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DELAYS IN DIAGNOSIS, REFERRAL AND MANAGEMENT OF HEAD AND NECK CANCER PRESENTING AT KENYATTA NATIONAL HOSPITAL, NAIROBI
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DELAYS IN DIAGNOSIS, REFERRAL AND MANAGEMENT OF HEAD AND NECK CANCER PRESENTING AT KENYATTA NATIONAL HOSPITAL, NAIROBI

J.F ONYANGO and I.M. MACHARIA

ABSTRACT

Background: The most important prognostic factor in head and neck cancer is the stage of the disease at presentation. Early cancer has an excellent prognosis following treatment. Unfortunately most patients present with late disease that requires radical treatment with considerable morbidity and mortality. Clinical experience at Kenyatta National Hospital (KNH) shows that most patients present with late disease.

Objective: To determine the causes of late presentation of head and neck cancer.

Design: A prospective descriptive study.

Setting: Kenyatta National Hospital, Nairobi.

Results: Forty four cases were seen among whom 34 were males and 10 were females. The age range was 20 to 90 years with a peak incidence between 50 and 60 years. Most of the patients had little or no education and the majority lived in the rural areas. Seventy one percent of the patients came from the Central and Eastern provinces. Tobacco and alcohol use were the most common risk habits. The larynx was the most common site affected followed by the tongue. In 61% of the cases the size of the tumours at presentation was unknown. In 14% the size was 1-2cm, in 7% of the cases it was 2-4 cm while in 5% of the cases it was 4-6 cm. In 14% of the cases the tumour size was over 6 cm. The most common presenting symptom was hoarseness followed by swelling. The majority of the patients attended a public health facility nearest them. For most patients the facility lay within 5 km and could be accessed by walking. However, most of the patients went through multiple referrals to get to KNH. By the time the patients reached KNH, 35 patients (77%) had been treated with unspecified medications, two (4%) had had tooth extraction, and seven (16%) had had biopsies done. The time-lapse between the first symptom and consultation ranged from zero and eight months. Forty five percent of the patients presented to a medical facility within one month of their symptom and 45% presented after three months. The time lapse between referral and attendance at KNH ranged from zero and thirteen weeks and 45% of the patients presented to KNH within two weeks of referral. The overall duration of symptoms by the time of diagnosis ranged from zero months to unspecified years. Thirty two percent of the cases had experienced symptoms for six months or less by the time of diagnosis. However, a number of patients had had their symptoms for a number of years by the time of diagnosis. The distribution of the tumours by stage at the time of final diagnosis were as follows: stage I were 2%, stage II 6%, stage III 14% and stage IV 56%.

Conclusion: This study showed that the referral system was the main cause of delayed presentation of head and neck cancer to Kenyatta National Hospital.

INTRODUCTION

The most important prognostic factor in head and neck cancer is the stage of the disease at the time of treatment. Head and Neck cancer has an excellent prognosis if the disease is treated early (1,2). Unfortunately, most patients present with late disease that requires radical treatment with considerable morbidity and mortality (3,4). Concerns for delays in patients seeking advice, diagnosis, referral and treatment in cases of head and neck cancers have been reported (3,5-12). However, most of these studies were carried out in the west. Few similar studies have been carried out in African populations, which have different cultural and socio-economic backgrounds and health care systems from those of the west (13). The purpose of this study was to identify the factors related to delay in the diagnosis and management of head and neck cancer in an African set-up.

MATERIALS AND METHODS

Materials for this study were based on an ongoing prospective study of head and neck cancers presenting to the Departments of Oral and Maxillofacial Surgery (OMFS) and Ear, Nose and Throat (ENT) surgery at the College of Health Sciences, University of Nairobi, and Kenyatta National Hospital (KNH). KNH is the largest national referral hospital in Kenya, which because of shortage of trained cancer specialists in the country, receives referrals of head and neck cancer patients from all over the country. It also houses most of the clinical departments of the College of Health Sciences. Consecutive patients presenting with head and neck cancer between January and December 2004 were interviewed and examined for the following parameters: sex, age, education level, residence, risk habits, presenting symptoms, location of the lesion, initial size of the lesion at discovery, patients' impression of the disease, patient knowledge of cancer, health facilities attended, initial treatment, time-lapse between onset and first consultation, time-lapse between referral and attendance, duration of symptoms, and stage of the disease at final diagnosis. This study was approved by Ethics, Research and Standards Committee of the Kenyatta National Hospital and University of Nairobi –approval No P3/1/2003 dated 22nd May 2003.

