Household Catastrophic Health Expenditure from Oral Potentially Malignant Disorders and Oral Cancer in Public Healthcare of Malaysia

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Abstract

Objective: Oral cancer causes a significant disease burden and financial distress, especially among disadvantaged groups. While Malaysia has achieved universal health coverage via its highly subsidized public healthcare, patient and family expenditure for treatment of oral potentially malignant disorders (OPMD) and oral cancer remains a concern in the equitability of care. This study thus aims to estimate household out-of-pocket (OOP) expenditures and the extent of catastrophic healthcare expenditure (CHE) while identifying its predictors. Methods: This three-part study consists of a cross-sectional survey to collect sociodemographic and health utilization data of patients, a retrospective medical record abstraction to identify resources consumed, and cost modeling to simulate expenditures in two tertiary public hospitals. Loss of productivity was calculated based on absenteeism related to disease management in the hospital. OOP payments for transport, care in public healthcare facilities, and other healthcare expenditures were tallied. A CHE was defined as OOP spendings of more than 10% from total annual household income. Multivariable logistic regression was further applied to identify the association between sociodemographic factors and the incidence of CHE. Results: A total of 52 patients with OPMD and 52 with oral cancer were surveyed and medical records were abstracted. A Kruskal-Wallis test showed a statistically significant difference in OOP share over household income between OPMD, early- and late-stage cancer, χ²(2)=51.05, p<0.001, with the mean percentage of 9%, 22%, and 65% respectively. This study found that the prevalence of CHE in the first year of diagnosis was 86.5% for oral cancer and 19.2% for OPMD. Indian ethnicity (OR=6.24, p=0.046) and monthly income group ‘less than USD 2,722’ (OR=14.32, p=0.023) were shown as significant predictors for CHE. Conclusions: Our study demonstrated the provision of subsidies may not be adequate to shield the more vulnerable group from CHE when they are diagnosed with OPMD and oral cancer.

Keywords: Oral cancer- OPMD- catastrophic health expenditure- out-of-pocket- universal health- inequality

Introduction

Oral cancer is amongst the most common cancers globally, corresponding to around 377,713 cases and 177,757 deaths in 2020. From these estimated worldwide figures, 65.8% of the patients reside in the Asian region and contribute disproportionately towards 74% of global deaths due to oral cancer (Sung et al., 2021). Besides posing a significant disease burden in terms of poor survival and quality of life, the economic strains from the illness were shown to negatively impact households and drain national healthcare coffers (Rezapour et al., 2018; Amarasinghe et al., 2019; Raman et al., 2021). The perturbing trepidation of oral cancer is that it is more frequently diagnosed in disadvantaged groups while simultaneously implicating immense financial distress for treatment, trapping them in an economic crisis (Warnakulasuriya and Greenspan, 2020; Sung et al., 2021).

Despite the overwhelming risk of oral cancer and oral potentially malignant disorders (OPMD) which often precedes it, policymakers and key stakeholders have been slow to react to the financial consequences of treatment.
due to a lack of evidence (Kimman et al., 2015). The available established values from high-income nations are not reflective of the reliance on out-of-pocket (OOP) financing to access preventive and curative care in most of the ASEAN countries. Such unforeseen payments for healthcare, coupled with the debilitating nature of the disease and treatment, can cause households to spiral towards poverty. The ASEAN Costs In Oncology (ACTION) initiative in 2012 reported almost half of the households with cancer patients experienced catastrophic health expenditures (CHE) (Kimman et al., 2015). Patients in advanced disease stages and socioeconomically disadvantaged were shown to be the most vulnerable.

Malaysia forms an interesting case study on the household financial implications of oral cancer in a middle-income country with universal health coverage. The public health system has been the backbone of health services with wide-ranging access to preventive and curative care at low charges. Patient charges for both inpatient and outpatient care are mostly subsidized using funds from general taxation and revenues from the federal government (Ng, 2015). The user fees are aimed to enable cost-sharing progressively in the public sector, although to date, remained paltry at 3 to 5% for any significant cost recovery (Wan et al., 2014). Despite these studies, the extent of expenditures in OPMD and oral cancer remains unknown and is expected to be multifold higher. The reason is that the treatment of oral cancer is often complex, multimodal, and necessitates prolonged care (Raman et al., 2021). Hence, this study aims to estimate the household OOP expenditures for the management of OPMD and oral cancer while exploring their differences. It also endeavors to fill the research gap in the literature on the prevalence of CHE and their predictors in the region so that focussed recommendations against financial toxicities can be devised.

