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Factors associated with delayed presentation among patients with oral cancer in Malawi

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INTRODUCTION

Worldwide oral cancer is the sixth most common cancer, affecting important structures for respiration, feeding and vision and is the leading cause of illness and death.[1,2]In developing countries such as India and Tanzania, many cancer patients visit healthcare facilities in the late stage of the disease. This results in delayed diagnosis, poor prognosis, and palliative care treatment. Comparatively in developed countries such as the United Kingdom (UK) where oral cancers are usually diagnosed early,[1,3] there is less disfigurement, and a reduction in management costs of oral cancer patients. [4]

Several factors associated with treatment delays have been identified, including gender, patient age, tumor site, lack of awareness, differences between rural and urban areas, fear of disfiguring surgery, and psycho-social factors .[3]

Among oral cancer patients in developing countries, one of the significant factors contributing to the severity of the disease is a lack of positive health-seeking behavior.[5] Health-seeking behavior is any action taken by a person who believes that they have a health problem or they are ill with the intention of finding a suitable treatment.[6] This is influenced by a lack of knowledge of oral cancers, culture, religion[2], challenges in accessing a health facility and high treatment costs.[1]

The delay can be stratified into three phases; first phase is patient delay, the time taken for the patient experiencing symptoms of a disease to visit the health care facility .[7] The second phase is healthcare worker delay, the time from when the healthcare worker has seen the patient with oral cancer symptoms to the time diagnosis is made.[1] The third phase is total delay, between the time from when the patient became aware of the symptoms to the time diagnosis is made.[4]

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In developing countries, an estimate of 20%-50% of patients will visit the health care worker in the range of 1-3 months after noticing the symptoms of oral cancer.[1, 8] and about 5 out of every 10 oral cancer patients have advanced-stage disease when they are first diagnosed. [1, 8] the patient›s delay accounts for most of the delay rather than health care worker delay. [9] It was also found that, 55.6% of the patients visited health facilities that did not offer oral health services and another reason for the delay was the absence of pain.[8] A study in India [10]reported that patients delay in seeking treatment was associated with low knowledge (p= 0.014) and 52%- 60% of patients presented to the hospital late after noticing symptoms and having to travel 10km on average to the nearest health facility.[10,11]

According to studies in Sri Lanka [11] and India, [10,] most patients (59- 61%) were diagnosed with advanced stage of cancer, which was attributed to delayed presentation (p=0.001). A study in India [10] reported a significant association of patients delaying for treatment at a health facility and fear (p =0.01). [7,10,11] Agarwal *et al* [11] reported that approximately 70% and 77% of patients were aware of oral cancer but not its symptoms. According to Rath *et al*, [5] ninety percent of patients were of the view that symptoms of oral cancer will disappear on their own and eighty percent of the patients went to the hospital because the lesion was increasing in size.[5, 12]

Malawi's population was approximately 17.4 million in 2017 with 64% under 15 years and life expectancy of 58 years was estimated for both genders[12]. The Malawi health system comprises private for-profit, non-profit, and public sector [12]. Moreover, the Ministry of Health offers public services and works with private sector such as the Christian Health Association of Malawi (CHAM) to provide essential health services. Although the public health services are free, but CHAM charges a user fee [12], the public health system is organised into a primary, secondary, and tertiary level. [12] The tertiary level provides advanced specialised care, secondary services are offered by district 4 hospitals which serve as a referral point for patients from the primary level[12]. The primary level of healthcare in Malawi consists of village clinics, dispensaries, and health centers. However, the distance to the nearest health center or dispensary exceeds 10 kilometers [12]. Despite that, a referral process is followed to ensure appropriate healthcare delivery. Patients are directed from dispensaries to health centers, and then further referred from district hospitals to central hospitals [12]. These factors are indicative of the challenges individuals face in accessing these services in Malawi.

