# Health Seeking Behavior of Oral Cancer Patients of Low Socioeconomic Status: A cross sectional study in a Tertiary Care Hospital of Karachi

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## ABSTRACT

**Purpose:** To assess the knowledge, behavior and practices of oral cancer patients of low socioeconomic status in our population.

**Method:** This cross sectional study was conducted in Department of Otolaryngology Unit 1 and 2 of Civil Hospital, Karachi between August 2011 to August 2012. Only those cases were included in the studies whose diagnosis of oral cancer was confirmed by histopathological investigation. Questionnaire was designed and filled by investigators after validation and reliability assessment. Statistical Package for Social Sciences Windows version 17 was used for database assembly and analysis.

**Result:** The mean age was found to be  $48.3 \pm 7.3$  years with 119 males and 71 females (male to female ratio 1.7:1). Most patients (82.1%) were of low socioeconomic status. From 190 cases, 88.9% admitted consumption of carcinogenic agents. Most patients (66.8%) used Gutka. Most patients (42.1%) presented with the lesion in the oral cavity. More than half (56.8%) first visited a doctor near their home, after appearance of symptom. Consultation to a doctor in any hospital, including the study center was reported by 35 (18.4%) of the cases. The mean disease appraisal time was  $36.6\pm11.2$  days. The mean illness time was  $126.7\pm37.6$  days. The mean behavioral time was  $18.3\pm5.9$  days. The mean scheduling time was  $0.26\pm0.09$  days. The mean treatment time was  $6.3\pm1.9$  days. The most common reason (81%) presented by patients for delayed presentation was lack of knowledge and education about the danger posed by their presenting complaints.

**Conclusion:** In our population of low SES patients, we report poor knowledge status and dangerous practices of consumption of carcinogens. The patient health seeking behavior is related to their educational status. Most patients delay seeking help due to lack of awareness about the severity of symptoms. We propose organization of multiple public health campaign to address the current problem at hand.

Key words: Oral cancer, behavior, gutka, betel nut, low socioeconomic status.

*How to cite this article:* Zahid T, Hussain SI, Siddiqui AH, Junaid ST, Ahmed Z, Noorani MM, Shoai M, Khaliq F. Health seeking behavior of oral cancer patients of low socioeconomic status: a cross sectional study in a tertiary care hospital of Karachi. J Dow Uni Health Sci 2014; 8(2): 72-79.

## **INTRODUCTION**

Oropharyngeal cancers, a group of cancers affecting the oral cavity and pharynx, are the sixth most common cancers affecting humans all over the world.<sup>1</sup> In South and South East Asia, 40% of the people with cancers

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have been diagnosed with it.<sup>2</sup> In Pakistan, it is the second most common cancer in women and third most common cancer in men. The Age Standardized Rates (ASR) for oral cancers are 13.8 and 14.1 in males and females respectively.<sup>3,4</sup> Recent studies document an increase in the incidence of this malady and it is now considered to be the second most common cancer in both genders.<sup>5,6</sup>

Sub sites of Oral Cavity: To study the incidence of oral cancer, its essential to know the different sub sites of oral cavity which are : cheek, upper and lower alveolus, tongue, floor of mouth and lips.

Smoking, alcohol consumption and sunlight have been implicated in the development of oral cancers in the

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developed countries. In addition to these, developing countries have their own set of risk factors. These include poor infrastructure of the health care system, illiteracy, poor socioeconomic status. A common risk factor shared by populations from all over the world is substance abuse. There exists a large volume of literature which links betel nut, areca, chewable tobacco and tobacco with development of cancer.<sup>7-9</sup>

Public health education in general population correlates with the cancer prevalence.<sup>8</sup> The personal perception of patients towards a health problem has been shown to be an important player in the decision to seek help earlier.<sup>10-13</sup> This coupled with the knowledge and attitude of patients towards disease, public health education and awareness of risk factors and causative agents and the socioeconomic status of the patients were important contributors in the decision to seek help for oral lesions.<sup>8,14-16</sup>

Our study is aimed at assessing the knowledge and practices of oral cancer patients of low socioeconomic status in our population. We also seek to determine the health seeking behavior of these patients and reasons for delayed presentation to the hospital.