Materials and Methods

Study design and sampling

This study consists of three workstreams- (1) a patient survey to collect sociodemographic and health utilization data of patients and (2) a retrospective medical record abstraction to identify resources consumed and (3) a simulation model for cost estimation in public healthcare facilities (Figure 1). Data collection was conducted from August 2019 to January 2020 at the Oral Maxillofacial Specialist clinics in Hospital Tengku Ampuan Rahimah (HTAR), Klang and Hospital Umum Sarawak (HUS), Kuching, Malaysia. Both of the publicly funded tertiary care hospitals are oral cancer referral centers, covering a diverse patient population in East and West Malaysia. The study was registered and approved by the Ministry of Health Medical Research Ethics Committee (NMRR -18-3842-45321) and the Universiti Sains Malaysia Human Research Ethics Committee (USM/JPEmM/18120789).

The sample size was estimated based on detecting a difference of 20% in the percentage of OOP spending over income and a standard deviation of 30% between OPMD and oral cancer, with a power of 80% and a two-sided level of significance of 5% (Iragorri et al., 2021). The required samples were further adjusted to reflect the distribution of cancer stages as reported in the cancer registry (Azizah et al., 2019). A total of 80 samples were required, with 40 for OPMD, 10 for early-stage, and 30 for late-stage oral cancer. The sampling frame consisted of adult patients attending review at the specialist clinics, with histologically confirmed cases of oral cancer or OPMD. An oral cancer diagnosis was classified following the International Classifications of Diseases 10th revision as ICD00 to ICD06 (World Health Organization, 2004). American Joint Committee on Cancer (AJCC) TNM system was applied to the staging of oral cancer. Stages I and II were categorized as early-stage, whereas Stages III and IV as late-stage cancer. OPMD conversely was defined according to WHO Collaborating Centre for Oral Cancer and Precancer. These lesions consisted of leukoplakia, lichen planus, oral submucous fibrosis, erythroplakia, and any other histologically confirmed dysplasias (Ariyawardana et al., 2007).

No restriction on post-treatment duration was set for eligibility. Nevertheless, cases were ensured for the completion of a minimum of a single treatment. This was designated as at least completion of any surgical or oncologic intervention for oral cancer. In OPMD, patients should have either completed excisional surgery or been treated using medications or allotted for clinical monitoring without active interventions.

Patient Survey

Patients were enlisted by stage-stratified convenience sampling. The interviewer-assisted survey used a structured questionnaire comprising of two parts: Sociodemographic Information and Health Utilisation Data. Postcode and township information was used to categorize patients into ‘urban’ or ‘rural’ residences following the local government classification list. Household income was split following the lower-40th percentile of the national median monthly income of MYR 4,360 (USD 2,722) or also known as the B40 group, as national policies are shaped by such delineation (Mahdin, 2017; Ng et al., 2018). Health Utilisation Data consisted of two domains- Other Healthcare Expenditures and Travel Expenses. Other Healthcare Expenditures were intended to estimate monthly healthcare expenditures related to oral cancer or OPMD at other than government facilities. This encompassed the expenditures to purchase medications, supplements, and medical equipment or to acquire support services and alternative treatments. Travel Expenses consisted of fares for public transport or mileage cost for personal vehicles per trip to public healthcare facilities.

Data Abstraction

A standard proforma was constructed following treatment guidelines (Pfister et al., 2020) and multidisciplinary-team discussions consisting of oral maxillofacial surgeons, dental public health officers, dentists, oncologists, radiologists, pharmacists, and nurses. Study investigators used the proforma to collect information on OPMD or oral cancer attributable events and services. This consisted of all activities and their respective frequencies in outpatient care,
biopsy, investigations, diagnostic tests, chemotherapy, radiotherapy, and inpatient care. The number of days of hospitalization was also calculated based on these recorded clinical events.