RESULTS

Forty four patients were included in this study, consisting of 34 (77%) males and 10 (23%) females (M: F = 3.4:1). The demographic data on the cases is summarised in Table 1. The age distribution of the patients ranged from 20 to 89 years with a peak incidence in the 50 to 60 year age bracket. The majority of the patients (71%) came from the Central and Eastern provinces. The number of cases diminished the further away the provinces were from the hospital. There were no cases recorded from Coast province. Ten (23%) patients had not attended school, 17 (39%) had attended primary school, nine (20%) had attended secondary school and only three (7%) had attended the tertiary level education. Five (11%) patients did not have their education level stated.

Table 1

Demographic variables of head and neck cancer

Variable	No.	(%)
Sex		
Male	34	77
Female	10	23
Age (years)		
20-29	1	2
30-39	3	7
40-49	7	16
50-59	19	43
60-69	6	14
70-79	4	9
80+	2	5
Unspecified	2	5
Residence		
Nairobi	3	7
Central	13	30
Eastern	18	41
Northeastern	1	2
Coast	0	0
Rift Valley	3	7
Nyanza	2	5
Western	1	2
Unstated	3	7
Education level		
Nil	10	23
Primary	17	39
Secondary	9	20
Tertiary	3	7
Unstated	5	11

The risk habits associated with the head and neck cancer is shown in Table 2. Eleven (25%) patients denied use of tobacco, alcohol or other risk habits while 26 (55%), gave a history of tobacco and alcohol use either in isolation or in combination with other habits. Nine (20%) patients did not have their risk habits recorded. Swelling and hoarseness of the voice were the predominant presenting symptoms (Table 3). Other significant symptoms included pain, ulceration, difficulty in chewing and difficulty in breathing.

Table 2

Risk habits associated with head and neck cancer

Risk	No.	(%)
None	11	25
Tobacco	4	9
Alcohol	8	18
Tobacco + Alcohol	10	23
Alcohol + Khat	1	2
Tobacco, alcohol + Khat	1	2
	-	-
Unstated	9	21
Total	44	100

Table 3

Presenting symptoms of head and neck cancer

Symptom	No.	(%)
Pain	4	9
Ulcer	3	7
Bleeding	2	5
Swelling	7	16
Difficulty in chewing	1	2
Difficulty in swallowing	1	2
Hoarse voice	10	23
Sore throat	1	2
Difficulty in breathing	1	2
Pain + ulcer	1	2
Pain + hoarse voice	1	2
Pain + difficulty chewing	2	5
Pain, bleeding and cough	1	2
Pain, bleeding and dysphagia	1	2
Pain, ulcer, bleeding + difficulty chewing	1	2
Unstated	7	16

The tumour variables are summarised in Table 4. The larynx was the most common site for cancer accounting for 39% of the cases. The next most common sites, in order of frequency were the tongue (11%), the mouth, the hypopharynx and the nasopharynx. Most (69%) of the patients did not have any recollection of the size of their lesions at presentation. Six (14%) of the patients estimated their lesions at between 1 and 2 cm and seven (17%) of the patients estimated their lesions at between 2 and 6 cm. At the final diagnosis 37 (84%) of the patients presented with advanced disease at stage III and IV. Only seven (16%) of the patients presented with early disease at stage I and II. At the time of initial presentation 35 patients (78%) did not consider their symptoms serious, attributing them

Table 4

Tumour variable

Variable	No.	(%)
Location		
Mouth	2	5
Cheek	2	5
Floor of mouth	1	2
Alveolus	1	2
Maxilla	1	5
Mandible	2	5
Tongue	5	11
Oropharynx	0	0
Nasopharynx	2	5
Hypopharynx	3	7
Larynx	17	39
Retromolar Trigone	1	2
Hard / soft palate	3	7
Nose	2	5
Initial Size		
1-2 cm	6	14
2-4 cm	3	7
4–6	2	5
6+	2	5
Do not know	23	52
Unstated	4	9
Stage at Diagnosis		
I	1	2
II	6	14
III	14	32
IV	24	56

to infection of the mouth or throat. Only four patients considered their disease serious. Five patients did not state their initial impression of the disease. At the time of the final diagnosis most of the patients did not know the nature of their disease.

