RESEARCH ARTICLE

Patient-Linked Factors Associated with Delayed Reporting of Oral and Pharyngeal Carcinoma among Patients Attending National Cancer Institute, Maharagama, Sri Lanka

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Abstract

Background: Diagnosis of cancer at an early stage improves prognosis following treatment. Unfortunately a large proportion of oral and pharyngeal cancer patients are diagnosed at late stages which require radical treatment with considerable morbidity and mortality. Many researchers have examined different types of delay that could occur between the onset of symptoms and diagnosis. The objective of this research was to identify patient-linked delays between the time of first noticing symptoms and definitive diagnosis, and its association with the stage at diagnosis among oral and pharyngeal carcinoma patients attending the National Cancer Institute, Maharagama, Sri Lanka. **Methods:** A hospital-based descriptive cross-sectional study was carried out on 351 patients with histologically confirmed carcinoma of oral cavity and pharynx. Data were collected using an interviewer- administered questionnaire and a data extraction sheet. If a patient had taken more than three months to visit a Health Care Practitioner, it was considered as 'Patient Delay-1'. If a patient had taken more than two weeks following referral to reach for specialized cancer care, it was considered as 'Patient Delay 2'. **Results:** Proportions of 'Patient Delay-1' and 'Patient Delay-2' were 19% (n=252) and 16% (n=322) respectively. Mean time duration between noticing symptoms to definitive diagnosis was 14.1 weeks (SD=10.3). The proportion of advanced-stage cancers at diagnosis was 59.8%. **Conclusion:** Stage at diagnosis was significantly associated with 'Patient Delay -1' (p = 0.001) but not with 'Patient Delay-2'. 'Patient Delay-1' was significantly associated with level of education (p = 0.001) and the cost of travelling (p = 0.048).

Key Words: Early detection of cancer - buccal cavity neoplasms - pharyngeal neoplasms - Primary Health Care

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Introduction

Oral and pharyngeal cancers together ranked in the sixth place among most common cancers in the world. The annual estimated incidence is around 275,000 for oral and 130,300 for pharyngeal cancers and two-thirds of them occur in developing countries (Warnakulasuriya, 2009). In 2009, a total of 16,888.0 new cancer cases were diagnosed in Sri Lanka where 2,293 (13.6%) were oral and pharyngeal cancers. (Annual Cancer Incidence Data, Sri Lanka, 2009). Cancer in the advanced stage is more painful and disfiguring and the treatment necessary is radical and expensive. If detected early, those factors and the healthcare cost could be minimized and the quality of life could be enhanced.

There is research evidence to suggest that TNM stage at diagnosis, significantly affects five-year survival. For mobile tongue, five-year survival for stage 1 disease is 80% while for stage 1V, survival drops to 15% (Warnakulasuriya, 2009). The average time period of delay varies in different populations and studies. Many researchers have examined the types of delay that could occur between the onset of symptoms and diagnosis. Delay in reporting of oral and pharyngeal cancer can occur at four stages during the diagnostic process: 1st stage is the period between the noticing of a symptom and consulting a Health Care Practitioner (HCP). 2nd stage is the time interval between first consultation and referral by a practitioner, 3rd stage is the time period between referral and first consultation at a specialized cancer care center and finally the 4th stage is the time period between first visit to the specialized service center and definitive diagnosis (Onizawa et al, 2003).

According to Teppo and Alho (2008 and 2009) and Yu et al (2008) diagnostic delay is categorized as (i) patient delay- the period between the patient first noticing the symptom and first consultation with a HCP and (ii) provider/ professional delay- the period between first consultation with the HCP and definitive diagnosis. However the second part of the diagnostic delay which is categorised under professional delay includes 3rd stage. As it is linked with patient`s factors in the Sri Lankan

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context for the present study this delay was considered as 'Patient Delay- 2'.

Scully et al (1986) reported a mean delay of 3.5 months from noticing the first symptom to referral from primary care while Onizawa et al (2003), reported a mean delay of 2.7 months to diagnosis in oral cancer patients. Jones et al (2002) in head and neck cancer patients found a mean delay of 4.9 months to present at secondary care. Socio-demographic factors such as, older age group, low socio-economic status and rural residences were found to be significantly associated with delay (Mohammad et al, 2014).

The association between the stage of delay and the stage of cancer at diagnosis has to be explored in order to apply preventive strategies to overcome the impact of delay on health of the population as well as economy of the country. Literature pertaining to this subject is limited in Sri Lanka.