Modelling OOP Expenditures

A modeling approach was adopted rather than patient-reported charges to avoid recall biases in our sample and to standardize charges between both facilities (Lu et al., 2009). A Theoretical Patient Expenditure Model was constructed using Microsoft Excel (2016) based on the designated clinical pathway and patient journey (Figure 2) to estimate household spending to access public healthcare facilities (Beacher and Sweeney, 2018; Pfister et al., 2020). The three main cost parameters simulated through the model were patient fees in public healthcare, travel and transport, and loss of productivity. OOP expenditures in public healthcare were enumerated to be as close to hospital itemized billing by taking into consideration individual payer status, exemption, cost bundle, and subsidization rates. The payment was calculated by multiplying the frequency of identified clinical events with their respective charges as stated in the Medical Fees Order (Cost of Services) 2014.

Travel costs were tallied according to the frequency of hospital visits obtained from medical record abstraction and per trip expenses reported by patients. The loss of productivity in the study was calculated using a human capital approach and only involved absenteeism from treatments in hospitals (Barton, 2001). The total number of days spent by patients and carers in the hospital was aggregated and multiplied with daily household wages. Daily wages were calculated by dividing the monthly income by 30 days as subjects arise from varied employment statuses.

Catastrophic Health Expenditure

Catastrophic health expenditure was defined as OOP spendings of more than 10% of total household income in a year (Loganathan et al., 2015; Wagstaff, 2019). In a highly subsidized healthcare system like Malaysia, an income-based approach was preferred as it will avoid overestimation from using a ‘capacity-to-pay’ method (Wagstaff, 2019). As cancer spendings demonstrate a large disparity between the initial and maintenance period upon diagnosis, total expenditures and further analysis on CHE ratio were split and calculated accordingly. The initial phase was defined as the first 12 months from the first healthcare visit. The CHE in the initial phase was calculated by dividing the total OOP expenditures by the total income accrued over the actual treatment duration to avoid underestimations (Barlow, 2009). The maintenance phase included all expenditures after the period of one year till the last care event recorded. Here the total OOP expenditures were first annualized and then divided with annual household income as costs are assumed to be constant in the maintenance period (Yabroff et al., 2008).

Results

A total of 52 patients with OPMD and 52 with oral cancer were surveyed, with all their respective medical records successfully abstracted. The number of patients

![Figure 1. Study Framework for Estimation of CHE](image-url)
with oral cancer according to TNM staging were: 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%). Table 1 shows the sociodemographic characteristics and clinical presentation of the patients. The average monthly household income of patients was MYR 2,254; SD=2,072; 95% CI=1,851-2,657 (M=USD 1,407; SD=1,293, 95% CI=1,155-1,659) and ranges from a MYR 200 (USD 125) to MYR 12,000 (USD 7,491). A large proportion of patients were from the B40 group (89.4%). There was a significant difference in the distribution of disease stage by patients’ residence, with late-stage cancer occurring more frequently in rural populations. Other sociodemographic factors remained comparable.