The health-seeking delay adversely affects the management planning and the treatment outcome of the patient.[8] Since most of the patients in poor nations depend on public health services, this delay has a huge impact on human capital and material resources.[8, 14] The delay in seeking care

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can eventually result in treatment that requires extensive ablative surgeries, a need for more expertise, a longer stay in the hospital, and possible significant morbidity because of structural and aesthetic defects in the patient. [8, 14]

In Malawi contributing factors to delay in seeking care among cancer patient are limited knowledge of the initial symptoms of cancer and financial constraint. [15, 16]Because of this, women with cervical and breast cancer delay for screening, diagnosis and treatment.[15,16]Other factors include long distance and unavailability of cancer screening facilities in the health centers .[15, 16] Another factor was the prolonged use of antibiotics before referral of the patients and also consultation of traditional healers oherbalist [16]. Patients took 42 weeks to visit the main referral hospital after noticing initial symptoms of cervical cancer in a study done in Malawi.[16] On average, 8 out of every 10 patients seeking medical care at the hospital are in a critical condition that cannot be treated in Malawi.[16, 17]

METHODOLOGY

This was a descriptive study conducted in all major referral hospitals in Malawi namely: Mzuzu, Kamuzu, Queen Elizabeth and Zomba Central Hospital from April to June 2023. This study population consisted of 68 patients, histologically diagnosed with oral cancer attending dental clinics during the study period. The inclusion criteria were all oral cancer patients who were willing to give consent. Excluding criteria was all the patients who did not consent, patients not able to provide any of the necessary details, patients with onset symptoms and patients less than 18 years. The sampling technique employed for this study was non-probability systematic sampling.

The independent variables were demographic variables; (age, sex, level of education), social economic status, level of education and organisational factors (long walking distance to the health facility. The dependent variables were oral cancer and the reason for delayed presentation. A closed ended structured questionnaire was used for data collection. The questionnaire translated from English to Chichewa was used to collect relevant information. A pilot study involving five patients in each central hospital was undertaken to adapt it to the local conditions.

The questionnaire was divided into social demographic information where age was categorised into distinct age ranges, using a grouping interval of 20 years. Marital status was divided into two groups: married individuals (including those who were married or cohabiting). While unmarried individuals consisted of singles, widows, widowers, and divorced individuals. The level of education was categorised based on different educational milestones or degrees achieved. The following categories were used: Illiterate (without formal education): Participants who had never attended primary school. Educated (formal education) Participants who had attended primary education, finished primary education, attended secondary school, finished secondary school, or obtained a college/university education.

Additionally, income level was categorised as follows: low income: Participants earning less than or equal to K 50,000 (equivalent to 1000 Rands).

Medium income: Participants earning between K 50,000 and K 100,000 (equivalent to 1000-2000 Rands). High income: Participants earning more than K 100,000 (equivalent to more than 2000 Rands). When it comes to Health seeking behavior, the distance to the nearest health facility was categorised into two groups: less than 10 kilometers and more than 10 kilometers. The patient was considered to have been delayed for treatment if it took more than two weeks to report to the health care worker upon noticing the initial symptoms. The diagnosis was recorded from the Pathology Laboratories of the Kamuzu Central and Queen Elizabeth Central hospitals.

Permission was obtained from the heads of departments of the dental units for the study to be conducted within their departments. Data was entered into an Excel spreadsheet, cleaned, validated, and analysed using STATA version 17. Data was presented using frequency distributions, pie chart and histogram. The independent variables were examined statistically for associations and a p-value of =0.05 was taken as significant. Logistic regression was used to determine socio-economic factors associated with delayed presentation. Each participant gave their written informed consent after receiving ethical approval from the Wits University Human Research Ethical Committees and Kamuzu University of Health Science (COMREC). The Research committees' of all central hospitals approved this study. The Heads of Department in the dental units gave permission for the study to be conducted in their departments.

RESULTS

The total number of participants was 68 patients with oral cancer of which 36(52.4%) were females (and thirty two (n=47.06%) were males Twenty-six percent were between 21-40 years while five (7.35%) of the patients were above 60 years see **(Table I)**.

