

Health care seeking behaviour characteristics of patients presenting with advanced ocular surface squamous neoplasia at Queen Elizabeth Central Hospital in Malawi

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ABSTRACT

Introduction: Ocular Surface Squamous Neoplasia (OSSN) is the most common adult malignant ocular neoplasm in Malawi and its incidence is known to be on the rise in Africa. Reasons for delayed presentation in patients having advanced disease have not been described in Malawi. We did a study to determine health care seeking behaviour characteristics of patients presenting with advanced ocular surface squamous neoplasia at Queen Elizabeth Central Hospital in Blantyre, Malawi.

Methods: This was a descriptive cross sectional study in which patients with stage T3-4d disease were recruited into the study. Interviews with patients were conducted and collected data was entered on Epi data and analysed using Microsoft excel.

Results: A total of 81 patients were recruited in this study and of these, 53% were females. Mean age was 37.4 (± 9.8 SD) years and 65.4% of patients were married. Eighty-nine percent of study patients sought health care at least one month after noticing tumour in the eye. Reasons for presenting later than a month after noticing the tumour included low suspicion of cancer (52.5%) and transport challenges (29.6%). Majority (77%) of patients in the study had no prior knowledge of the disease and lack of awareness on availability of treatment services for ocular surface squamous neoplasia was reported in 83% of all patients. Only 19% of the patients in this study regarded their eye disease as life threatening.

Conclusion: Majority of patients made their first contact with health facilities after a month of having noticed the tumour on the eye. Lack of awareness of the disease and availability of its treatment was found in OSSN patients. We recommend programmes aimed at increasing public awareness of the disease and its treatment.

INTRODUCTION

Ocular Surface Squamous Neoplasia (OSSN) is the commonest adult ocular malignant neoplasm in Malawi and its incidence is known to be on the rise in Africa^{1,2}. This disease can progress in weeks to months from a mild disease (T1) to advanced disease (T4)³. In African studies on health care seeking behaviour, lack of knowledge of the disease, lack of education, treatment at a lower level health facility, long distance to health facility and transport costs have been reported as common reasons why most patients with different conditions fail to seek help early⁴⁻⁹. This was observed in patients with club foot, cervical cancer, malaria and congenital and developmental cataracts⁴⁻⁹.

Malawi has free public health services system for all patients. The public health care system in Malawi is structured in such a way that there are three levels; primary, secondary and tertiary levels being provided at health centers, district hospitals and central hospitals respectively. The central and district hospitals also

provide primary health care services to their immediate target population.

Available literature from Malawi has shown that 23% of OSSN patients presented with advanced disease (T3-4d) at a central hospital⁴. However, factors associated with late presentation of OSSN patients at a central hospital have not been described. We therefore carried out this study to determine health seeking behaviour characteristics of patients presenting with advanced ocular surface squamous neoplasia at a tertiary hospital in Malawi. Specific objectives of the study were:

- (i) To determine time taken by OSSN patients to make a first contact with health care system after noting a swelling (tumour) on the eye.
- (ii) To determine the proportion of OSSN patients having knowledge of the disease.
- (iii) To determine the proportion of OSSN patients who regard their problem as minor.
- (iv) To determine the socio-demographic characteristics of patients presenting with advanced OSSN disease.

MATERIALS AND METHODS

Study design: This was a descriptive cross sectional study.

Setting: The study took place at Lions Sight First Eye Unit, Queen Elizabeth Central Hospital. This is a major referral centre in the southern region and the main teaching hospital for the College of Medicine, University of Malawi. The hospital is located in Blantyre city and it also serves as a primary and secondary level hospital for Blantyre district.

Study population: Stage T3-4d ocular surface squamous neoplasia patients.

Sampling method: All ocular surface squamous neoplasm patients with advanced disease seen during the study period April- August 2014 who consented to participating in the study.

Inclusion criteria: Clinical diagnosis of ocular surface squamous neoplasia was used. The research enrolled stage T3-4d patients who fulfilled these study criteria:

- (i) Patients having the disease that extended into the globe.
- (ii) Patients with orbital extension.
- (iii) Patients having metastatic pre-auricular or submental lymph nodes.
- (iv) Those who had given informed consent.
- (v) Those that had enucleation or exenteration in the past 6 months due to the disease.

Exclusion criteria: Children with ocular surface squamous neoplasia.

Data collection and management: Clinicians working in the hospital were sensitized about this study. Patients fulfilling inclusion criteria were offered information about the study by a study assistant and consent was sought by the same study assistant. The researcher administered the questionnaire only to patients who consented. The questions were in both English and Chichewa and based on patient's preference either one was used. Data collected included demographics, duration of the tumour, prior treatment sought by patients, mode of transport and patients' perception of the disease. This data was entered on EpiData 3.1 data base.

