

Delay in presentation of oral cancer: A multifactor analytical study

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ABSTRACT

Background. Patients with oral cancer often present late to the doctor making treatment difficult, expensive and sometimes unsuccessful. Delay in presentation may be considered to be a health risk-taking behaviour. The present study analyses the psychosocial factors related to delay in presentation of oral cancer patients through the Triandis' model of health-seeking behaviour and also examines the relationship between delay and the stage of cancer.

Methods. Seventy-nine oral cancer patients were interviewed after evolving a valid and reliable questionnaire, and determining the sample size. Univariate and multivariate logistic regression analysis was applied between demographic variables, psychosocial factors, primary delay (defined as delay between the first symptom and the seeking of medical advice), secondary delay (interval between the first consultation and presentation at the medical college), tertiary delay (delay in definitive treatment even after being seen at a tertiary care centre) and stage of the disease. Multiple logistic regression was also carried out.

Results. Primary delay ranged from less than a week in 5 (6.3%) patients to more than 1 year in 8 (10%) patients. A linear relationship was found between primary and secondary delay (F -statistic $p < 0.0152$). A majority of patients (70.9%) had advanced oral cancer. The stage of cancer at presentation to the hospital was significantly related to primary (G -test 6.3; $p < 0.0121$) but not to secondary delay. Multivariate analysis revealed that five variables, 'ill fated to have cancer', 'cancer a curse', 'non-availability of transport', 'trivial ulcers in mouth are self-limiting' and 'prolonged treatment renders family stressful' were significant independent predictors of primary delay.

Conclusion. The identified independent predictors of primary delay should be used to develop the main theme of an educational intervention programme for patients with oral cancer.

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INTRODUCTION

Oral cancer—cancer of the oral mucosa and lip (excluding the skin)—is the most common cancer in the Indian subcontinent. It can be easily detected by feeling or seeing a lesion in the oral cavity. However, approximately 60% of patients with oral cancer reporting to the King George's Medical College have advanced cancer and may have delayed seeking medical advice. This delay is an important determinant of survival that could be favourably influenced by public education.¹ Early presentation of cancer has been hypothesized to lead to earlier detection and a greater likelihood of successful therapy. Descriptive studies of delay and its determinants by cancer patients have been reported.^{2,3} These studies have shown a wide range of delay from initial symptoms to the seeking of medical care by patients. Some of the reported determinants of patient delay include ethnicity and social class, availability of satisfactory medical care, knowledge and attitude towards cancer, social support, etc. In India, though delay may be an important factor in cancer control and prevention, only a few studies on this subject have been reported.^{4,5}

We planned to determine the predictors of delay using a well-constructed detailed instrument structured on a health risk-taking behavioural model.⁶ These data are likely to provide the basis and the components of a strategy for secondary prevention, that is, early detection of oral cancer when treatment is successful, less expensive and more cosmetic.

PATIENTS AND METHODS

This study was conducted at the Department of Surgery, King George's Medical College, Lucknow on a cross-section of 79 oral cancer patients. A detailed questionnaire was constructed which consisted of demographic factors such as age, gender and a composite scale for socio-economic status (SES)⁷ including education, occupation and income. Those with a score of 1 were at a higher SES and those at 4 or 5 were below the poverty line. For psychosocial variables a detailed closed ended questionnaire was designed on a 3-point Likert scale⁸ in which subjects specify the degree of agreement—fully agree, uncertain and fully disagree. The questions on psychosocial factors were based on Triandis theory of health risk-taking behaviour.⁶ This theory has several determinants of intention (planned future behaviour) to perform an activity on the right side of the equation including habit, motivation, facilitating conditions, social factors, affect and perceived consequences.

The main research hypotheses of our study were:

1. Psychosocial factors are important in determining primary delay in the presentation of oral cancer patients to a medical practitioner.
2. Delay in presentation is associated with an advanced stage of oral cancer.

Data collection

Consecutive patients were enrolled at the outpatient clinic of the Department of Surgery. The questionnaire was administered to all the patients by a trained social scientist. Clinical staging of the tumour was done in 4 stages according to the TNM system of the American Joint Commission of Cancer Staging.⁹

Months were used as the unit to measure delay in presentation of oral cancer patients. Primary delay (PD) was defined as the time taken by patients to seek the first medical opinion and secondary delay as the time taken to consult a specialist (our hospital) where treatment was possible.