### Table 1. Sociodemographic and Clinical Characteristics of Patients

| Characteristic       | OPMD (n=52) freq (%) | Early cancer (n=10) freq (%) | Late cancer (n=42) freq (%) | p-value<sup>a</sup> |
|----------------------|----------------------|------------------------------|----------------------------|----------------------|
|                      | All group            | Cancer                       |                            |                      |
| **Age**              |                      |                              |                            |                      |
| < 60                 | 25 (48.1)            | 6 (60.0)                     | 20 (47.6)                  | 0.766                |
| ≥ 60                 | 27 (51.9)            | 4 (40.0)                     | 22 (52.4)                  | 0.726                |
| **Gender**           |                      |                              |                            |                      |
| Male                 | 18 (34.6)            | 6 (60.0)                     | 18 (42.9)                  | 0.313                |
| Female               | 34 (65.4)            | 4 (40.0)                     | 24 (57.1)                  | 0.483                |
| **Race**             |                      |                              |                            |                      |
| Malay                | 14 (26.9)            | 1 (10.0)                     | 6 (14.3)                   | 0.279                |
| Chinese              | 6 (11.5)             | 4 (40.0)                     | 10 (23.8)                  | 0.77                 |
| Indian               | 27 (51.9)            | 4 (40.0)                     | 20 (47.6)                  |                      |
| Indigenous           | 5 (9.6)              | 1 (10.0)                     | 6 (14.3)                   |                      |
| **Location**         |                      |                              |                            |                      |
| Urban                | 26 (50.0)            | 8 (80.0)                     | 15 (35.7)                  | 0.036                |
| Rural                | 26 (50.0)            | 2 (20.0)                     | 27 (64.3)                  | 0.015                |
| **Education**        |                      |                              |                            |                      |
| None/primary         | 18 (34.6)            | 3 (30.0)                     | 27 (64.3)                  | 0.009                |
| Secondary/tertiary   | 34 (65.4)            | 7 (70.0)                     | 15 (35.7)                  | 0.075                |
| **Occupation**       |                      |                              |                            |                      |
| Not working          | 21 (40.4)            | 2 (20.0)                     | 21 (50.0)                  | 0.292                |
| Employed             | 20 (38.5)            | 2 (20.0)                     | 10 (23.8)                  | 0.193                |
| Retired              | 11 (21.1)            | 4 (40.0)                     | 11 (26.2)                  |                      |
| **Household income** |                      |                              |                            |                      |
| < MYR 4,360          | 47 (90.4)            | 9 (90.0)                     | 37 (88.1)                  | 0.115                |
| > MYR 4,360          | 5 (9.6)              | 1 (10.0)                     | 5 (11.9)                   | 0.898                |
| **Healthcare insurance** |                  |                              |                            |                      |
| Covered              | 3 (5.8)              | 2 (20.0)                     | 2 (4.8)                    | 0.228                |
| No cancer coverage   | 49 (94.2)            | 8 (80.0)                     | 40 (95.2)                  | 0.163                |
| **Anatomic site**    |                      |                              |                            |                      |
| Buccal mucosa        | 32 (61.5)            | 4 (40.0)                     | 21 (50.0)                  | 0.347                |
| Tongue               | 13 (25.0)            | 5 (50.0)                     | 9 (21.4)                   | 0.359                |
| Alveolar             | 1 (1.9)              | 0 (0.0)                      | 3 (7.1)                    |                      |
| Others<sup>b</sup>   | 6 (11.5)             | 1 (10.0)                     | 9 (21.4)                   |                      |
| **Treatment modality** |                     |                              |                            |                      |
| Observation          | 15 (28.9)            | NA                           | NA                         | NA                   |
| Oral/topical therapy | 29 (55.8)            | NA                           | NA                         | NA                   |
| Surgery, S           | 8 (15.4)             | 7 (70.0)                     | 12 (28.6)                  |                      |
| Multimodal           | NA                   | 3 (30.0)                     | 30 (71.4)                  |                      |

NA, not applicable; <sup>a</sup> Fisher’s exact test with two-sided significance set to p<0.05 was applied. ‘All group’ difference was compared between OPMD, early- and late-cancer, while ‘cancer’ comparison was between early- and late-cancer alone. <sup>b</sup> Consists of the gingiva, lip, floor of mouth, palate, mandible, and other sites.
Table 2. Annual OOP Healthcare Expenditure, income Share and Prevalence of CHE

