

Original Research Article

Patient centric factors affecting delay in self-diagnosis and seeking medical care for oral cancer: a cross-sectional study

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ABSTRACT

Background: Oral cancer is often detected in the advanced stage, with a low survival rate of 5 years and with increase in mortality which, affects patient quality of life. The early diagnosis would reduce the mortality rate and morbidity rate, by bringing a change in the quality of life.

Methods: The study utilized convenient sampling method to select the participants. Participants who were diagnosed with oral cancer currently at 3rd and 4th stage. Data collection was done using pre-validated self-administered questionnaire, which was provided to the participants through Google forms.

Results: The study demonstrated 43.1% people diagnosed with stage-3 oral cancer had an average delay of 34.6 months and 26% of stage-4 cancer patient had an average delay of 59.9 months to their first visit to treatment center. In this study 34% of the study participants were unaware and had lack of knowledge about oral cancer related symptoms. Self-medications/herbal medications, fear for the treatment, socio-economic factors, COVID-19/lockdown restriction were also other reasons reported by patients.

Conclusions: The prompt treatment is necessary in both advanced cases and early cases of oral cancer. Radiotherapy, chemotherapy, and surgery are all part of the treatment when given timely. Thus, early diagnosis plays a vital role in saving many lives.

Keywords: Early diagnosis, Oral cancer, Patient delay, Quality of life

INTRODUCTION

Cancer is an unregulated cell proliferation that invades and cause damage to the adjacent tissues. The most common form of head and neck cancer is oral cancer. Although the incidence of oral cancer varies widely from country to country, it is generally agreed that oral cancer is the 6th most common cancer worldwide and 3rd most common cancer in India based on its anatomical location. Based on histological features; oral squamous cell

carcinoma (OSCC) is the most prevalent malignant epithelial neoplasm affecting the oral cavity. It accounts for up to 80-90% of all malignant neoplasms of the oral cavity.¹ In 2020, there were 177,757 deaths of lip and oral cavity cancers worldwide; Asia accounts for more than 70% of these cancer deaths.² The majority of oral cancer cases and one-fourth of the global burden are found in India.³ In India 20 per 1,00,000 population are affected and 52,000 deaths were reported annually by oral cancer, which makes up roughly 30% of all cancers.

Tobacco, alcohol, poor nutrition, poor oral hygiene and high-risk types of human papillomaviruses are the risk factors of oral squamous cell carcinoma. However, 15 to 20% oral cancer patients present without any habits.^{4,5} Cancer is typically labelled in stages from I to IV; this staging system use the TNM system (the primary tumour -T category, the lymph nodes- N category, metastasis- M category) to divide cancers into stages. These stages refer to the extent of cancer, such as how large the tumour is and if it has distant metastasis or not.⁶

In India, the five-year survival rate for oral cancer cases is about 60%. This percentage has been proven to increase from 70% to 90% with just early detection in stages I and II, but it drops to less than 20% to 30% with advanced stage of the disease. Unfortunately, the majority of the cases are detected in advanced stages. The primary factor contributing to cancer being discovered at an advanced stage is a lack of knowledge about early oral cancer symptoms. A study conducted in India by Joshi et al mentioned that despite most of the patients observed abnormal lesions, majority delayed the decision to visit a physician early due to fear related cancer and its outcome.⁷

Radiotherapy, chemotherapy and surgery are all part of the treatment, which when given timely would play a vital role in saving many lives. According to the study conducted by Pollaers et al in Australia, patients with stage 4 oral cancer spent two times more than patients with stage 1 oral cancer.⁸ Early detection lowers the cost of treatment and significantly increases the likelihood of survival. From this it is clearly understood that the delay in diagnosing and treating oral cancer give rise to a severe health risk to the countries going through economic transition

Traditionally delays in diagnosis of oral cancers have been classified into 3 distinct categories: “patient delay, professional delay and treatment delay”. Patients delay is the time taken by patients to approach the doctor, this delay is the most prolonged time period and a largest factor contributing on time delay. Evidence of many literatures shows that delays related to the patients were more when compared to the professional delay.⁹ The study conducted by Kerdpon et al in Thailand reported that about 42% of the stage-3 oral cancer patients had patient delay for more than 1 month and 20% of the stage-4 oral cancer patients had a patient delay for more than 3 months, respectively.¹⁰ This could be impacted by various factors like psychosocial, lifestyle, self-medication, locality, religious belief and socioeconomic factors.

Early detection of oral cancer is important for prognosis and helpful for treatment plan, which would definitely reduce the mortality rate and morbidity rate, by bringing a change in the quality of life.¹¹ Since there is no light in this segment among Indian population this study aims to

determine the patient centric reasons for the delays in self-diagnosis and seeking medical care for oral cancer.