Analysis

The demographic and psychosocial factors were studied as explanatory factors (independent variables) and primary delay (in months) was taken as the outcome factor. This was, therefore, on a continuous scale. A prediction model using univariate and ordered logistic regression analysis were used to determine the best predictors of delay in seeking medical advice by oral cancer patients.

RESULTS

Twenty-nine patients were interviewed for the pilot study and 27 of these records were complete. The test-retest repeatability was tested by administering both the initial and final questionnaire again to the same patients after 7 days in a sample of 10 subjects. The reliability of the final instrument was acceptable (coefficient of reliability 81%). This was an intra-class correlation coefficient generated from ANOVA.¹⁰ The sample size detecting an R^2 of 30% from a linear regression with 6 independent variables and $\alpha=0.05$, power=90% was 49 patients.¹¹

The results are described in 4 parts—demographic characteristics; details of delay; stage of cancer and psychosocial predictors of delay. For parts 1 to 3, a total of 79 records (27 from the pilot and 52 from the final study) were analysed. These data were combined as there was no difference in the recruitment and information. For part 4, results of the 52 subjects who completed the final questionnaire are reported.

Demographic characteristics

There were 45 (57%) men and 34 (43%) women patients. Their ages ranged from 24 to 82 years with a mean (SD) of 48.8 (12.6). The majority (57; 72.2%) of subjects were illiterate and 22 (28%) had high school education or more. Most of the patients (64; 80%) belonged to a lower SES.

Delay (Figs. 1 and 2)

Primary delay (PD) ranged from 3 days to nearly 3 years while secondary delay was up to 4 years. Only 5 (6.3%) patients visited a qualified doctor within the first week of perceiving a problem in their mouth and 8 (10%) delayed doing so till the second or third year. The proportion of delay-of-1-month between PD (27.8%) and secondary delay (21.5%) was not significantly different (χ^2 , $p=0.356$). The proportion of secondary delay of more than 6 months was significantly higher than PD (24.1% v. 13.9%) at a confidence interval of 90%.

A relationship between PD and secondary delay was investigated by linear regression analysis (Fig. 2). This gave an F-statistic, $p<0.0152$, showing a somewhat linear relationship between PD and secondary delay. After excluding two extreme observations (PD=30 months and secondary delay=44 months), a highly significant relationship at $p<0.0001$, $R^2=0.21$ and an

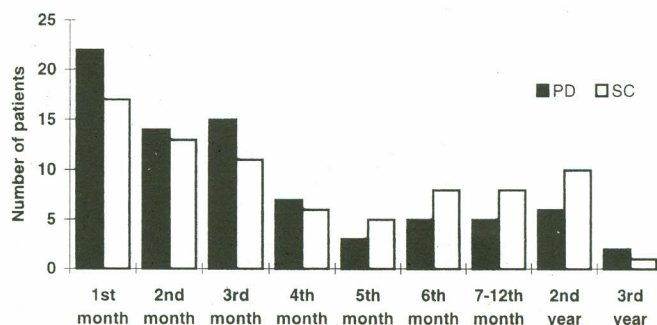


Fig 1. Histogram of number of subjects in each category of delay

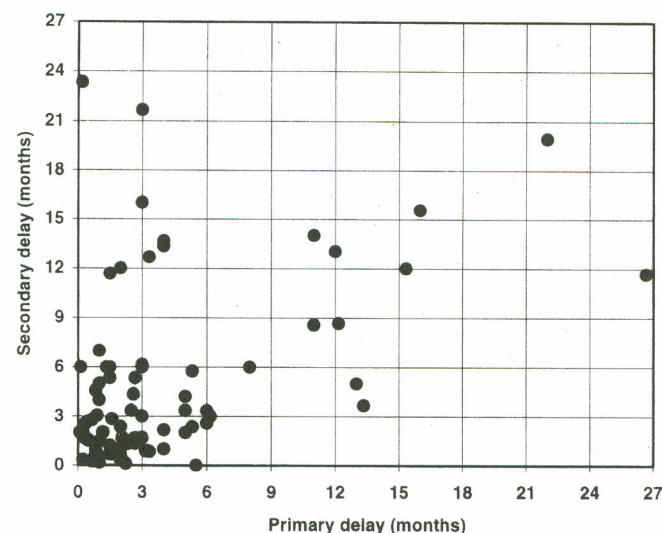


Fig 2. Relationship between primary and secondary delay

equation: secondary delay=3.04+0.49PD, was obtained. It shows that a reluctant patient first delays consulting a family physician and then a specialist.