## **METHODS**

This descriptive cross sectional study was conducted from August 2011 to August 2012 in Departments (I & II) of Otolaryngology, Civil Hospital, Karachi (CHK). It is a 1900 bed teaching hospital that is associated with Dow University of Health Sciences. This public sector tertiary hospital provides free health care services to large patient population visiting from all the over the country.

The patients visiting our setting belong to the low socioeconomic strata with most of the patients earning below Pakistani Rupees (PKR) 10,000 (~<120 USD). These patients come from all parts of Pakistan seeking free treatment from experienced doctors. Most of the patients are illiterate or dropped out of school before completing primary school.

We included all consecutive patients above 18 years with confirmed diagnosis (after biopsy sampling and histological confirmation) of oral cancer, admitted to Otolaryngology wards. The biopsy specimen was removed by a doctor and was sent to Central Laboratory, CHK where it was examined by qualified pathologists, not part of our study.

#### **Exclusion Criteria:**

The following patients were not included in our study:

- 1. Patients with age below 18 years.
- 2. Patients belonging to high socio-economic strata.

3. Patients refusing to participate in the study.

4. Patients without attendants from whom provided information could be verified.

The study was conducted with the help of tool (questionnaire) which was designed after reviewing relevant literature on the subject and conducting a pilot study. Open ended questions with detailed history were asked from 30 random confirmed oral cancer cases. Patient's responses to the questions were analyzed and were utilized in the design of final study instrument. The final questionnaire was pre-tested on 25 random confirmed oral cancer cases. The test-retest repeatability was tested by administering both the initial and final questionnaire to the same 10 patients after 7 days. The Cronbach alpha for final questionnaire was greater than 0.75.

The questionnaires for this study were filled by investigators in the ward, after seeking informed oral consent from the patients. In order to ensure that the information provided by the patient is not subject to recall bias, all the provided information by the patient was confirmed by the attendant of the participant. The mean duration of patient interview was around 25 minutes.

The questionnaire consisted of five sections. The first section dealt with the demographic information of the cases. This included age, gender, education, socio-economic status (SES), ethnicity, marital status (married/single/divorced/widowed), addiction history and co-morbid conditions along with presenting complaint of the patient.

The second section of the questionnaire consisted of questions which aimed to determine the knowledge and practices of the cases.

The third section was meant to determine the health seeking behavior of our cases.

Section four had questions regarding the delay in patient presentation. We classified time periods on the following stages of delay as provided by Andersen BL, Cacioppo JT in their study.<sup>17</sup> These five stages can be categorized into patient and physician associated. First three deals with the former one while the later two deals with physician. Scheduling time and treatment time were confirmed from the patient's hospital records.

1. Appraisal time between when a person first detects an unexplained symptom and the moment they infer illness.

2. Illness time between when a person first infers illness to when they decide to seek medical help (tertiary care hospital).

3. Behavioral time between when a person decides to seek medical help to when they act on scheduling an appointment.

4. Scheduling time between when a person schedules an appointment to the first contact with a health care professional.

5. Treatment time between when a person first seeks medical attention to when they begin treatment Section five dealt with patient views regarding cancer as a preventable disease, utility of screening programs in early detection of oral cancer and possible change in consumption behavior after treatment.

The study protocol was reviewed and accepted by the Institutional Review Board (IRB) at the Dow University of Health Sciences.

Statistical Package for Social Sciences Windows version 17 was used for database assembly and analysis. Only those questionnaires were included which were completed. Descriptive analysis (means, standard deviations and percentages) was performed. To determine significant associations between variables, cross-tabbing of the variables was performed and Pearson Chi squared test was applied. Values were considered significant when they were below 0.05 (p<0.05).