Table 1: Social- demographic characteristics

Social demographic characteristics	Frequency (68)	Percentage
Sex		
Male	32	47.06
Female	36	52.4
Age group		
0-20	12	17.65
21-40	26	38.24
41-60	25	36.76
>60	5	7.35
Education		
Illiterate	51	75
Educated	17	25
Marital status		
Married	39	57.35
Unmarried	29	42.65
Primary	**32**	**47.06**
Secondary	23	33.82
Tertiary	13	7.35
Occupation		
Employed	21	30.88
Farmer	39	57.35
Student	8	11.76
Income		
Less than K50,000 (1000R)	51	75
Between K50,000 and K100,000 (1000-2000R)	11	16.8
More than K100,000 (>2000)	5	7.3 5

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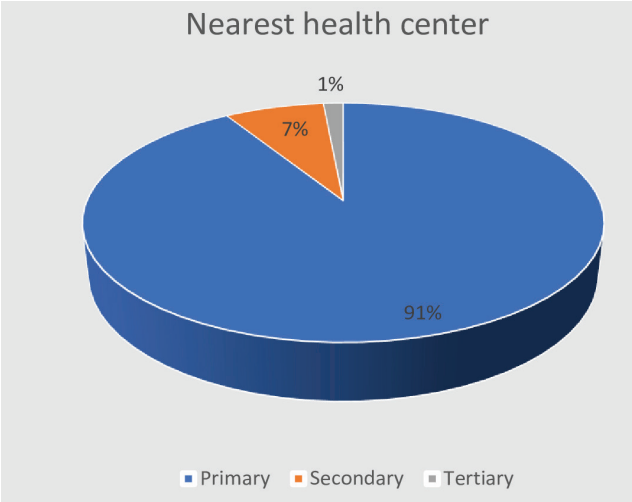
Most of the patients were farmers (n=39, 57.35%) and twenty-one (30.88%) of the patients were employed, while (n=51, 75.88%) were illiterate with a level of income of less than K50, 000 (1000R) a month (n=51, 75%). Fifty patients (73.53%) reported that the distance to the nearest health facility was more than 10 km. The nearest health facility for most of the patients (n=62, 91.18%) was a primary health care facility and only one (1.47%) of the patients was close to the central hospital **[Figure 1].**

Figure 1: Distribution of patients according to the health facility they attended.



Most of the patients (n=45, 66.18%) reported unavailability of dental services at the nearest health facility. More than that, thirty-two patients (47.06%) were referred from primary healthcare facilities, followed by those who were referred from district hospitals (n=23, 33.82%). While a smaller proportion (n=13, 19.12%) directly arrived at the tertiary health centers without prior referral. Thirty-eight patients (55.88%) were able to inform their relatives when they are sick, and of which (n=22, 32.35%) informed their spouses. Thirty-six patients (52.94%) and (n=31, 45.59%) reported that the main reason for visiting the hospital was pain and increasing symptoms respectively.

Most participants (n=55, 82.35%) experienced a delay in seeking healthcare after recognising the initial symptoms. Twelve patients (17.65%) sought care within one to two weeks, forty (58.82%) waited for more than three weeks to six months, and, sixteen (23.53%) reported waiting for over 12 months. There was no statistically significant between delayed visit to healthcare facilities after symptom recognition and various social demographic characteristics, including marital status (p = 0.064), age group (p = 0.411), occupation (p = 0.170) and educational level (p = 0.463). However, there was a statistically significant correlation (p = 0.042) was found between the delay in reporting to the nearest healthcare facility and the distance to that facility. There was significance (p = 0.000) between the delayed presentation and the nearest health care facility as well as disclosure of symptoms to a relative or a spouse **[Table II].**

Factors	Delayed	Not Delayed	Chi-Square	P-Value
Age				
0-20	9	3	2.9	0.411
21-40	23	3		
41-60	21	4		
>60	3	2		
Education				
Educated	13	4	0.5	0.463
Illiterate	43	8		
Marital status				
Married	35	4	3.43	0.064
Unmarried	21	8		
Employment				
Employed	16	5	5.02	0.17
Farmer	33	6		
Student	7	1		
Gender				
Male	29	7	0.2	0.68
Female	27	5		
Distance				
Less than 10km	12	6	4.4	0.042
More than 10km	44	12		
Nearest Health facility				
Primary H/C	55	7	19.76	0.000
Secondary H/C	1	4		
Tertiary H/C	0	1		
Disclosure of cancer				
Yes	51	5	12.29	0.000
No	5	6		

Table II: Different factors associated with delay.

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The histology results were available to 47 patients, (69.12%) at one to two weeks and to 21 patients (30.88%) at more than three weeks. Seventeen patients (25%) reported to the health facility when oral cancer was at stage I and 41 patients (60.29%) reported to the health facility when oral cancer was at stage II.