Stage of cancer

Fifty-six (70.9%) patients had an advanced stage of oral cancer at the time of presentation. There was no significant difference between the age, gender, SES and educational level of those with early and advanced clinical stage of cancer. Univariate logistic regression analysis between clinical stages and primary/secondary delay showed that the stage of cancer at presentation to this hospital was related to primary delay (G-test 6.3, $p<0.0121$). The coefficient and constant of logistic regression showed that the longer the duration of PD, the more the probability of having an advanced stage of cancer. The stage of cancer did not significantly relate to secondary delay (Table I).

Psychosocial predictors of delay

Univariate logistic regression analysis was applied to all the independent variables (60 items in the questionnaire) and those with $p<0.2$ (13 variables) were entered in the final model (Table II).

These 13 selected variables were then included in the model and tested for coefficient significance using the t-test. The ones with $p>0.05$ were excluded from the model in descending order

until all the variables had $p < 0.05$ for their coefficients. During this process, 5 variables were excluded and only 8 variables with a significant coefficient ($p < 0.05$) formed the model with $p = 0.0000$ and $R^2 = 0.68$.

Table III shows the collinearity between the above 8 variables. Two variables were considered collinear if $p < 0.1$. There were no highly collinear variables. The ones with a bigger p in the model were excluded—visited the doctor regularly, SES and relative/friend having cancer were excluded from the model. The clinical significance of these issues was, however, not unimportant. The final model (Table III) consisted of 5 variables: ill-fated to have cancer (fate), cancer a curse (curse), non-availability of transport (trans), trivial ulcers in mouth are self-limiting (trivia), and prolonged treatment renders the family stressful (stress). The following equation to predict primary delay was obtained:

TABLE I. Univariate logistic regression between stages of cancer and types of delay

	Log likelihood	G test	p value	Note
Stage of cancer (advanced=1, early=0)	Lo=-47.65			
Primary delay	-44.5	6.3	0.0121	Coefficient=0.108 Constant=1.397
Secondary delay	-47.49	0.22	0.57	

TABLE II. Selected variables entered in the multiple regression analysis model

Variable	p value (F-test)
Patient's fate (1=no; 5=completely agree)	0.0334
God's destiny (1=no; 5=completely agree)	0.057
Escorted by someone	0.021
Availability of transport	0.0398
Cancer can develop if tobacco is used	0.0206
Visiting a doctor for early detection of cancer	0.134
Necessity of consulting a doctor for small ulcers in the mouth for those who use tobacco	0.182
Regular visit to doctor in the past 12 years	0.018
Domestic remedies/medicine before consulting a doctor	0.181
Any family member/relative/friends had cancer	0.190
Tired of treatment	0.088
Family's tension due to long treatment	0.0416
Socio-economic status (higher class=1, lower class=0)	0.0008

TABLE III. Final multiple linear regression analysis model for primary delay in presentation of oral cancer patients to a qualified doctor

Variable	Coefficient	Standard error	95% CI of coefficient
Patient's fate (1=no; 5=completely agree)	0.651	0.275	-1.205; -0.097
God's destiny (1=no; 5=completely agree)	0.865	0.278	0.304; 1.425
Availability of transport	-1.335	0.411	-2.162; -0.509
Necessity of consulting a doctor for small ulcers in the mouth for those who use tobacco	-0.996	0.324	-1.648; -0.343
Family's tension due to long treatment	-1.315	0.369	-2.059; -0.569
Constant=15.816			

$$\text{Primary delay} = +15.816 + 0.65\text{fate} + 0.865\text{curse} - 1.335\text{trans} - 0.996\text{trivia} - 1.315\text{stress}$$

The above results and the constructs from the questionnaire used in the study provide material to define components of a non-formal education package and secondary prevention of oral cancer in India.