#### Abbreviations and Operational Definitons:

SES: Socioeconomic Status

Agency: Hakeem, Quacks, Spiritual healer, Doctor in locality, doctor in hospital

Hakeem: A practioner of using traditional remedies of herbal medicine (Greco-Arabic medicine) in India and Muslim countries

Quacks: A person dispensing medicine and treating medical condition for which he is not certified by the licensing authority of Pakistan (CPSP)

Spiritual Healer: (baba) A person claiming to cure diseases by methods poorly defined by mainstream science. These include reciting verses from holy scriptures, reiki and other similar methods

Carcinogenic Agents frequency and criteria to include in addiction.

Gutka/Mainpuri: betel nut, catachu, tobacco, lime, saffron, flavoring. It is consumed by placing a pinch of the mixture in the mouth between the gum and cheek and gently sucking and chewing. The excess saliva produced by chewing may be swallowed or spit out.

Addiction: If used 5 times in a week.

Mawa: tobacco, slaked lime, areca nut Addiction: If used 5 times in a week.

Naswar: tobacco, slaked lime, indigo, cardamom, oil, menthol, water.

Addiction: If used 5 times in a week.

Betel Quid (Pan masala): Tobacco, areca nuts, slaked lime, betel leaf. "Chewing tobacco" is sometimes used, and flavoring agents such as menthol, camphor, sugar, rosewater, aniseed, mint, or other spices are sometimes added in different regions

Addiction: If used 5 times in a week.

Zarda: tobacco, lime, spices, vegetable dyes, areca nut Addiction: If used 5 times in a week.

Paan: Areca catechu, betel quid, tobacco Addiction: If used 5 times in a week.

Smokeless tobacco: "Snuff" Addiction: If used 5 times in a week.

Areca Nut (Chaalia/Supari): Addiction: If used 5 times in a week.

Mawa: Tobacco, slaked lime and Areca nut Addiction: If used 5 times in a week.

Cigarette/hand rolled cigarette (bidi): If used >10times in a week.

Alcohol: If used once weekly

During the study period, 262 suspected cases of oral cancer reported to the ambulatory clinic. After biopsy of the lesions, 225 cases (85.8%) were confirmed as patients with oral cancer and admitted in hospital. Out of these 23 refused to take part in the study and 12 did not conform to our inclusion criteria, giving an overall response rate of 72.5% in our sample. Total 190 cases were considered for statistical analyses. (See Figure 1).

#### **Demographics:**

The mean age of the participants was  $48.3 \pm 7.3$  years. Mean age of male cases was higher (50.4) than the mean age of female cases (44.7). There were 119 male cases in study sample and 71 female cases with male to female ratio of 1.7:1. Most of the cases 156 (82.1%) belonged to low socioeconomic status (SES) with monthly household income ranging from 1,000-10,000 Pakistani Rupees (~US Dollar 10-120). The educational profile of the patients indicates that most patients 161 (84.7%) did not pursue academic activity beyond 5<sup>th</sup> grade. Very few patients 10 (5.3%) reported continuing their education further than the 10<sup>th</sup> grade. Patients who identified themselves as Muhajirs (ethnic group) constituted majority of the patients 99 (52.1%) in study sample. They were followed by those who identified themselves as Sindhis 53(27.9%), Pathans 20 (10.5%), Balochis 15 (7.9%) and Punjabis 3 (1.6%). Most study cases were married 136 (71.5%) in our study. For complete demographics, see Table 1.

