female	34 (68.0)	4 (40.0)	24 (57.1)		
Race	Malay	13 (26.0)	1 (10.0)	6 (14.3)	0.471	0.770
	Chinese	6 (12.0)	4 (40.0)	10 (23.8)		
	Indian	26 (52.0)	4 (40.0)	20 (47.6)		
	Indigenous	5 (10.0)	1 (10.0)	6 (14.3)		
Location	Urban	26 (52.0)	8 (80.0)	15 (35.7)	0.030	0.015
	Rural	24 (48.0)	2 (20.0)	27 (64.3)		
Education	None/primary	17 (34.0)	3 (30.0)	27 (67.5)	0.004	0.07
	Secondary/tertiary	33 (66.0)	7 (70.0)	13 (32.5)		
Occupation	Not working	21 (42.0)	2 (20.0)	21 (50.0)	0.212	0.193
	Employed	20 (40.0)	4 (40.0)	10 (23.8)		
	Retired	9 (18.0)	4 (40.0)	11 (26.2)		
Income category	< RM1,000	10 (20.0)	1 (10.0)	18 (42.9)		
	RM1,000–RM4,360	34 (68.0)	8 (80.0)	18 (42.9)	0.062	0.094
	> RM4,360	6 (12.0)	1 (10.0)	6 (14.2)		
Anatomic site	Buccal mucosa	31 (62.0)	4 (40.0)	21 (51.0)	0.140	0.194
	Tongue	13 (26.0)	5 (50.0)	9 (21.4)		
	Others	6 (12.0)	1 (10.0)	12 (28.6)		
Treatment modality	Single	50 (100.0)	7 (70.0)	16 (38.1)	-	-
	Multimodal	–	3 (30.0)	26 (61.9)		

Notes: [a] Fisher's exact test with significance set to $p < 0.05$ was applied. 'All group' difference was compared between OPMD, early cancer and late cancer, while 'cancer' comparison was between early cancer and late cancer alone.

Table 2 Summary and comparison of HRQOL measures by diagnosis and cancer stages

Instrument	OPMD		Early cancer		Late cancer		*p*-value[a]	
	Mean	SD	Mean	SD	Mean	SD	All group	Cancer
EQ-5D-5L	0.842	0.139	0.822	0.150	0.626	0.310	< 0.001	0.049
VAS	81.20	11.67	80.50	12.12	67.14	18.18	< 0.001	0.043

Notes: [a]Kruskal-Wallis H test with significance set to $p < 0.05$; 'All group' difference was compared between OPMD, early cancer and late cancer, while 'cancer' comparison was between early cancer and late cancer alone.

were identified between all diagnosis groups and between early- and late-stage cancer. Further analysis of the frequency of reported severity levels between oral cancers and OPMD via Kruskal-Wallis H test showed a significant difference in mobility ($H[1] = 5.07$ $p = 0.024$), self-care ($H[1] = 6.57$, $p = 0.010$), usual-activity ($H[1] = 8.52$, $p = 0.004$) and pain/discomfort ($H[1] = 12.54$, $p < 0.001$) domains. However, interestingly no significant difference was observed in the levels between early- and late-stage cancer, mobility ($H[1] = 1.46$, $p = 0.227$), self-care ($H[1] = 0.14$, $p = 0.710$), usual-activity ($H[1] = 0.91$, $p = 0.341$), pain/discomfort ($H[1] = 2.72$, $p = 0.099$) and anxiety/depression ($H[1] = 3.11$, $p = 0.078$). The calculated effect size for EQ-5D-5L was 1.285 between OPMD and oral cancer, and 1.307 between early- and late-stage cancer. The values demonstrated a good discriminative property of EQ-5D-5L to distinguish between disease severities.

The findings of univariate analysis and multiple linear regression to assess the association between EQ-5D-5L utility values and independent factors are partly shown in Table 3. Patient age, gender, education level, and employment status, in addition to the primary site of lesion, duration of follow-up, and treatment with chemotherapy or radiotherapy were not statistically associated with health utility scores ($p > 0.1$). Results of the multiple linear regression indicated that ethnicity, income, residency, diagnosis and treatment modality were only able to significantly account for 25% of EQ-5D-5L utility values, $F(10,91) = 3.83$, $p < 0.001$, $R^2 = 0.360$.