DISCUSSION

Early diagnosis and treatment, in general, is the sheet anchor of the management of cancer patients. This is even more true for patients with oral cancer because the lesion remains localized for a long time and a cure rate of above 90% can be achieved in stage I disease.¹²

No single aetiological factor was found which led to a delay in the patient consulting a physician. This finding is similar to a previous study on patients with cancer in general.¹³ Another study had found the site of cancer to be a determinant of delay.¹⁴ A number of studies have stressed the obvious benefits of early detection in oral cancer patients.¹⁵⁻¹⁷ Taking a cue from these, field epidemiologists have embarked upon intervention programmes.¹⁸⁻²⁰

There are three important facts about oral cancer in India. First, it is preventable. Primary prevention is possible by decreasing the use of tobacco through educational programmes and legislation. Second, it is preceded by pre-cancerous lesions that can act as early warning signals of the cancer. Third, even if it occurs, it is eminently curable if detected in the early stages. Distant metastases generally occur late. Yet at least half of the oral cancers when presenting to a tertiary care centre in India are in the advanced stage.¹⁶

Patients of oral cancer presenting to a hospital often admit to a long time lapse between first noticing the symptoms related to cancer and presenting to the hospital. Often, this delay runs into months or even years. In a study of 100 patients of oral cancer in northern India, it was found that 66 had delayed seeking treatment for more than 6 months.⁵ Delay was of 3 types: (i) primary delay, (ii) secondary delay, and (iii) tertiary delay.

Primary delay may be regarded as a form of health risk-taking behaviour. We expected that defining the demographic and psychosocial determinants of this behaviour in oral cancer patients would help in deducing the components of an intervention plan. Admittedly, such a large-scale intervention in a country the size of India should not be taken up without such studies and field trials.

There have been several studies on the determinants of delay in presentation of cancer patients in general,^{12,13,20} in breast cancer^{4,22-25} and in malignant melanoma.²⁶ A prospective, population-based study of various cancers of elderly New Mexicans (>65 years of age)¹³ reported that 20% of the subjects delayed

seeking care for at least 12 weeks and 7.4% delayed it for 1 year. From a stratified multivariate analysis, the site of the cancer appeared to be the strongest determinant of the delay, while regular check-up was another important factor. The authors did not find psychological status, social support and age as important determinants of delay. However, they had very few cases of oral cancer in their sample and did not analyse it as a separate group. For this reason, we included only those cancers of the head and neck that are present in the visible part of the mouth, i.e. from the lip to the palatoglossal fold.

Temoshok²⁶ examined the relationship between specific behaviour, the stage of the cancer and prognostic indicators of cancer patients. It was shown in melanoma patients that delay in seeking medical attention was the most significant variable predicting tumour thickness. They developed the concept of a 'type C' individual—a co-operative, unassertive patient, who suppresses negative emotions (particularly anger) and who accepts and complies with external authority. On the other hand, a 'type A' individual has been demonstrated to be predictive of coronary heart disease. Their study showed that 'type C' individuals had thicker tumours than 'type A' patients. It was also shown that psychosocial factors play a greater role in younger patients, and environmental factors in older patients. The environmental and genetic background predetermines the personality traits described by these authors. These are difficult to change. Though the results of such studies are interesting to read, they do not provide specific answers or inputs for an educational campaign.

A few studies have also examined the problem of delay in oral cancer patients. A study on half a million people in the UK surveyed all cases of cancer of the mouth and oral cavity and found that nearly half (48%) postponed seeing a doctor for ≥ 3 months.²⁷ Pain, younger age and tumours of the buccal mucosa and anterior two-thirds of the tongue were associated with early diagnosis.

Elwood and Gallagher investigated factors influencing the time gap between the first symptom and first consultation in 160 patients with cancer of the mouth.²⁸ The only factor significantly correlating with the time lapse was gender, being significantly shorter in men. The other factors tested were age, regular dental care, SES, alcohol consumption, smoking and marital status. Dimitroulis *et al.* studied referral patterns of 51 patients with oral cancer in Australia. Thirty-eight per cent of patients delayed seeking advice for more than 3 months (mean delay: 4.5 months).²⁹

In an open-ended questionnaire study,⁵ the major factors responsible for delay in presentation of oral cancer for more than 6 months were ignorance (76%), people living in rural areas (64%), small social pretext (48%); while belief in destiny (10%), a fatalistic attitude (4%) and fear of mutilating surgery (4%) were the minor factors. Since only descriptive statistics were given in this study and there was a considerable overlap among the predictive variables, the independent value of any of these predictors was hard to assess. It is from this study, however, that a matrix of the items included in the present study was developed and scaled responses were obtained in a pilot study.