|                      | OPMD          | Early cancer | Late cancer | p-value |
|----------------------|---------------|--------------|-------------|---------|
|                      | Mean | SD  | Mean | SD  | Mean | SD  | Mean | SD  | All group \(a\) | Cancer \(b\) |
| Total Cost (MYR)     |      |     |      |     |      |     |      |     |              |               |
| Initial              | 2.320 | 2.262 | 7.628 | 6.323 | 10.133 | 9.960 | <0.001 | 0.378 |
| Maintenance          | 424   | 573  | 528  | 929  | 497   | 636   | 0.729  | 0.533 |
| (A) Household productivity loss (MYR) |      |     |      |     |      |     |      |     |              |               |
| Initial              | 1.106 | 942  | 4.368 | 5.135 | 5.112 | 8.116 | <0.001 | 0.935 |
| Maintenance          | 674   | 610  | 620  | 893  | 499   | 600   | 0.359  | 0.865 |
| (B) OOP healthcare expenditure (MYR) |      |     |      |     |      |     |      |     |              |               |
| Initial              | 1.214 | 1.715 | 3.260 | 1.918 | 5.021 | 1.934 | <0.001 | 0.39  |
| Maintenance          | 1.132 | 1.810 | 1.525 | 1.886 | 1.151 | 945   | 0.192  | 0.91  |
| (I) User fees in public healthcare (MYR) |      |     |      |     |      |     |      |     |              |               |
| Initial              | 61   | 129  | 1.082 | 1.169 | 1.463 | 1.184 | <0.001 | 0.341 |
| Maintenance          | 21   | 41   | 19   | 23   | 43   | 68    | 0.738  | 0.734 |
| (II) Travel and transport (MYR) |      |     |      |     |      |     |      |     |              |               |
| Initial              | 380  | 1.013 | 989  | 1.416 | 2.788 | 4.322 | <0.001 | 0.102 |
| Maintenance          | 192  | 268  | 184  | 203  | 404  | 326   | 0.009  | 0.042 |
| (III) Other healthcare expenditure (MYR) |      |     |      |     |      |     |      |     |              |               |
| Annual reported values \(c\) | 940 | 1.449 | 1.189 | 1.916 | 1.577 | 2.552 | 0.584  | 0.57  |
| OOP healthcare income share (%) |      |     |      |     |      |     |      |     |              |               |
| Initial              | 9.1  | 18.9  | 22.3  | 19.1  | 65.5  | 65.1  | <0.001 | 0.015 |
| Maintenance          | 4.3  | 6.4   | 10   | 15.7  | 10.3  | 8.7   | 0.005  | 0.282 |

|                      | n   | %   | n   | %   | n   | %   | All group \(a\) | Cancer \(b\) |
|----------------------|-----|-----|-----|-----|-----|-----|-----------------|--------------|
| Number of households facing CHE |      |     |      |     |      |     |                 |              |
| Initial (over 1-year) | 10 | 19.2 | 8 | 80 | 37 | 88.1 | <0.001 | 0.5  |
| Maintenance          | 4  | 15.4 | 3  | 33.3| 8  | 50  | 0.055 | 0.42 |

\(a\) ‘All group’ difference was compared between OPMD, early- and late-cancer, while ‘cancer’ comparison was between early- and late-cancer alone
\(b\) Kruskal-Wallis H test with two-sided significance set to \(p<0.05\); \(c\) Fisher’s exact test for proportions with two-sided significance set to \(p<0.05\);

Other healthcare expenditure values were obtained from the patient survey and annualized. The assumption made was the cost remained consistent regardless of the treatment phases as longitudinal data was not available.

Table 2 summarises healthcare expenditures by cost components, OOP income share, and prevalence of CHE. The only significant difference between the early and late-stage cancer was travel costs in the maintenance phase, with the latter being higher. Additionally, there was a statistically significant difference in the annual travel cost between urban and rural areas, \(\chi^2(1, n=104)=12.78, p<0.001\), with the mean value of MYR 986 (USD 559) and MYR 1,870 (USD 1,167), respectively. Patients with cancer incurred a larger productivity loss compared to OPMD, which coincided with a significant difference in absenteeism from treatment, at 59.6 and 12.4 days respectively, \(\chi^2(1, n=104)=56.0, p<0.001\). No significant difference was observed in loss of productivity between early and late cancer, which also corresponded to no significant difference in absenteeism from treatment, at 51.1 and 61.7 days respectively, \(\chi^2(1, n=52)=1.54, p=0.2142\). The OOP expenditure income share in the initial phase demonstrated a significant difference between cancer stages, with late-stage cancer being larger. Catastrophic health expenditure was experienced by more than 80% of households with oral cancer in the initial phase.

Table 3 shows the association between sociodemographic factors and diagnosis with the probability of incurring CHE. Results of the multivariable logistic regression indicated that there was a significant collective effect between age group, race, income group, and diagnosis with CHE, \(\chi^2(7)=68.95, p<0.001\). Only race (Indian) and income group were shown to be the significant predictors of CHE when all other variables were held constant.