DISCUSSION

Our findings showed that patients treated in late-stage of oral cancer experienced notably worse HRQOL compared to those in early stages or with OPMD. Concurrently, our regression model further evidenced that monotherapy and diagnosis of OPMD were significantly associated with better QOL relative to multi-modal treatments and oral cancer, respectively. Such results were consistent with the literature where patients with the worst disease severity or later stages of cancer had an overall lower HRQOL (Noel *et al.*, 2015; Govers *et al.*, 2016; Pourrahmat *et al.*, 2021). For example, Noel *et al.* (2015) reported more severe head and neck cancer patients requiring salvage surgeries, chemotherapies, or tracheotomy had overall lower utility scores compared to those not requiring them. The findings were

Table 3 Association between EQ-5D-5L health utility scores with sociodemographic and clinical factors

Variable [a] (Reference value)	Comparator	Coefficient	Lower CI	Upper CI	*p*-value	Adjusted coefficient	Adjusted *p*-value
Race (Malay)	Chinese	–0.09	–0.20	0.02	0.104	–0.10	0.053
	Indian	–0.15	–0.25	–0.06	0.001	–0.11	0.017
	Indigenous	–0.06	–0.23	0.12	0.529	-0.03	0.649
Income (> RM4,360)	< RM1,000	–0.16	–0.30	–0.03	0.015	–0.15	0.046
	RM1,000–RM4,360	–0.09	–0.20	0.00	0.070	–0.16	0.003
Location (Urban)	Rural	–0.10	–0.19	–0.00	0.044	–0.06	0.129
Diagnosis (OPMD)	Early cancer	–0.02	–0.12	0.08	0.685	–0.18	0.122
	Late cancer	–0.22	–0.32	–0.11	< 0.001	–0.37	0.002
Surgery (absent)	Surgery	0.11	0.02	0.20	0.021	–0.13	0.205
Multi-modality	Single-modality	0.06	–0.04	0.15	0.257	0.17	0.004

Notes: [a] Only variables with $p < 0.1$ in univariate analysis were entered in the multiple linear regression model, except for treatment modality

contributed by both the disease morbidity from extensive invasion and metastasis, in addition to the adverse consequences of intensive treatment regimens. However, there is still a lack of knowledge on the relationship between EQ-5D-5L utility scores with oral cancer staging, severity or treatment modalities in the literature (Meregaglia & Cairns, 2017). Hence it is difficult to make meaningful comparisons of values in Malaysia with other populations.

Nevertheless, Doss *et al.* (2017) in their large longitudinal study of oral cancer in Malaysia found that the cohort of Stages III and IV patients had poorer HRQOL relative to Stages I and II. Despite using a different profile-based approach via the application of the Head and Neck Functional Assessment of Cancer Therapy (FACT-H&N) instrument, the lower HRQOL indicator of late stages was consistent over a range of summary scores. They concluded that the consequences of late-stage diagnosis and treatments were severe and longer-lasting relative to earlier stages. While no specific EQ-5D-5L dimensions were able to be identified for the differences between stages in our analysis, the negative impact in their study was seen in physical well-being and concerns domains (Doss *et al.*, 2017). This was in agreement with the findings from Gurney *et al.* (2008), who demonstrated factors such as free flap reconstructive surgeries in later stages led to lower scores in speech and eating domains. On the contrary, patients in the early stages with smaller lesions required fewer radical surgeries or modalities, leading to a reduced detrimental impact on eating and coped better post-treatment.