Oral cancer screening programme utilizing the risk factor model is being conducted all over Sri Lanka from 2013. Yet a significant proportion of oral and pharyngeal cancer is diagnosed at a late stage. Out of the oral and pharyngeal cancers, where staging information was available (18%), 77.7% of the cancers had been diagnosed at stages III and IV (Annual Cancer Incidence Data, Sri Lanka, 2009). This study would be able to find out whether patient-linked delays contribute to late stage at diagnosis and the association of socio-demographic factors for these delays.

Aim of this research was to identify patient-linked delays between the time of noticing the symptoms and definitive diagnosis and its association with the stage at diagnosis and socio-demographic factors among oral and pharyngeal carcinoma patients attending National Cancer Institute, Maharagama.

Specific objectives of the research were:

1) To disclose the proportion of patients who delayed in seeking allopathic medical care after noticing the initial symptom;

2) To estimate the proportion of patients who delayed in reporting for specialized care after being referred by the primary Health Care Practitioner (HCP);

3) To assess the stage at diagnosis of these patients;

4) To identify the association between stage of cancer at diagnosis and type of patient delay;

5) To assess the association between patient-linked delay and socio-demographic factors;

among oro-pharyngeal cancer patients attending National Cancer Institute, Maharagama, Sri Lanka.

Material and Methods

This research was a hospital-based descriptive cross-sectional study, carried out in all oncology clinics at the National Cancer Institute, Maharagama (NCIM). Study population consisted of all patients who were classified from C-00 to C-14 except C-07 and C-08 according to ICD-O3 classification (International Classification of Diseases for Oncology, 2000). Inclusion criteria were those who have been diagnosed with oral and pharyngeal cancer within 3 months of the interview date. Mentally handicapped patients and patients who were debilitated and unable to respond were excluded.

The sample size calculated was 362 for the prevalence of 66% for late stage cancers at NCIM (National Cancer Registry Database) and an expected non-response rate of 5%. Since there were no studies on the prevalence of delayed reporting of cancer patients in Sri Lanka, proportion of oral and pharyngeal cancer patients diagnosed in stages III and IV was taken as a proxy for the prevalence of patients with delayed reporting. This was taken on the assumption that diagnosis of oral and pharyngeal cancer at an advanced stage would be due to the delayed reporting of patients.

Each consecutive patient was recruited until the required sample size had been achieved. To collect data, a pre-tested Interviewer- Administered Questionnaire and a Data Extraction Sheet were used.

Data collection was done by a trained pre-intern medical graduate. When the stage at diagnosis was not mentioned in the diagnosis card it was obtained by discussing with the treating oncologist. Dates of noticing symptoms were taken from the patients. Patients were able to recall the dates in relation to a specific life event like 'week before the daughter`s wedding', 'a day following the 'Vesak Poya day' or 'three days before reaping the harvest' and so on. Dates were double checked with referral notes or case-notes by history of complaint and the dates were regarded as accurate with a probable error margin of one week. Time taken to contact HCP after noticing the symptom was obtained by patients directly and this period also was taken as accurate to about one week.

Coded responses were entered, summarized and analysed using the "IBM SPSS Statistics" software package. Data were presented using frequency distributions and mean values. Possible associations were analysed using chi square test. P value of <0.05 (95%CI) was considered as statistically significant.

For this study if a patient had taken more than three months, to visit the HCP after noticing the symptoms for the first time, it was considered as 'Patient Delay-1'. If a patient had taken more than two weeks to reach a specialized cancer care centre after being referred, it was considered as 'Patient Delay-2'.

Results

Results of the data obtained from 351 oral and pharyngeal carcinoma patients registered at the National Cancer Institute, Sri Lanka are presented below. Response rate was 96.9%.

The age range of study sample was 28-87 years with a mean age of 59.1 years (SD=9.9). Majority (81.4%) of them was between the 51.0-70.0 years whereas thirty seven percent of the study sample was between 51- 60 years. Male to female ratio was 8.3:1.0. Proportion of Sinhala was 89.2%. A large proportion (49.9%) had not attended a school at all or had only primary education,

Table 1. Association of 'Patient Delay-1' with Some Selected Socio-Demographic Characteristics of the Patient and Accessibility to the First Health Facility