#### **Knowledge & Practices:**

Most people (88.9%) interviewed admitted consumption of agents which have been determined as carcinogens. Of all the agents consumed, the most commonly used agent reported was gutka 127 (66.8%). This was Health seeking behavior of oral cancer patients of low socioeconomic status: a cross sectional study in a tertiary care hospital of Karachi

		Ν	%
Age	18-30	5	2.6
	31-45	25	13.2
	45-60	154	81
	>60	6	3.2
Income	1000-10000	156	82.1
	10001-20000	31	16.43
	>20000	3	1.5
Education	Upto 5 <sup>th</sup> Grade	161	84.7
	5 <sup>th</sup> -10 <sup>th</sup> Grade	19	10
	Over 10 <sup>th</sup> Grade	10	5.3
Ethnicity	Muhajir	99	52.1
	Sindhi	53	27.9
	Pathan	20	7.9
	Balochi	15	10.5
	Punjabi	3	1.6
Marital Status	Married	136	71.5
	Bachelors	23	12.1
	Divorced	12	6.3
	Widowed	19	10

followed by Betel Quid 101 (53.1%), Cigarette 86 (45.2%), Areca nut 66 (34.7%) and Paan 61 (32.1%). 123 (64.7%) patients reported using more than one of the addictive agents. Most patients (80%) asserted that they intended to give up their substance abuse addiction after treatment. Routine checkup by a doctor (13.1%)or a dentist (4.2%) was considered important only by a few patients (15.2%). The realization that substance abuse led to the development of oral cancer was present in 132 cases (69.4%). When asked about what substances can be potentially implicated in development of oral cancer 104 (54.7%) cases indicated that that they knew about the sources. The agents most commonly identified by the patients were Cigarette 117 (61.5%), Gutka 90 (47.3%), Betel Quid 34 (17.8%) and betel nut 34 (17.8%). see Table 2.

#### **Health Seeking Behavior:**

The primary presenting complaint of most cases was noticing a lesion in the oral cavity 80 (42.1%). Figure 2 gives a graphical representation of the presenting complains. Most of the patients interviewed 108 (56.8%) reported visiting a doctor's clinic in their area with their primary complains. First consultation was made with Hakeem, Quacks and Spiritual healers in 31 (16.3%), 3 (1.6%) and 13 (6.8%) cases respectively. Consultation to a doctor in any hospital, including the study center was reported by 35 (18.4%) of the cases. Regarding self-disclosure of the diagnosis, most married patients reported that they informed their spouses (66.8%) and children (52.1%) of their condition. Parents (16.3%) and siblings (35.7%) were informed in fewer cases than spouses and children. Relatives and close associates or friends were informed in (21.5%) Table 2: Addiictions

		Ν	%
Addiction History	Alcohol	21	11.0
	Areca Nut (Chaalia/Supari)	66	34.7
	Betel Quid (Pan masala)	101	53.1
	Cigarette	86	45.2
	Gutka/ Mainpuri	127	66.8
	Mawa	13	6.8
	Naswar	40	21
	Paan	61	32.1
	Smokeless Tobacco	10	5.2
	Zarda	22	11.5
Considered as a source of cancer by the respondents	Alcohol	6	3.1
	Areca Nut (Chaalia/Supari)	29	15.2
	Betel Quid (Pan masala)	34	17.8
	Cigarette	117	61.5
	Gutka/ Mainpuri	90	47.3
	Mawa	34	17.8
	Naswar	8	4.2
	Paan	22	11.5
	Smokeless Tobacco	4	2.1
	Zarda	15	7.8

Figure 2: Graphical representation of the frequency of most prevalent symptom that appeared first in Oral cancer patients.



of cases in married people. For people who were not married at the time of study, disclosure of their condition was reported higher in siblings (31.1%), parents (18.4%) and close associates or friends (16.3%). Advice to visit an agency for relief from the primary complain of oral cancer was most often provided by spouses (43.6%) in the case of married persons and friends (15.8%) in the case of people who were not married at the time of study.