Data analysis: Was done using excel and was descriptive. The level of significance was set at 0.05. Nine patients had bilateral involvement. In all these patients, one eye had T1 to T2 lesions and the other eye had advanced tumour (T3 or more advanced stage). The eye with more advanced tumour was therefore used for analysis.

Ethical considerations: A research proposal was submitted to the College of Medicine Research and Ethics Committee (COMREC) for review and approval. Permission was sought in writing from the hospital authorities at QECH before conducting the study. Written informed consent was sought from the study participants in their vernacular language (Chichewa). Patient's privacy was upheld by interviewing one patient at a time in a room and study files were only accessed by study team.

RESULTS

General demographics: A total of 81 patients were recruited into the study and 4 did not consent because they were not willing to participate in the study. Nine percent of patients had bilateral OSSN disease. The ages of patients ranged from 17 to 64 years. Over 60% of the patients recruited in the study were aged between 30 and 50 years. The mean age of study participants was 37.4 years (± 9.8 SD). Of the recruited patients, 74% were HIV positive, 13.5% were HIV negative and HIV status of the remaining 12.5% was unknown.

Table 1: Demographic characteristics of patients in the study (n=81) Parameter

Frequency	No.	(%)
Sex		
Male	38	47.0
Female	43	53.0
Age (years)		
<20	2	2.5
20-29	13	16
30-39	35	43.2
40-49	19	23.5
50-59	10	12.3
60-69	2	2.5
Marital status		
Married	53	65.4
Single	9	11.1
Divorced	13	16.1
Widow/widower	6	7.4
Ethnicity		
Lhomwe	28	34.6
Yao	13	16.0
Chewa	11	13.6
Ngoni	11	13.6
Sena	8	9.9
Others	10	12.3
Education (Formal)		
Primary	43	53.1
Secondary	27	33.3
Tertiary	3	3.7
No education	8	9.9

Duration of symptoms and presentation at health facility: Only 15 patients (18.5%) in this study had history of tumour of less than 5 months duration. Eighty-nine percent of the patients made their first consultation with health system one month or more after noticing a tumour in their eye.

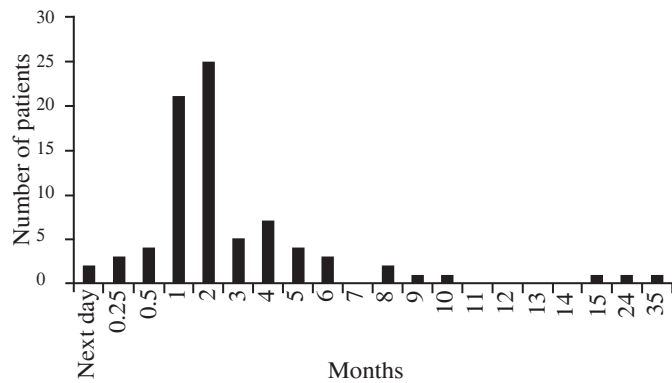


Figure 1: Time taken by patients to present with OSSN at any health facility for the first time (n=81)

In regard to the tumour, 89% of the study patients sought health care at least one month after noticing tumour in the eye. Major reasons given by patients for this finding included: low suspicion of cancer (52.5%) and lack of transport (14%). Other minor reasons included: fear of surgery, consulting religious leaders, superstitious beliefs and trying other treatment options.

Patients' knowledge of ocular surface neoplasia, treatment and perception of the disease: More patients (77%) had no prior knowledge of OSSN diseases and 83% were not aware of availability of treatment of OSSN. Of the patients in the study, 54% regarded their problem (OSSN) as a minor problem. About a third of the patients regarded their problem as worrisome and only 19% of patients in the study thought their condition was life threatening.

Health seeking pattern of OSSN patients: Self-treatment with over the counter eye drugs was reported in 32 patients (39.5%) and 20 patients treated themselves for a period of more than a month. Traditional healers were consulted by 24 (29.6%) patients. Some study participants had earlier on received treatment at different levels of the health system. Half of the patients in the study sought treatment at health centres and also half of all the patients in the study were seen at the district hospitals.

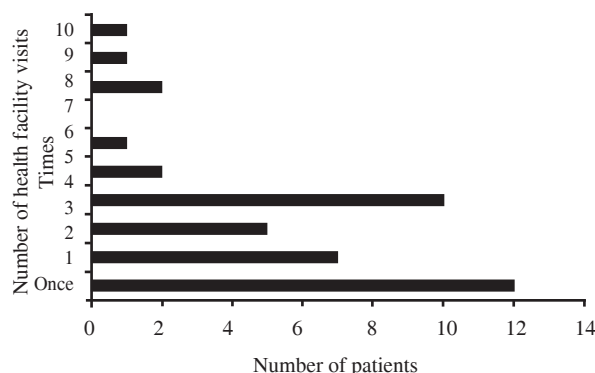


Figure 2: Frequency of patients' consultation with health centre (n=41)

Amongst those that consulted the health centre, 70.7% visited the health centre facility more than once. The

main reasons for not consulting health centres amongst those that did not consult a health centre included: lack of confidence in the facility (53%) and proximity to higher level facility (40%).

