



## Exploring determinants of care-seeking behaviour of oral cancer patients in India: A qualitative content analysis



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### ABSTRACT

**Background:** A major public health concern in India is the high morbidity and mortality rates of oral cancer because of late diagnosis. Among the several determinants of this late diagnosis, the most important is the healthcare-seeking behaviour of the oral cancer patients. The aim of this study was to explore the care-seeking behaviour and its determinants among oral cancer patients.

**Methods:** A face-to-face in-depth interview was conducted among 70 oral cancer patients using a semi-structured questionnaire, and qualitative content analysis of the results was performed.

**Results:** All the patients had squamous-cell carcinoma and none had attended any screening programme. The most common site affected was the buccal mucosa with a non-healing wound. Most of the patients contacted a doctor available nearby; only 7% of patients consulted a dentist. Only one patient approached a traditional healer. The median patient delay was 30 (4–365) days and the professional delay was 40 (4–650) days. Enablers included determinants such as increasing symptoms (80%), influence of the society (74%), fear (10%), and social media (3%). The main barriers were lack of awareness (97%), hope that the lesion will heal spontaneously (90%), lack of perception of seriousness (64%), financial constraints (55%), provider switching (47%), and missed diagnosis (44%).

**Conclusion:** The care-seeking path among oral cancer patients is complex, customised, and influenced by multiple patient-related and system-related factors.

### 1. Introduction

India contributes up to 7.8% of the global cancer burden and 8.33% of global cancer deaths [1]. Oral cancer is the third most common type, accounting for more than 30% of all cancers in the country; 90% of these oral cancer cases are squamous-cell carcinomas. Age-adjusted rates of oral cancer reported by various registers in India vary from 8 to 20 per 100,000 population and are rated high; [2] these rates are expected to increase according to a recent projection report [3].

Oral cancer is a significant public health concern [4]. In a recently conducted study 5-year observed survival among oral cancer patients was 59.1% for localised cancer, 15.7% for cancers with regional extensions, and 1.6% for those with distant metastases [5]. Despite the advantage of the possibility of early detection because of the position of the lesion in an accessible part of the body, a national oral cancer screening programme still exists only at the planning stage, and most oral cancers are diagnosed late, leading to a serious treatment outcome [6,7]. Among several determinants of this late diagnosis, the most important is the healthcare-seeking behaviour of the oral cancer patients.

Healthcare delivery in India is represented by five major sectors, namely: the public health sector, the private sector, the indigenous system of medicine (including homeopathy and Ayurvedic), voluntary health agencies, and national health programmes. In India, healthcare delivery is largely a governmental function. The public sector comprises three levels of healthcare: primary (sub-centres and primary health centres), secondary (community health centres and district hospitals) and tertiary (medical colleges and specialised hospitals) [8].

Healthcare-seeking behaviour has been defined as any action undertaken by an individual who perceives themselves to have a health problem or to be ill for the purpose of finding an appropriate remedy [7]. It includes the time difference between the onset of an illness and first contact with a healthcare professional, the type of healthcare provider from whom patients sought help, how compliant the patient is with the recommended treatment, reasons for choice of healthcare professional, and reasons for not seeking help from a healthcare professional [9,10]. The sequential steps followed are known as the care-seeking path, and this is influenced by several determinants [11].

Delays occurring at different stages of the care-seeking path can be

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further categorised into different components of delay, such as patient delay, healthcare provider delay, referral delay, and system delay [12].

The care-seeking path along with reasons for delay in seeking healthcare among oral cancer patients has been explored in a few countries. In a British study, the most common cause for delayed reporting was failure to perceive the lesion as cancer [13]. A Dutch study among head-and-neck cancer patients reported an average patient delay of more than 3 months before consultation with healthcare personnel [14]. A Karachi study among oral cancer patients of low socio-economic status reported that important determinants of healthcare-seeking behaviour were lack of awareness about the severity of symptoms as well as educational status [15].

A systematic review on oral cancer patients involving eight relevant studies reported patient delay as an important component in care-seeking behaviour, yet the reasons for such delays are poorly understood and under-researched. Hence there is a need for high-quality and theory-driven research in this particular area [16]. However, data regarding healthcare-seeking behaviour among oral cancer patients is lacking in India.

The main research questions addressed were the following. What is the usual care-seeking path of oral cancer patients in India? What are the factors that influence the care-seeking path, including both enablers and barriers? What are the estimates for different types of delays?