#### **Delay in Presentation:**

The mean disease appraisal time was  $36.6 \pm 11.2$  days. The mean illness time was  $126.7 \pm 37.6$  days. The mean behavioral time was  $18.3 \pm 5.9$  days. Patient associated delays were found to be significantly associated with age, general education, knowledge regarding oral cancer, gender, marital status and SES (p<0.05). We found no significant association between ethnicity of cases and patient associated delays. The mean scheduling time was  $0.26 \pm 0.09$  days. The mean treatment time was  $6.3 \pm 1.9$  days. Physician associated delays were found to be significantly associated with the presenting complains of the patient, prior visit to quack, Hakeem, spiritual healer or a doctor in locality, addiction history to Gutka, Naswar and Paan (p<0.05). We found no significant association of physician associated delays with patient demographics. The most common reason (81%) presented by patients for delayed presentation was lack of knowledge and education about the danger posed by their presenting complains. This was followed by barriers faced due to monetary constraints (75.3%). Other causes include fear of diagnosis of cancer (38.4%), fear of surgery (36.4%), and treatment from Quacks, Hakeems and Spiritual healers (26.3%).

#### **Patient Beliefs:**

About half (52.6%) the patients interviewed, expressed their belief that cancer was a disease that can be avoided by prevention. The utility of early diagnosis in preventing disease progression and improving prognosis was admitted by 76.8% of the cases. When patients were asked whether there should be screening programs which could catch cancer in pre-malignant stage, 82 cases (43.1%) responded that this would be beneficial.

## **DISCUSSION**

We deem our study to be a strong candidate for assessing the health seeking behavior patterns of patients who belong to low SES in the society. This is because of the fact that our study sample is selected from a population made up exclusively of patients with low SES.

Most of the patients belonged to age group between 45 and 60 years. This finding is consistent with different studies conducted all over the world which report increase prevalence of oral cancer in older age individuals.<sup>14,18,19</sup> A major part of our sample was constituted by males. This is in accordance with reports from other studies.<sup>4,20,21</sup> These factors are significant and warrant special attention because older age and male gender has been shown to be associated with increased risk of oral cancer.<sup>8</sup> This is important in our society where consumption of carcinogens is often started in the early years. With the passage of time, this habit takes strong roots and is hard to get rid of. Over the period of time, additional insults superimposed

by continuous intake of such materials lead to development of cancer. It is important to mention here the possibility of a shift in the trends of development of oral malignancy with more frequent involvement of younger generation. This is expected to occur in the foreseeable future with the younger generation beginning this unhealthy habit at an earlier age.<sup>22,23</sup> In Pakistani culture, there is a general trend of males being the bread earners of the household. With this economic edge over females, men are in a more convenient position to indulge in consumption of substances which lead to development of oral cancer.<sup>24-28</sup>

Socioeconomic status has been implicated as an independent risk factor for development of oral cancers.<sup>29-31</sup> With the current wave of unemployment hitting the global markets, it has become very difficult for people hailing from low SES families to make end meets. In order to escape from the psychological stress imposed by the real world problems, one tends to find an escape in alternate reality. This desire to break free from problems leads to development of substance abuse habits in people who are under stress.<sup>32,33</sup>

Gutka and betel nut have been commonly correlated with an increased risk for oral cancer.<sup>34,35</sup> The usage of gutka and other betel and areca products along with cigarettes is prevalent because they are easily available from roadside shops for a very cheap amount. This economic mode of addiction is thus preferred over the far more expensive alternates like alcohol.

This survey of patients revealed the general trust patients place in doctors who practice near their locality. This is demonstrated by an overwhelming majority's first visit for their primary complains to such doctors. This can be seen as a potential favorable variable if it were to be included in efforts against oral cancer. In order to correctly identify pre-malignant lesions at their initial stages, adequate training programs with proper exposure of general physicians to these cases is required. We believe that the strategy for tackling rising number of oral cancer cases is two pronged. Where adequate physician training is called for, one also needs to place an emphasis on the awareness of the general population towards the risks posed by readily available carcinogens. It is noteworthy to mention here the steps taken by the Government of Pakistan whereby they have made it mandatory for companies selling cigarettes to print pictures of oral cancer lesion on their product box along with a health warning. However, the authors believe that this measure can be aptly termed as "too little, too late". At this crucial period where there is a trend shift of oral cancers, with increase chances of involvement of younger individuals, rigid measures are required which regulate the sale of these carcinogenic materials.