Referral system: In this study, 64.2% of patients were referred by health providers from district hospitals while the other 35.8% of patients presented at the eye hospital on their own without being referred by health providers. Approximately two-thirds (65.3%) of all referred patients reached QECH within one week of being referred at a district hospital. Most of the patients (71.6%) in this study made personal arrangements for their transport. The remaining patients benefited from government's provision.

DISCUSSION

This study shows the health seeking behaviour and barriers to health care among patients presenting with advanced ocular surface squamous neoplasia at a tertiary eye hospital in Malawi, Africa. This study reports poor knowledge of OSSN among OSSN patients, delayed presentation in seeking health care and multiple patient consultations with lower level health facilities before being referred to higher level health facilities.

Occurrence of OSSN in the age range of 30 to 50 years is consistent with prior reports^{1,10}. In Malawi, the high occurrence of advanced ocular surface squamous neoplasia in this age range reflects the high prevalence of HIV infection in the same age range as reported by Malawi demographic survey¹¹. HIV infection is a known risk factor for development of malignant squamous neoplasia. It is therefore not surprising to see the high numbers of advanced OSSN in this age group.

In this study, there were more females (53%) than males although the difference was found to be statistically insignificant. Other studies in OSSN done in Malawi and Tanzania have also reported findings similar to the ones reported in this study^{1,12}. Female gender has been linked to low utilization of health services in a number of studies^{4,5}. Some of the reasons that prevent women from accessing health care include lack of control over household finances and African communities regard women as less important in the society⁵. This finding may also be due to high HIV prevalence in women¹¹.

Failure to recognise a disease and its symptoms was reported to be one of the reasons why patients delayed in presenting at health facilities in Tanzania and Malawi in childhood cataracts and clubfoot diseases respectively^{5,9}, and this study reports low levels of knowledge on OSSN and availability of its treatment in OSSN patients. Furthermore, half of the study participants regarded their condition as a minor problem. Low suspicion of tumour

could have been due to lack of knowledge of the disease and this may have influenced the pattern of health care seeking behaviour reported in this study.

According to a study in Tanzania by Al-Attas *et al*¹³, two thirds of patients with ocular trauma presented at a health facility within 24 hours of occurrence of the trauma. It was however noted that poor decision making by health workers at these facilities resulted in patients delay from presenting at specialist facility. Kalua *et al*¹⁴ reported low competency levels in primary eye care providers in Malawi. These findings raise concern about the health sector's ability to detect the disease and institute right management.

Lack of transport and long distance were found to be barriers for patients in accessing health care services. This finding is consistent with existing literature on barriers to health care services. Distance is known to be a barrier to accessing medical care and was reported as one of the reasons why patients delayed in presenting at health facilities in Tanzania as shown by Mwende *et al*⁵.

Referral process from a low level health facility to a higher level facility has been reported as a barrier to health care access⁵. This study however reports a different picture as over 60% of the referred patients got to a tertiary eye hospital within one week. Some of these patients used the government established ambulance system but others used personal resources. It is likely some patients were motivated to use their personal money for transport to seek specialist care as a result of good understanding of the disease.

Other factors associated with poor health care seeking behaviour include self-treatment, off channel treatment (informal health care providers) and belief in traditional medicine. These were also reported in some studies on African continent^{5,8}. This study found that 39.5% of all patients in the study treated themselves at some point during their illness. One third of all patients in the study consulted traditional healers. These two factors are associated with poor health care seeking behaviour although they are difficult to assess because patients know that self-treatment and use of traditional medicine is not encouraged by medical practitioners.

Limitations of this study included use of clinical diagnosis and recall bias. The study did not collect and analyse histological results of recruited patients. Recall bias or poor recall was most likely encountered since almost all information collected was based on what could be remembered by the patient. Future studies on the knowledge and practise of primary and secondary health care workers in regard to OSSN is recommended in order to further understand pre-referral management of OSSN. Increasing public awareness about the disease is also recommended¹⁵.

CONCLUSION

Majority of patients made their first contact with health facilities after a month of having noticed the tumour on the eye. Reasons for delayed hospital presentation included low suspicion of cancer and logistical challenges in accessing health facilities. Most patients did not have any prior knowledge of OSSN disease and were not aware of availability of OSSN treatment.

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