Thus, psychosocial factors responsible for intention to seek early medical advice in patients with mouth cancer in India were formulated in vernacular in an organized questionnaire format. These psychosocial factors and their effect on delay are likely to be peculiar to the subcontinent.

The questionnaire evolved during this study was in the local language and provides material that can form the basis of an educational intervention programme. This questionnaire was

organized to test a hypothesis, i.e. which social behaviours or demographic variables predict delay. The scores obtained from pre-tested scaled responses to each item were added to get a mean score of a particular social behaviour. This instrument showed excellent reliability. It demonstrated good intra-observer repeatability for a short period with an intra-class correlation coefficient (0.81) with its measurement of study factors, when administered for the second time to 10 randomly selected subjects. Similarly, the frequency of the study factors showed good dispersion. The items selected from the pilot study in the final questionnaire had high correlation coefficient values with the sub-scales measuring the item-totals.

The age, gender and SES are demographic variables generally used to predict delay but none of these correlated significantly either in the univariate or multivariate analysis. These results were similar to those of some earlier studies.^{14,27,30} Demographic factors were analysed as determinants of psychosocial factors. We observed that the scores of motivation and perceived consequences were significantly higher in the urban as compared to the rural population. Affect and motivation were lower in the older age group. There was no significant difference between the sexes. The mean scores of perceived consequences and intention to seek early medical advice were higher in those with an education above high school level and, similarly, social factors and perceived consequences were higher in the high SES group. These findings are in general agreement with the published reports of delay in cancer treatment.^{14,28}

The components of the education programme have been fine-tuned by using each of the 60 items in the questionnaire as independent variables of primary delay. The final model consisted of five variables. An educational package aimed at reducing these misconceptions would be most effective in reducing the delay in presentation of oral cancer.

There are no comparable studies in the literature, either from India or any other ethnic groups in which such an analysis has been performed on the demographic and psychosocial determinants of delay in oral cancer presentation. A secondary research question in this study was to assess the relationship between total delay (primary and secondary delay) and stage of the disease. It was found that these correlated to some extent. As the total delay increased, the patients had more advanced stages of the disease. This is also in keeping with our common perception of cancer.

In a study from Yorkshire over 15 years (1962–73), in a population of half a million, Williams concluded that late diagnosis in the majority of cases of oral cancer is inevitable.²⁷ In the early stages the symptoms were minimal and there was no correlation between the duration of symptoms and the stage of the tumour at the time of diagnosis. However, the duration of symptoms was taken from case records, which may not be really reliable for this purpose. Also, the 223 patients included in the study were those with lesions of the posterior one-third of the tongue and oropharynx that are notorious for not producing any symptoms. The common cancer in India is that of the buccal mucosa and buccal-alveolar ridge. A non-healing ulcer and pain in two-thirds of the patients, excessive salivation in half of them and partial ankylosis in a quarter of the patients, were the early presenting symptoms of oral cancer.¹⁶ If the patients were aware of these symptoms they would consider them serious enough to perform a self-examination. This can be the basis of an educational programme. Therefore, one cannot accept that late detection of the majority of cases of oral cancer is inevitable.²⁷

The correlation observed between primary and secondary delay shows that there is a large scope for educating primary care physicians and dentists for an early referral of patients. In a study published from the UK, it was reported that 70% of medical and dental general practitioners were unable to recognize carcinoma of the mouth.³¹ In an earlier study, Kumar *et al.* reported that 22% of patients delayed reporting to hospital for more than 6 months after seeing their family doctor.⁵ Paucity of dental practitioners in India, inability of the family doctor to recognize the gravity of the lesion, a pessimistic outlook towards treatment and recourse to alternative medical treatment were some of the factors responsible for secondary delay. Fear of disfigurement, belief that destiny was inexorable and a nihilistic attitude were minor factors (4%). Secondary delay can be greatly reduced by a reassuring and convincing primary health care physician.

To be effective, an educational campaign for the masses in India will have to be in vernacular and elaborated scientifically. The programme will need to be directed towards the population at risk (tobacco users)—educate them regarding early self-detection of oral cancer by recognizing the gravity of trivial symptoms and the ability to conduct an oral self-examination. People should therefore be motivated to protect themselves by early self-detection. A plan for motivation should thus be developed and field-tested.

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