METHODS

General study details

This cross-sectional study was carried out for a period of one month from July to September 2022 to know reasons for the delays in diagnosis and treatment of oral cancer from patient’s perspectives. The ethical clearance was obtained from our institution. The study was conducted according to ethical guidelines established by the declaration of Helsinki and other guidelines like good clinical practice guidelines and those established by the ICMR.

Objective

The purpose of this study was to determine the patient centric reasons for the delays in self-diagnosis and seeking medical care for oral cancer.

Study participants

This study was conducted among the 50 oral cancer patients between the age group of 18-70 years. This study utilized convenient sampling method to select the participants. Participants who were diagnosed with oral cancer currently at 3rd and 4th stage, Participants who were above 18 years of age and who gave consent to participate in the study were included in the study. The participants were informed that their participation would be entirely voluntarily and were assured that their details would be kept confidential. Study participant who met the eligibility criteria were recruited our institution and a cancer palliative care centre at Chennai.

Study methodology

Data collection was done using pre-validated self-administered questionnaire, which was provided to the participants through Google Forms. The pre-validated questionnaire was developed from Akram et al and the questionnaire showed acceptable validity with Cronbach’ alphas in the range of 0.51-0.68.¹² The questionnaire was designed in English language but, trained interviewers were made available for anyone who needed assistance in language and the content. The questionnaire was constructed of 20 items which included 2 sections; section-A included questions to assess socio-demographic details like name, age, gender, annual income etc. and section-B included question related to the delay in diagnosis and treatment of oral cancer from the patient perspectives. The procedure took about 15-20 minutes for each participant to complete the questionnaire. Patient delay was estimated by calculating the time interval between the provided information date from when the first cancer related sign/symptom was noticed by the patient till they sought treatment centre. This study also

considered the professional delay's as it might have a possible influence factor for patient's delay in treatment even after the diagnosis.

Statistics

Sample size calculation

The study sample size calculation was performed according to the study conducted by Akram et al.¹² Considering study with an 80% power and $\alpha=0.05$, the minimum sample size was arrived as 50 sample using G-Power software version 3.1.

Statistical analysis

Data was compiled systematically in Microsoft Excel 2019 spreadsheet and a master table was prepared and presented in the form of graphs and tables. The data were analyzed using the Statistical Package for the Social Sciences (IBM SPSS Statistics for Windows, version 20.0. Armonk, NY: IBM Corp). Depending upon the nature of the data, the statistical tests were chosen. P value of <0.05 was considered to be significant. Kolmogorov-Smirnov and Shapiro-Wilks normality tests, the variables followed normal distribution. Descriptive

statistics was used to determine the frequency distribution and ANOVA to compare difference between each stage of oral cancer.

RESULTS

The study evaluated 50 oral cancer patients who fulfilled the inclusion criteria. The relevant data are displayed in Tables 1 and 2 in which 34% were female and 66% were male; their mean age was 53.6 years, ranging from 37 to 70 years.

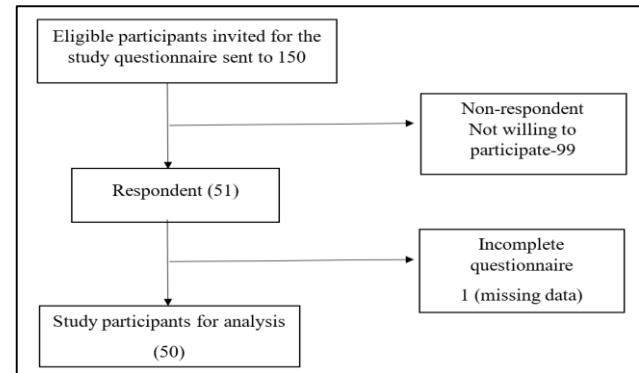


Figure 1: Study participants' flow diagram.

Table 1: Demographic data of study population based on stages of cancer.

Demographic variables N (%) n=50		Stage-1	Stage-2	Stage-3	Stage-4
Gender	Male (66%)	3	5	16	10
	Female (34%)	3	5	5	3
Residence	Urban (72%)	4	8	13	10
	Rural (28%)	1	2	8	3

Table 2: Characteristics of study population and questions related to delay in reason for self-diagnosis and opting for medical treatment for oral cancer.

Questions N (%) n=50		Stage-1	Stage-2	Stage-3	Stage-4
Who was the first person you visited?	General physician (42%)	3	4	8	6
	Dentist (38%)	1	5	8	5
	Siddha/ayurvedic and others (18%)	2	1	4	2
	Treatment centers (2%)	0	0	1	0
Did you take any self-medications?	Yes (64%)	1	5	15	11
	No (36%)	5	5	6	2
Afraid of post-treatment side effects?	Yes (78%)	4	6	18	12
	No (22%)	2	4	3	1

Initially, when noticing the first symptom 42% of participant visited general physician while, 38% visited dentist. 78% of participant delayed their treatment after diagnosis due to post-treatment side effects and 36% participant had self-medications and delayed their treatment.