The referral pathway of the patients attending KNH is summarised Table 5. Almost all patients went through multiple referrals before getting to KNH. For most of the patients the first choice of health facility was the dispensary, the health centre or the district hospital. The national referral hospital was attended as the first point of consultation by only two patients. At the second level of consultation, the district hospital was once again the most common facility of attendance. The number of patients attending the national hospital also went up at the second level of consultation. Most of the patients attended the national referral hospital at the third level of consultation. The remaining number of patients attended the national referral hospital on fourth consultation. Most of the patients (84%) lived within a distance of five kilometres to the nearest primary health facility and could reach them by walking. Those who required public transport spent no more than eighty shillings, the equivalent of one dollar, for a round trip. Access to secondary and tertiary facilities became increasingly more expensive to the majority of patients. By the time the patients reached KNH, 35 (77%) had been treated with unspecified medication, two (4%) had had dental extractions and seven (16%) had had biopsies done.

The time lapse between onset of symptoms and first consultation and between the time of referral to and attendance at KNH are shown in Figures 1 and 2 respectively. The time lapse between the onset of symptoms and first consultation ranged from zero to nine months, with 45% of the patients seeking medical care within one month (Figure 1). Another 45% of the patients attended after three months of their symptoms. The average time-lapse was 1.6 months. The time-lapse from the time of referral to KNH and attendance ranged between 0 – 14 weeks, with the average attendance within three weeks of referral (Figure 2). Forty five percent of the patients attended within two weeks of their referral. The overall duration of symptoms ranged from a few months to unspecified years, with an average of nine months (Figure 3). Thirty two percent of the patients had had their symptoms for six months or less, while 68% of the patients had had their symptoms for over six months by the time of diagnosis. Four cases had had symptoms for a number of unspecified years while six cases did not state the duration of their symptoms.

Table 5

Health facility attended

Facility	1st	2nd	3rd	4th
Dispensary	12	1	-	-
Health centre	8	5	-	-
District hospital	14	13	1	-
Provincial hospital	0	0	26	-
National referral hospital	2	11	2	29
Company clinic	1	0	0	-
Missionary hospital	1	0	2	-
Unstated	6	11	-	-
Total	44	41	31	29