Sociodemographic factors were also observed to be significant predictors of poorer HRQOL. For the Indian ethnicity, the health utility value was expected to reduce by 0.150 points compared to the Malay ethnicity, who forms the major race in Malaysia. This decrease was important as it was larger than the established minimally important clinical difference (Pickard *et al.*, 2007). The main determinant hypothesised was the severity of oral cancer as the Indian ethnicity formed almost half of the proportion of patients with Stages III and IV in the sample. Nevertheless, the risk persisted even after controlling for severity and sociodemographic factors such as income and location in the regression model. Thus ethnicity may play an independent role in a patient's responses to disease and treatment. Two large cross-sectional studies among cancer patients in Malaysia identified race and religion as significant determinants of HRQOL responses, with the Indian ethnicity reported as a negative predictor (Farooqui *et al.*, 2013; Akhtari-Zavare *et al.*, 2018). It was postulated that poor socioeconomic status and spiritual concerns arising from cultural differences may have confounded the lower QOL values (Simha *et al.*, 2013; Akhtari-Zavare *et al.*, 2018).

Oral cancer patients at the bottom 40th percentile of the Malaysian national income average (less than RM4,360) faced a reduction in their HRQOL relative to the more affluent populations in our sample. A possible rationale postulated was that a larger proportion of patients from lower socioeconomic status were diagnosed at later stages due to financial barriers, hence reporting poorer HRQOL (DiMartino *et al.*, 2017). However, there was no significant difference between the income and diagnosis groups in our sample. Therefore, HRQOL responses were likely to be independently implicated by patients' financial stability. The ASEAN Costs In Oncology (ACTION) study evidenced similar decrements in health utility values among patients experiencing catastrophic financial expenditures. While the study did not explore the association between financial status and disease severity, they concluded that economic disadvantages had an underlying relationship with health and QOL outcomes in cancer (ACTION Study Group *et al.*, 2015).

There has been a paradigm shift recently in oncology, moving from a paternalistic treatment approach towards respecting the

autonomy and personal journey of patients. Some of the ways the change was achieved were by adopting various QOL tools and instruments to guide healthcare providers on patients' viewpoints besides survival and clinical outcomes. Concurrently, proxy values of well-being such as HRQOL have also been increasingly applied in health technology assessments in the form of cost-utility and cost-effectiveness analysis. In the present study, the preference-based measure using EQ-5D-5L was shown to be able to precisely reflect both disease status and responses post-treatment. The high discriminative properties demonstrated between disease severity validates the application of the utility index scores for economic assessments of policies and clinical evaluation of care in Malaysia. Such measures of the EQ-5D-5L instrument in oral cancer were also reported by several studies in other cancers and chronic diseases (Rowen *et al.*, 2012; Noel *et al.*, 2015; Aoki *et al.*, 2019).

There were nevertheless several limitations with this study. Primarily both pre-treatment and longitudinal data were not available for comparison of changes in HRQOL. The lack of such data limits the ability to distinguish whether patient responses were contributed by the disease state, or the treatment received. Secondly, a large heterogeneity was also introduced by not restricting the follow-up period of patient treatments. As literature has evidenced adaptions and response shifts among treated patients, this may water down the true effect of the care received and consequently the HRQOL scores. However, the decision for the approach was taken to reflect accurately the reality of a diverse surviving oral cancer population. These composite values represent a snapshot of patient care in public healthcare to benchmark future policy reformations. Lastly and crucially the smaller sample size of early cancer may have limited the ability of our tests to detect the marginal HRQOL differences with OPMD, in addition to detecting associations between sociodemographic factors. Thus, taking into consideration the lower detection rate of oral cancer in Malaysia, a further larger or nationwide study is warranted to ascertain if such differences and associations exist.

CONCLUSION

This study echoed previous findings of oral cancer severity impacting patients' post-treatment HRQOL. The debilitative nature of the disease and surgical interventions may continuously influence the physical well-being of patients despite the fact certain psychological and social adaptations may occur with time. For patients with OPMD, it was evidenced that their HRQOL was comparably lowered, reflecting a severity that is often underestimated. Moreover, the evaluation of a patient should not only be constructed based on clinical aspects but also by integrating sociodemographic factors such as ethnicity and economic status. This is because these features in combination may have a significant negative impact on their HRQOL. Importantly, this study acts as a reminder to continuously focus treatment decisions and follow-up supportive care to be patient-centred.

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