Patient education and awareness about health in general and healthcare providers is essential. Although it makes common sense to allow someone to choose their method of treatment, the low educational status of patient places them in a unique situation. In most cases without adequate understanding of intricacies that exist in real world, less educated people remain gullible. This can be an important factor in patients accepting treatment from anyone who claims to possess the cure for their ailments. Such faith healers and practitioners of nonallopathic systems of medicine are usually referred from the relatives to the patients. Such ventures into scientifically unproven territories often prove to be perilous for the patients. One can thus safely say that patient education at all levels is important.

The delay in seeking medical help was attributed mostly to the lack of knowledge about the danger posed by the presenting complain. This factor along with financial limitations was found to act as an effective barrier which prevented patients from seeking help earlier. The statistical significance of these reasons for delayed presentation have been established in our study where patient associated delay was found to be significantly associated with the SES of the patients. Similar findings have been reported by other studies conducted by peers. The delay in the presentation of the patient to the healthcare provider after making decision of seeking help was found to be significantly associated with prior visit to quacks, Hakeems, spiritual healers or a doctor in locality. A possible explanation for this is that the visit to sources other than hospitals puts the patients in a state of false satisfaction that they are being treated for their condition. This is not always the case, as one can safely assume that quacks, Hakeems and spiritual healers do not provide a well-documented cure for cancer.

## CONCLUSION

In our population of low SES patients, we report poor knowledge status and dangerous practices of consumption of carcinogens. The patient health seeking behavior is related to their educational status. Most patients delay seeking help due to lack of awareness about the severity of symptoms.

## RECOMMENDATIONS

In order to limit the spread of oral cancer in our population, several steps are required. Starting at grass

root levels, public education should be given priority. To promote the cognitive capacity of the population, the educational system needs to be structured in such a manner that it promotes and encourages reasoning and logical thinking.

As demonstrated in our study, most people identified cigarettes as a carcinogen. This is a favorable point for the anti-smoking campaigns that have been conducted by the government agencies and nongovernmental organizations. We propose that the think tanks at such institutions identify other carcinogens which are in common use in our country. Such an effort will enable them to conduct similar informative and effective campaigns about other carcinogens. This will play an important role in combating the potentially rising number of cases of oral cancer in the near future.

The current scenario highlights the need for stricter regulations and an efficient system that checks the growing use of carcinogens by the people. Legislation is required which imposes fines and jail terms for those who take part in the production and distribution of such harmful agents.

The dangers presented by Hakeems, quacks and spiritual healers need to be taken into account if the agencies responsible for public health promotion are serious about their efforts. All such practitioners who pose a threat to the well-being of the patients should be forced to close their practice. Adequate training of healthcare professionals is needed. This is important because of the increased trust people place of doctors in their locality. We believe that the correct identification of pre-malignant or malignant lesions at an earlier stage will reduce patient delay time. Furthermore, counseling service provided by physicians practicing near the place of residence of patients will play an important role in decreasing unhealthy habits of the population.

## **LIMITATIONS**

The most important limitation that is a major constraint to the generalization of our study is the fact that this was a single center study. Although the sample is representative as it derives from the target population, consecutive sampling requires future studies with randomization of the samples.

#### **Competing Interests:**

Authors declare no competing interest that could bias their work.

#### Author's Contribution:

MMN is the principal investigator of the study. MFK,

TZK, AS, MS and UAS are the co-investigators. The statistical analysis was performed by AS and MS. MMN, TZK, MFK and UAS designed the study. UAS, MS and AS carried out and contributed to data collection and data entry. Manuscript was written by MMN, MFK and TZK. Manuscript was reviewed and finalized by all the authors.

#### **Funding Source:**

The expenses of this study were shared by all authors.

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