## 2. Materials and methods

This study, a qualitative cross-sectional survey, was conducted by the Department of Public Health Dentistry, SCB Dental College, Cuttack, in collaboration with the Acharya Harihar Regional Cancer Institute (AHRCI), from May 2016 to July 2016. A convenient sample of 70 head-and-neck cancer patients reporting to the institute consented to participation and were included in the study.

Information on sociodemographic details – including type of oral cancer – were collected from all the patients by a highly structured interview which was documented on a properly enrolled schedule. Information on the grade of cancer was obtained from hospital records and classified by Broder's grading system [17]. Detailed aspects of the patients' care-seeking behaviour in chronological order was obtained by semi-structured interview which was voice-recorded. The schedule for the interview was based partially on similar studies found in the medical literature [13–15], and was pilot-tested and modified on the basis of the test results.

After obtaining ethical clearance from the Institutional Ethical Committee of SCB Medical College, Cuttack, the study was conducted with an interviewer (SS), a recorder (EM) and an observer (GS). The information obtained by the interviewer (SS) using the highly structured interview were entered appropriately by the recorder (EM) into the schedule. The semi-structured interview, conducted by the interviewer (SS), was voice-recorded by the observer (GS) who also took field notes. Relevant missing information was collected from hospital records (EM). Each interview was carried out in the local language and lasted for approximately 45–60 min.

Total delay is defined as the sum of patient delay and professional delay. Patient delay is generally defined as the time from the patient's first awareness of a symptom to their seeking the first consultation with a healthcare professional. Professional delay is defined as the time from the patient's first consultation to the commencement of definitive treatment; this includes referral delay (time from consultation to referral being made), appointment delay (time to appointment at a specialist centre), and treatment delay (time from diagnosis to commencement of definitive treatment) [12].

The analysis of qualitative data after transcription of the verbatim interviews was carried out through translation and codification; theme generation was then carried out. The qualitative data were analysed manually using thematic content analysis [18,19,20,21,22]. All the audiotaped interviews were transcribed verbatim and translated into

**Table 1**  
Bivariate analysis of demographic characteristics associated with total delay among study participants (N = 70).

Variable	Category	n(%)	Chi-square	p
Age (in years)	< 44	18(25.7)	17.68	0.001
	45–55	17(24.3)		
	56–62	21(30)		
	> 62	14(20)		
Gender	Male	56(80)	5.21	0.022
	Female	14(20)		
Monthly Income (in US \$) <sup>a</sup>	≤ 100	45(64.3)	2.82	0.419
	101–150	11(15.7)		
	151–300	7(10)		
	> 300	7(10)		
Education	Graduate/PG	4(5.7)	3.33	0.64
	Intermediate/post high school	6(8.6)		
	High school certificate	11(15.7)		
	Middle school certificate	12(17.1)		
	Primary school certificate	31(44.3)		
	Illiterate	6(8.6)		
Occupation	Profession	3(4.3)	3.85	0.42
	Semi-profession	5(7.1)		
	Clerical, Shop owner, Farmer	41(58.6)		
	Skilled worker	5(7.1)		
	Semi-skilled	13(18.6)		
	Unskilled	–		
	Unemployed	3(4.3)		
Stage of oral cancer	I	36(51.4)	0.27	0.87
	II	32(45.7)		
	III	2(2.9)		

<sup>a</sup> 1 USD = 65.13 INR (10/05/2017).

English within 24 h (GS). Back translation ensured that meanings of narrations were not lost during translation (EM).

The first author (HR) developed coding schemes and identified themes. The themes identified were then evaluated and checked by GS, who also independently coded five randomly selected transcripts. Themes identified by both authors were compared, with emphasis on consistency and redundancy. Any disagreements in coding were clarified by consensus. The accuracy of each step of the qualitative data analysis was checked by all four authors.

## 3. Results

### 3.1. Participants' characteristics

Of the 263 oral cancer patients reporting to the hospital during the study period, 70 consented to the study. They included 56 males (80%) aged 26–96 years; mean (standard deviation) age of the participants was 55 (14) years. Most of the participants were married and belonged to the lowest income group (64.3%). The education level of most participants (44.3%) was primary school only, and their chief occupations were farming and shop-keeping (58.6%) (Table 1). Around 70% of the participants admitted to having heard about oral cancer, 40% knew about its cause, but only 3% knew about its symptoms and none knew about the treatments available. None of the patients had undergone screening for oral cancer.

### 3.2. Care-seeking behaviour

The care-seeking behaviour of the participants – including the path travelled and the determinants – are portrayed in Figs. 1 and 2 and Tables 2–4.

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