When the patient (among stage-3 and stage-4) was first diagnosed; the average delay found was 20 months in

stage-1, 34.6 months in stage-2, 48.8 months in stage-3 and 59.9 months in stage-4. Statistically significant difference was observed with p value of 0.004* (Table 3).

Reason for the other delays reported by the study participants were unawareness of symptoms (34%), COVID lockdown (24%) careless or ignorance of symptoms (8%) financial issues (14%) as listed in Figure 1.

Table 3: Frequency and average patient's delay in diagnosis and treatment of oral cancer.

Stage of cancer first when first diagnosed?	Mean±SD (months)	P value
Stage-1 (n=6)	20±12.3	0.004*
Stage-2 (n=10)	34.6±24	
Stage-3 (n=21)	48.8±18.4	
Stage-4 (n=13)	59.9±17.9	

(*ANOVA p value <0.05 = statistically significant)

DISCUSSION

The early diagnosis of oral cancer helps to implement effective and appropriate treatment in early of the disease, leading to less invasive procedures, quicker recovery, and improved patient survival. On the other side, treating oral cancers would be difficult when the diagnosis is delayed which would result in increased morbidity and fatality rates. Delayed diagnosis increases the healthcare and treatment costs for outpatient or extended hospital stay, with major consequences for the most economically disadvantage.

The prognosis of oral cancer decreases as the disease advances. South Central Asia has the highest reported age-standardised death rate of 3.0 among the Asian nations.¹³ Studies have found that oral cancer affects older age groups more than younger age groups, and that oral cancer incidence rises with age worldwide, typically occurring after the fifth decade of life.¹⁴ In this study the mean average age people affected by oral cancer was 53.6 years of age.

This study comprised of 50 oral cancer patients, out of which 66% were males and 34% were females. The gender variations in oral cancer would mostly be a result of societal inequalities in cultural norms, behaviour and lifestyle habits. Globally incidence of oral cancer is higher among males which shows males are more likely to develop oral cancer than females.¹⁵ This might be as a result of men's increased indulgence with the risk factors. About 75% of oral cancer is attributable to tobacco use and alcohol consumption.¹⁶

Reason for delay in diagnosis and treatment had various reasons among the oral cancer patients. The total delay reported in present study was higher when compared to many other studies.¹⁷ The mean average of patient delay at stage-1 cancer was 20 months, stage-2 was 34.6 months, stage-3 was 48.8 months and stage-4 cancer was 59.9 months which showed statistical difference.

Since it was not possible to determine the precise date for the onset of symptoms, the patient's stated exact date of discovering the symptom may not be accurate. Patient delay was estimated by calculating the time interval between the provided information date from when the first cancer-related sign/symptom was noticed. The study included professional delay's as it might influence

patient's delay factors such as patient delay even after the diagnosis to receive treatment. In this study majority of patients were reported at a late stage.

The common reason for delay in diagnosis and treatment were neglected symptoms or lack of knowledge on risk factors, symptoms, difficulty in visualizing the lesion/symptom in the oral cavity delay in seeking specialized services which specialists to consult for a diagnosis and treatment.^{7,16} In this study 42% of participant visited general physician while, 38% visited dentist where 18% of people sought assistance from ayurvedic/siddha medicines.

Self-treatment driven by financial constraints led to delay in obtaining professional care. In this study 64% of study participants took self-medication and 36% did not take any self-medication. Fear of diagnosis and negative disease-coping strategies were also reported as causes of patient delay which would be related to the negative belief of the population that receiving a cancer diagnosis is equivalent to receiving a death sentence.

Many studies reported belief and fear of post-treatment side effects were major reason for patient delay.^{16,18} In this study 78% of participant delayed their treatment due to post-treatment side effects.

Due to the severity of the pandemic, the population fear and anxiety of acquiring COVID-19, had led many patients to underestimated the symptoms and signs of other serious diseases; delay in the self-diagnosis of oral cancer could also be one among them. In this study 24% participant delayed self-diagnosis and treatment due to COVID-19 spread and lockdown restrictions.

The results of the present study shall be interpreted considering the following limitations. This study utilized a convenience sampling technique from two medical centre and hence might not be representative of all the oral cancer patients. Information obtained in the study was not collected from the medical records, and ability of recalling information about the onset of sign/symptom of oral cancer was difficult in few patients, which might have biased the study results.

CONCLUSION

The study demonstrated 43.1% of people diagnosed with stage-3 oral cancer had an average delay of 34.6 months and 26% of stage-4 cancer patients had an average delay of 59.9 months to their first visit to the treatment centre. In this study, 34% of the study participants were unaware and had a lack of knowledge about oral cancer-related symptoms. Lack of knowledge was the major reason for patient delay in this study followed by fear of post-treatment side effects, use of self-medications/herbal medications, socio-economic factors, COVID-19/lockdown restriction etc., were also other reasons reported for the delay.

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Ethical approval: The study was approved by the Institutional Ethics Committee

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