Figure 1

Duration between onset and first consultation

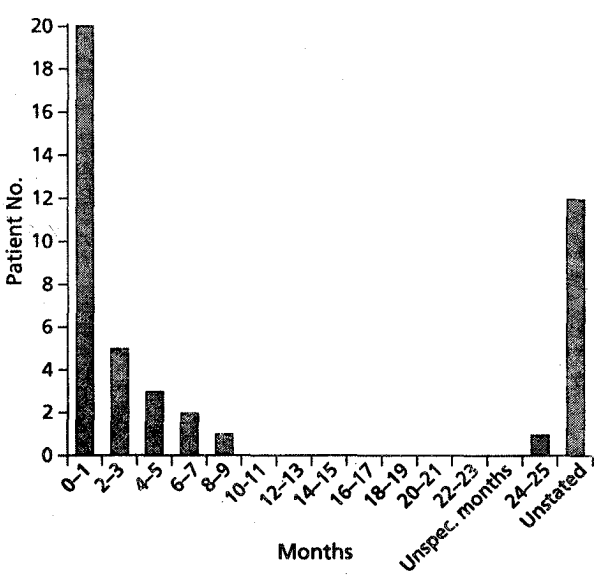


Figure 2
Duration between referral to, and attendance at KNH

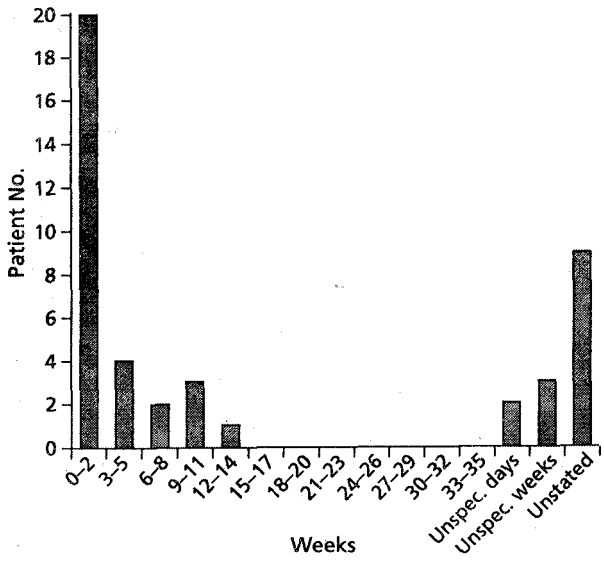
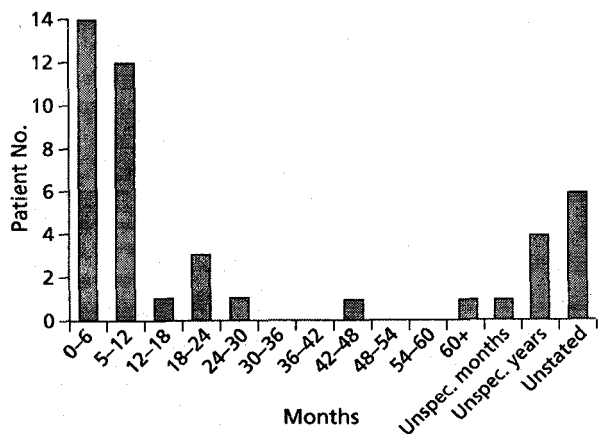


Figure 3
Duration of symptoms



DISCUSSION

The analysis of pathways to diagnosis for specific detectable disease provides a means to pin-point intervention strategies for both the medical practitioners and lay persons. This observation is particularly true when the disease is cancer. Delays in seeking care, in making a diagnosis and in instituting treatment add to the lag time between disease onset and treatment; and impact on survival significantly. Concerns for delays in patients seeking advice, diagnosis, referral and treatment of head and neck cancer have been reported (4,5,7-12,14). These studies have shown that patient delays and professional delays are still major contributors to delayed diagnosis and treatment of head and neck cancers, although their relative contribution may differ in different clinical settings. Patient delays have been attributed to lack of public awareness while professional delays have been attributed to inability to diagnose early cancer and institute urgent referrals. As a result of these and similar studies, recommendations for continuing education of medical and dental practitioners as well as increasing public awareness, have been made (15). However, most of these studies and the resulting recommendations address circumstances prevailing in the developed countries and may find little application in a developing country such as Kenya which has different socio-economic backgrounds and health care systems. This study, therefore, was intended to identify those country-specific factors that lead to late presentation of head and neck cancers in a Kenyan setting as a basis for formulating appropriate management strategies.

The results of our study show that the head and neck cancer seen at KNH is not significantly different from that reported elsewhere with respect to age, sex, site distribution, and associated risk factors (2,3). It is predominantly a male disease, occurs mainly in those aged 40 years and above and is strongly associated with tobacco and alcohol. The majority of patients in this study were illiterate or had low levels of education and lived in the rural areas. This finding reflects the socio-economic realities in this country which is largely an underdeveloped rural agricultural economy. Most of the patients came from the two provinces of central and eastern Kenya. However, this is probably a reflection of the relative close proximity of the two provinces to KNH rather than increased incidence of cancer in these regions. The presenting symptoms for head and neck cancer were many and varied, depending on the site of the lesion. However, it is significant that none of the symptoms are specific to cancer and are likely to be ignored by both the patient and the primary health worker. It was also significant that all patients were symptomatic at presentation because it indicated advanced disease. This assumption is supported by the reported sizes of lesions at the time they were first noticed. At that time, only six cases could be classified as early disease (T_1 and T_2), the rest were either definitely advanced or of unknown size.

It was significant that only four out of the 44 patients realised the seriousness of their disease while the majority of the patients believed that they were suffering from infection of the mouth or the throat. This re-emphasises the non-specific nature of symptoms of head and neck cancers and the ease with which they can be confused with symptoms of banal conditions that are common to the mouth and throat. This lack of knowledge of cancer is an important potential contributor to late presentation as it may lead to complacence in seeking medical attention.