**Discussion**

**Inequities and CHE**

The prevalence of CHE in the first year of oral cancer at 86.5% was significantly higher compared to findings from other local and international studies. The ACTION study reported that the average prevalence of CHE in households with all-type cancer was 48% (Kimman et al., 2015). The lower occurrence was likely contributed by a higher CHE cut-off point of 30% of the OOP-to-income ratio relative to our 10%, which was the more commonly applied threshold to define the ability to pay. Replacing the threshold with 30% in our study would reduce the prevalence of CHE to a comparable 50%. Thus while showing a disparity at first glance, our study echoed a similar financial burden as other ASEAN countries. Likewise, a study by Azzani et al.
among colorectal cancer patients in Malaysia reported that 47.8% of households faced financial catastrophe a year after diagnosis (Azzani et al., 2017). While the study was similar in terms of setting and methodology, they adopted a different threshold of ‘40% above nonfood expenditure’ to define CHE.

Household economic status was demonstrated as a vital determinant of CHE. This was partly given as catastrophic expenditure was defined in relation to the budget share of OOP spendings. A large health payment portion can be contributed by either a higher OOP spending or by a lower household income. Our analysis evidenced that OOP expenditures were constant across different diagnosis groups based on income categories. Thus, consistent with findings in the region, household income played a major role in CHE in Malaysia (Kim and Yang, 2011; Kimman et al., 2015; Leng et al., 2019). Perplexingly, factors that are interconnected with lower household income such as age, rural area, education level, and occupation showed no association with CHE in our sample (Kimman et al., 2015; Koris et al., 2017).

### OOP expenditures and productivity loss

Our findings demonstrated that traveling to access health services can become a financial barrier, even if consultations and treatments are subsidized. The combination of a high frequency of visits and greater distance traveled to tertiary care in the initial phase adds up to the inflated cost. Several studies conducted in India, for instance, echoed similar logistic expenditures taking more than 50% of patients’ OOP share (Chauhan et al., 2019). Such trend persists and is expected to rise as patient load and congestions continue to surge in hospitals, necessitating numerous visits to the multidisciplinary team and services. The higher unit cost of transportation further amplifies the traveling expenses. More than half of our subjects were from rural areas. They regularly need to travel a longer distance or hire private vehicles to seek treatment in tertiary care located in urban areas.

Our study found no significant difference in the household loss of productivity cost between early and late-stage cancer. This was predominantly contributed by a comparable number of days of absenteeism for disease treatment. Such a trend was expected in oral cancer as the frequency of outpatient clinic visits and inpatient hospitalization for surgeries tend to relatively be identical in Malaysian public healthcare facilities (Azzani et al., 2017). While public healthcare may remain consistent, hospitalization for surgeries tend to relatively be identical in Malaysian public healthcare facilities (Azzani et al., 2017). While public healthcare may remain consistent, our finding largely underscores the true absenteeism from recuperation and consequently the ability to detect differences between stages. Pearce et al., (2015) in their study based on an employment status survey for example reported the average total time taken off work for recuperation post-surgical interventions in head and neck cancer was almost nine months, differing according to the severity of the disease and treatment regimes.

Despite the invaluable contribution of our recent findings, these values need to be pieced together cautiously by taking into consideration several limitations. Firstly, the main limitation of the study stems from the design of costing estimation via a simulation model. While such a design avoids constraints of recall biases, the values tend to grossly underestimate productivity losses. This is because the loss of productivity days outside the public healthcare setting was not included. Secondly, a broad inclusion criterion was adopted in this study to ensure the robustness of estimates. The drawback of such an approach is an incomplete financial burden from shorter follow-ups. Lastly, the study was not powered to identify the factors associated with CHE as the primary objective.
This study was part of an approved student’s Master’s degree thesis in Universiti Sains Malaysia.

**Data availability**

The data that support the findings of this study are available from the corresponding author, [AA Shafie], upon reasonable request and approval from the Director-General of Health Malaysia.

**Conflict of Interest**

The authors declare no conflict of interest.

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