Fifty (73.53%) of patients reported that they have never heard of oral cancer and all the patients were not afraid to see the doctor. Most participants (n=45, 66.18%) had already started taking medication prior to their visit to the health facility, with 45 (66.67%) of them self-prescribing the medication. Fifty nine of the participants (86.76%) stated that they had sufficient time to make a visit to a health facility.

The logistic regression analysis results for factors predicting delayed hospital reporting are presented in Table 4. An odds ratio of 3.6 suggests that individuals who are more educated are 3.6 times more likely to have heard about oral cancer in relation to those with a lower level of education, with p value of 0.584 which is not statistically significant. Furthermore, individuals who are located more than 10km are 3.7 times more likely to have a delayed presentation for treatment compared to individuals who are located less than 10km; the association is statistically significant (p-value 0.05). More than that the odds ratio of 3.4 suggests that individuals close to primary healthcare (HCF) are 3.4 times are more likely to have delayed presentation in seeking treatment unlike individuals located close to secondary and tertiary healthcare, this difference with a p=0.004 was statistically significant.

Table III: Logistic regression analysis for predictors of late reporting to the hospital

Factor	p-Value (logistic regression test)	0R (95% CI)	
Level of education vs hearing about oral cancer	0.584	3.6 (.1672752	2.739744)
Less than 10km vs more than 10km	0.05	3.7(1.000086	13.44329)
Primary H/C vs Secondary and Tertiary H/C	0.004	3.4 (1.119468	5.775417)

DISCUSSION

This study was done in all central hospitals of Malawi which serve as the main referral centers in the country. In the Malawi healthcare system, patients with oral cancer are referred and treated through a similar process. Thus, patients initially seek care at primary healthcare facilities such as dispensaries or health centers, where a clinical diagnosis is made. [8] Subsequently, they are referred to a district hospital and then to central hospitals, where specimens are collected for histological diagnosis and later treatment. [3, 8] These findings enhance the understanding of the delay in diagnosis and treatment-seeking among oral cancer patients, and the similarities have been noted in prior studies.[5, 8]

Moreover, in this study women were more affected compared to men, the same findings were reported in Tanzania, which has a similar healthcare system as Malawi. [8] However, this contrasts with numerous studies in India where men were more affected than females.[13, 18] According to the findings of this study, men tend to exhibit a higher tendency to delay seeking medical attention when experiencing oral cancer symptoms compared to women.[19] This could be attributed to the fact that women generally visit healthcare facilities more often to seek help than men. [20, 21] But also, women rely on larger social networks for emotional support and advice which potentially reduces the delay. [19, 21]

The delayed presentation of oral cancer patients especially men can be attributed to cultural factors.[19]despite being more susceptible to risk factors, such as tobacco smoking and outdoor work .[19] Bassey et al, [18] found that oral cancer predominantly affects the most disadvantaged population group, particularly men, with a prevalence of 25%.[18] This is, not different to the present study where most of affected patients were men from rural areas, especially farmers. Additionally, having a low-income status of less than or equal to 1,000R (K50,000) per month which is consistent with research findings in Tanzania and India .[5, 8, 14]

The results of the current study also align with those of research done in Malaysia, which found that patients' knowledge and education levels have an impact on how they interpret symptoms, use coping mechanisms, and engage in health-seeking behaviors' [2] Similarly, Scott et al [4] reported a strong positive correlation between a delayed presentation and inadequate knowledge of head and neck cancer, considering it as one of the three independent predictors of patient delay. [1, 2,7] Several studies, concluded there is a significant association between patient delay and education level, with a p-value of 0.001 [10] although this was not the case in the current study (p = 0.463).[6,7,9,10]

Most patients in this study reported farming as their occupation, which coincides with low-income levels. This higher occurrence of SCC especially among farmers might be attributed to continuous exposure to the sun and carcinogens present in the chemical composition of fertilisers, however the malignant lesions that are diagnosed at Stage I have a cure rate of more than 90%.[22,23] Early detection and timely interventions are crucial in enabling individuals to accurately evaluate oral symptoms, thereby reducing the risk of misinterpretation, and associated harmful behaviors like prolonged self-medication.[1] This will enhance the chances of successful treatment, the preservation of function, esthetics, survival rate and psychological outcome.[3, 23]