In our study the time-lag between onset of symptoms and first consultation are comparable with those reported elsewhere (6,16-19). Flamant *et al* (16) found that 45% of patients suffering from carcinoma of the tongue sought consultation within two months from the first clinical symptom. In comparison, Smith (17) found that eleven of fourteen patients (80%) with carcinoma of the tongue consulted a physician or dentist within three months. Pogrel on the other hand stated that more than 80% of malignant tumours of the oral cavity waited three months or longer before consulting a physician or dentist (18). Delays for up to five years have been recorded (6,19). In the investigation by Jorgensen *et al*, 17% of the patients waited 12 months or longer before consulting a physician or dentist (19). In our study most the patients sought consultation within one month of onset of symptoms, with an average time-lapse of 1.6 months between onset of symptoms and consultation. However, the significance of the time lapse between symptom and consultation needs to be treated with some caution. First, the timing of onset of symptoms is a subjective parameter and can be varied by the patient depending on their recollection and motive, secondly, onset of symptom does not predict early disease. In a review of two cohorts of patients, one retrospective and the other prospective to find out about delays in diagnosis of head and neck cancer McGurk and associates (4) found that the proportion of patients presenting with advanced disease had not changed in 40 years despite public education. It was their opinion that some tumours may be silent and that initial symptoms do not reliably predict early disease.

The best opportunity to influence the outcome of the disease occurs when the patient attends a medical facility. It is at that point that a care provider can counsel the patient and facilitate treatment by referring the patient to the appropriate consultant. In our study there were no direct referrals to KNH from the primary health facilities. Almost all patients went through several referrals before getting to KNH. This multiplicity of referrals is a reflection of the current structure of the public healthcare system in Kenya. A patient seeking medical care in Kenya often goes through a long chain of consultations and referrals starting with the dispensary or health centre, from where he/she would be referred to the district, provincial and finally a national referral hospital depending on the nature of the illness. Each of these levels of health care facilities are manned by healthcare professionals of different levels of training and skill; few of whom have specific training in the diagnosis of early cancer of the head and neck. Each of these multiple points of referral served as potential points of delay in diagnosis and treatment while adding little value to the overall patient management. Out of the 44 patients only seven (16%) received treatment that was appropriate to their condition prior to getting to KNH. In this study it was not possible to determine the degree of delay that resulted from the referral system because of the difficulties in getting reliable information. However, it was noted that once the patients were referred to KNH they attended the hospital by the third week of referral. It is, therefore, reasonable to attribute most of patient delay to the referral system rather than patient compliance. In a similar study Oburra (13) found that, for patients presenting with laryngeal and nasopharyngeal cancer, there was an average delay of 8.7 months between the first medical attention at a primary health facility and the first appointment at the national hospital. Our study would appear to corroborate these findings.

The finding that a significant proportion of cancers had a relatively short overall duration of symptoms while almost all cancers were at advanced stages at diagnosis raises the fundamental question regarding the nature of tumour growth in this population. While it is possible to have a long period of silent cancer growth the possibility of an aggressive growth pattern in some cancers must also be considered. It is recognised that rapid cancer growth occurs in some instances and carries with it a much poorer prognosis (20). Indeed, it has been postulated that cancers presenting in African populations may exhibit a more aggressive growth pattern with a poorer outcome in comparison to

those seen in the west. Rapid diagnosis and treatment is particularly essential in these cases if survival is to be achieved.

The finding that, despite presenting with advanced disease and severe symptoms, only 15(34%) of the patients knew what they were suffering from, was reflection of the poor level of communication between the patients and their care providers as they went through the health care system. With this poor level of communication the quality of management is also likely to be poor. Our overall impression in this study was that although most head and neck cancer patients presented to primary health facilities within reasonable times from the onset of their symptoms and acted promptly for attention at KNH once referred, there was a considerable delay in the diagnosis and treatment as a result a cumbersome referral system. In our opinion primary health facilities, because they are located within easy reach of most patients, should form the primary point of diagnosis and referral of head and neck cancer to tertiary facilities.

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