Characteristic	Patient Delay -1			Significance
	≤ 3 Months	> 3 months	Total	
Age in Years	No.(%)	No.(%)	No.(%)	
≤ 50 Years	39 (81.3)	9 (18.7)	48 (100)	p = 0.230
51-60	78 (82.1)	17 (17.9)	95 (100)	
>60	87 (79.8)	22 (20.2)	109 (100)	
Total	204 (81.0)	48 (19.0)	252 (100)	
Sex				
Male	185 (79.7)	47 (20.3)	232 (100)	p = 0.095
Female	19 (95.0)	1 (5.0)	20 (100)	
Total	204 (81.0)	48 (19.0)	252 (100)	
Ethnicity				
Sinhala	184 (80.7)	44 (19.3)	228 (100)	p =0.931
Tamil	16 (84.2)	3 (15.8)	19 (100)	
Other	4 (80.0)	1 (20.0)	5 (100)	
Total	204 (81.0)	48 (19.0)	252 (100)	
Educational status				
Studied up to grade 5 or less	93 (78.2)	26 (21.8)	119 (100)	p =0.001
Studied beyond grade 5	111 (83.5)	22 (16.5)	133 (100)	
Total	204 (81.0)	48 (19.0)	252 (100)	
Distance in Km				
≤ 10	135 (81.8)	30 (18.2)	165 (100)	p =0.630
> 10	69 (79.3)	18 (20.7)	87 (100)	
Total	204 (81.0)	48 (19.0)	252 (100)	
Cost in SLR				
< 100	41 (91.1)	4 (8.9)	45 (100)	p =0.048
101-500	115 (76.2)	36 (23.8)	151 (100)	
> 500	49 (85.7)	8 (14.3)	56 (100)	
Total	204 (81.0)	48 (19.0)	252 (100)	

76.9% had spent less than 500 SLR to meet their HCP and 68.1% of the patients had travelled less than 10.0Km to health care facility.

Patient Delay-1: For the assessment of the proportion of patients with 'Patient Delay 1', only those whose symptoms were noticed by themselves or by a person other than a health care provider was considered. Thus, 99 patients whose symptoms had been first identified by a healthcare practitioner were excluded in this analysis.

Patient Delay-2: If a patient had taken more than two weeks to reach a specialized cancer care centre after being referred by the HCP, it was considered as 'Patient Delay 2'.

For the assessment of 'Patient Delay-2', only those who had a referral date in the patient file were considered. The patients (29) who had gone directly to a specialised unit having seen the symptoms and patients (15) who did not have referral dates were excluded.

Table 2. Association between Type of Delay and Stage at Diagnosis

	Early stage	Advanced Stage	Total	Significance
	No(%).	No.(%)	No.(%)	
Patient Delay 1				
Present	6 (12.5)	42 (87.5)	48 (100)	p = 0.001
Absent	90 (44.1)	114 (55.9)	204 (100)	
Total	96 (38.1)	156 (61.9)	252 (100)	
Patient Delay 2				
Present	19 (38.8)	30 (61.2)	49 (100)	p = 0.880
Absent	103 (39.9)	155 (60.1)	258 (100)	
Total	122 (39.7)	185 (60.3)	307 (100)	

Proportion of patients with 'Patient Delay-2' was 16% with a mean duration of 2.1 weeks (SD=7.3, n=258.0). Two percent of patients had delayed for more than 6.0 months to report to a cancer center after being referred.

For the analysis of associations between stage of cancer and type of delay, cancers of stages I and II were considered collectively as 'early stage' cancers and cancers of stages III and IV as 'advanced stage' cancers. Out of the total sample (351), 210.0 (59.8%) were at an advanced stage at the time of diagnosis.

The total diagnostic delay- the period elapsed since noticing the first symptom until the definitive diagnosis ranged one to 86 weeks with 65.2% of patients being diagnosed within 14 weeks. The mean period of delay was 14.1 weeks (SD=10.9). However 6.3% of the patients had delayed for more than 26 weeks (6 months).

Discussion

Sri Lanka is one of the countries with a very high incidence of oral and pharyngeal cancers in the world. In spite of the substantial progresses which have been achieved related to cancer therapy and rehabilitation, the prognosis of the affected people has not improved over the years. Diagnosis at late stage would be the main problem in treating oral and pharyngeal cancers, leading to higher morbidity and mortality rates.

Delay can occur at several stages during the diagnostic pathway. In this study, only patient -linked delays: delay in seeking medical advice after noticing symptoms ('Patient Delay-1') and delay in reporting to a specialized unit by the patient after being referred ('Patient Delay-2') were looked into. This was a hospital-based descriptive cross sectional study. Most of other studies done on this subject were also hospital-based studies (Hollows et al, 2000; Onyango and Machari, 2006; Mohammad et al, 2014).