This study, found that in the early stages of oral cancer, patients frequently disregard painless lesions similar to the conclusion reached by Azhar et al,[2] but tend to visit the health care facility when in pain or upon worsening of symptoms.[2, 9] and, the persistence of symptoms was perceived as a signal that something was wrong, prompting individuals to seek medical attention. The intensity of symptoms affects the time for an individual to seek medical care. [1] Hence, the cognitive and emotional reactions to symptom detection, personal beliefs about seeking assistance, and the contextual factors surrounding symptom manifestation all contribute to the decision-making process regarding seeking help.[1]

Ravi et al, [20] in their study reported that fear was a significant factor contributing to the delay in seeking treatment.[20] Several studies [2, 15, 20] have indicated that an increase in fear is related to a higher likelihood of delayed seeking help, although the underlying reasons remain unclear. [2, 19] But fear did not have any impact on delayed presentation in this study, similar to a study in Pakistani. [23] However, delay was associated with disclosing symptoms (p=0.000) and was statistically significant however, in other studies disclosing symptoms to

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others and patient delay was not statistically significant. [19,20,23] Literature [2, 18, 21] has shown that, as oral cancer progresses in TNM staging there is persistent of symptoms, increasing concern and worry among patients. As there is deterioration of oral function affecting emotional well-being of individuals and overall quality of life, motivating patients to seek medical care. [2] This has been explained through the utilisation of the Self-Regulatory Model (SRM) which is utilised to understand the cognitive processes and mechanisms involved in individuals' perception and response to health threats. [2, 9]

The SRM provides insights into the underlying reasons behind the delay. [2,9]The model proposes that participants have four types of coping mechanisms; self-remedy based on previous experience, self-medication such as pills and mouthwashes, and consulting traditional healers', which are cheap means and readily accessible and little time cost than consulting GPs.[2] Psychologically, these coping mechanisms result in delayed presentation of patients to the HCF [9] this was observed in this study whereby patients took self-medication before seeing a clinician and hoping that the lesion will heal on its own. Thus, the application of the SRM can widen our knowledge of the processes behind patients' delay, [2,9.]

Many researchers [4, 9, 21, 23] have discussed the factors that affect patients with malignant melanoma, oral cancer, and breast cancer to delay for treatment. Factors like the severity of symptoms, anxiety, and humiliation, can contribute to the delay for medical attention in patients with breast cancer.[21] Likewise, individuals with ovarian cancer may also associate significant symptoms with an existing benign condition or coexisting illness. [21] But quick identification of specific symptoms, such as a breast lump, reduces the delay in seeking medical attention compared to patients with nonspecific symptoms.[21]

There have been studies on the delayed presentation of patients with oral cancer in Tanzania, India, and London, though the length of the delay which was considered the time the first signs of oral cancer are noticed until the patient sees a health personnel varied.[8, 14, 23] and it ranged from 31days to 2 years. [8, 14, 23] similarly, a 2–6-month delay was found in this study. But also, professional delay can also impact the treatment modalities for patients, even if they arrive at the hospital in time.[5] This study provided evidence that aligned with this where it was found that histology reports took one to two weeks to become available to the patients, although this aspect was not the focus of this present study.

The limitation of this study, the sample size was small, and the duration of data collection was short, diseases like oral cancer need a longer duration hence, it's difficult to generalize the findings must be generalized with caution. Another challenge encountered was measurements of patients' delay. The patients had to recall when they first noticed the symptom and presented it to the physician, this is prone to errors due to recall bias.

CONCLUSION AND RECOMMENDATIONS

Oral cancer was diagnosed among the young age group at central hospitals, and patients with stage I and II cancer reported delays in seeking treatment. Factors contributing to delay were living far from healthcare facilities, lack of dental staff at primary healthcare facilities, lack of knowledge about oral cancer, and the delay in receiving the previously investigated pathological results. Therefore, education and awareness campaigns should be used as a tool for guidance towards intervention programs to reduce patient delayed presentation at the primary health care level and to ensure proper diagnosis also continuing education must be offered to dental health personnel as well as health care workers at primary health care facilities. An additional measure can be the provision of Standard Operating Procedures for monitoring pre-cancerous lesions at any health Care facility. Hence conducting another study specifically targeting health care profession delays would provide valuable insights into this aspect of oral cancer management.

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