Age range of the study sample was compatible with the latest published National Cancer Incidence Data, 2009 where 83% of oral and pharyngeal carcinomas had been identified at the age 55 years and above. Mean age of the study sample (59.1 years) was very close to the national figure of 62.6 years. This gives an indication of the external validity of the study.

Study conducted in Kenya, reported a similar age range of 20- 89 years with the peak incidence between 50-60 years (Onyango and Macharia, 2006). Average age at presentation was 57.5 years in a retrospective note-based study which was conducted in the UK (Pitchers and Martin, 2006).

Proportion of 'Patient Delay-1' varies in different studies. A study conducted in India found patient delay to be 60% (Mohammad et al 2014), 45% in a Kenyan study (Onyango and Macharia, 2006) and 29% in a study conducted in South Yorkshire, an English metropolitan country (Hollows et al, 2000) .

Comparative low proportions of 'Patient Delay-1' recorded in this study could be due to universal free healthcare provided by the government of Sri Lanka. Reduced proportion of delay could also be due to delayed noticing of symptoms by Sri Lankan patients. This is highlighted by the fact that 59.8% of the patients have reported in late stages though the proportion of 'Patient Delay-1' was 19%.

A review article by Gomes et al (2010) quoting many studies report that socio-demographic variables such as age, gender, marital status, area of residence, religion or education are not associated with patient delay. Even though the same finding was obtained in the present study with respect to age, sex and ethnicity, the level of education was significantly associated with patient delay (P=0.001).

A large proportion (49.9%) of the present total study sample had not attended a school at all or had only primary education. Previous research conducted in Sri Lanka had revealed a low level of knowledge on symptoms of OPMD. A community-based study conducted in Sabaragamuwa province of Sri Lanka reported that 70.0% of subjects were not aware that a white patch, a red patch and persistent ulcer in the mouth as OPMD symptoms (Amarasinghe et al, 2010). Another hospital based study done at the dental hospital Peradeniya, reported that only 44.9% of the participants knew of existence of an entity called oral pre-cancer (Ariyawardana and Vithanaarachchi, 2005). Poor level of education could have contributed to poor level of knowledge on symptoms of OPMD and oral cancer which would have been a main reason for 'Patient Delay -1'. This assumption is further strengthened by the fact that a very small proportion of patients had delayed in reporting to a specialized care centre ('Patient Delay-2'=16%) when they were referred.

Present study revealed that 68.1% of the patients had travelled less than 10Km and the distance to health care facility had not been associated with 'Patient Delay -1'. However in a study conducted in India found that rural residence was significantly associated with patient delay (Mohammad et al 2014). The difference of observation could be due to availability of health care facilities within a short distance in Sri Lanka than in India. Though there is increase accessibility and availability with universal health services in Sri Lanka cost of travelling was significantly associated with 'Patient Delay-1' (p=0.048)

According to a Kenyan study 45.0% of patients had reported to a cancer care center after been referred within two weeks (Onyango and Macharia, 2006). Present study recorded this proportion to be 84%. This high proportion without having 'Patient Delay-2' would also strengthen the assumption that improved knowledge on OPMD and oral cancer would reduce the diagnostic delay.

According to Pitchers, 2006 estimates, one week delay will progress the cancer by 0.045 of a stage (Pichers and Martin 2006). Thus adding a period of 2.1 weeks of Patient Delay-2 to the total delay cannot be ignored and it is necessary to look in to factors associated with 'Patient Delay-2' as well.

There is a marked difference in the average total delay (3.5 months) compared to the 7 months average obtained in an Indian study (Joshi et al 2014). A study done in Teheran reported an average duration of 270 days between the first notice of the problem and visiting a primary care clinician (Jafari et al 2013). Further Jones et al (2002) in

head and neck cancer patients found a mean period of 4.9 months to present at secondary care.

Even though the total delay reported in present study was not very high when compared to many studies, majority of patients have reported at a late stage. This would be due to identification of lesions at late stage by patients in Sri Lanka. Thus it is recommended to improve the awareness of general public on early identification of OPMD and oral cancer.

In this study only those who have been diagnosed with oral and pharyngeal cancer within 3 months of the interview date were included to minimize recall bias. However the exact date of noticing the symptom mentioned by the patient may not be accurate.

It was not possible to obtain the exact date for the onset of symptoms and sometimes (if the date was not mentioned in patient`s file) the exact date the patient visited the HCP after noticing the first symptom. Therefore the mean 'Patient Delay-1' could not be calculated.

In this study only patient –linked delays were looked into. Thus it is necessary to conduct further research to evaluate professional diagnostic delay as well.

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Conflict of interests: None

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