

Self-negligence and awareness among oral precancerous and cancer patients – A cross-sectional questionnaire study

Vezhavendhan Nagaraj¹, Priya S², Sivaramakrishnan Muthanandam¹, Devi M³, Umamaheswari Giri¹, Aravind Babu M⁴

¹Department of Oral and Maxillofacial Pathology and Oral Microbiology, Indira Gandhi Institute of Dental Sciences, Sri Balaji Vidyapeeth University, Pondicherry, ²Private Practitioner, Pondicherry, ³Department of Oral and Maxillofacial Pathology and Oral Microbiology, Adhiparasakthi Dental College and Hospital, Melmaruvathur, Tamil Nadu, ⁴Department of Oral and Maxillofacial Pathology and Oral Microbiology, Indira Gandhi Institute of Dental Sciences, Sree Balaji Dental College and Hospital, Bharath University, Chennai, Tamil Nadu, India

Abstract

Background: The National Institute of Health and Family Welfare (NIHF) reports that India has the highest global prevalence of oral cancers. The incidence is significantly more in developing countries when compared to the developed countries. Early detection is key to increasing the survival rate of the patients. Important causes for this late diagnosis could be self-negligence, lack of patient awareness about the causes and asymptomatic and subtle clinical presentation of the lesions.

Aim: To assess the causes of self-neglect and awareness levels among oral cancer and pre-cancerous patients.

Settings and Design: A cross-sectional questionnaire study was conducted among pre-cancerous and cancerous patients.

Methods and Material: A questionnaire with 16 closed-ended questions was framed relating to the causes of self-neglect and awareness of the patients. A total of 45 patients were selected by convenient sampling technique from the Institutional Tumour Board register of which 62 per cent were male patients and 38 per cent were female patients.

Statistical Analysis: Data analysis for demographic data, patients' awareness, and causes of self-neglect about precancer and cancer was done using SPSS Version 10.

Results and Conclusions: The present study concluded that the patients had adequate awareness that deleterious habits could lead to cancer but had a low level of awareness about the other causes of cancer, symptoms and management options available to treat cancer. The study result emphasizes that the government should plan for more cancer-screening camps in order to prevent the progression of cancer and to increase the awareness. (Reference I.D.: 2015-05006 for funding the project.ICMR)

Keywords: Cancer awareness, oral cancer, pre-cancer, self negligence

Address for correspondence: Dr. Vezhavendhan Nagaraj, Professor, Department of Oral and Maxillofacial Pathology and Oral Microbiology, Indira Gandhi Institute of Dental Sciences, Sri Balaji Vidyapeeth University, Pondicherry, India.

E-mail: vendhandent@gmail.com

Submitted: 04-Dec-2021, **Revised:** 23-Jan-2023, **Accepted:** 24-Apr-2023, **Published:** 13-Jul-2023

Access this article online

Quick Response Code:



Website:

www.jomfp.in

DOI:

10.4103/jomfp.jomfp_420_21

This is an open access journal, and articles are distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 License, which allows others to remix, tweak, and build upon the work non-commercially, as long as appropriate credit is given and the new creations are licensed under the identical terms.

For reprints contact: WKHLRPMedknow_reprints@wolterskluwer.com

How to cite this article: Nagaraj V, Priya S, Muthanandam S, Devi M, Giri U, Babu MA. Self-negligence and awareness among oral precancerous and cancer patients - A cross-sectional questionnaire study. J Oral Maxillofac Pathol 2023;27:282-6.

INTRODUCTION

Cancer is a significant public health issue worldwide, and India accounts for 75,000 to 80,000 new cases every year. The National Institute of Health and Family Welfare (NIHFW) reports that India has the highest global prevalence of oral cancers. In the year 2013 oral cancer resulted in 1,35,000 deaths up from 84,000 deaths in the year 1990. The incidence of occurrence is significantly more in developing countries when compared to the developed countries. According to the WHO report of 2004, the estimated number of new cases will be 50 per cent more in the next 20 years of time period. In India, the incidence rate of oral cancer has increased to 12.6 per lakh population.^[1] It has been reported that 40 per cent of cancer deaths are due to consumption of tobacco and alcohol. Non-habitual-related carcinomas have also been reported in recent literatures. The unhealthy lifestyle, malnutrition, genetic factors and infections in low socio-economic groups contribute to the non-habitual-related carcinomas.

In recent years, various advanced treatment modalities including surgical management, radiotherapy, and chemotherapy have been used in cancer management. In spite of advanced approaches, the survival rate of cancer patients in underdeveloped countries including the Indian subcontinent is comparatively less. Early detection is a key to increasing the survival rate of the patients, but unfortunately most of the oral cancer patients in underdeveloped and developing countries present with advanced stage at the time of diagnosis, which could directly affect the prognosis of the treatment.^[2] Important causes for this late diagnosis could be self-negligence, lack of patient awareness about the causes, asymptomatic and subtle clinical presentation of the lesions, etc.

The number of cancer patients continues to increase, but the survival rate has shown no signs of improvement for decades, in spite of various advancements in modern medicine.^[3,4] Early detection is a key to increasing the survival rate of the patients, but unfortunately most of the oral cancer patients in underdeveloped and developing countries present with advanced stage at the time of diagnosis, which could directly affect the prognosis of the treatment. Important causes for this late diagnosis could be self-negligence, lack of patient awareness about the causes, asymptomatic and subtle clinical presentation of the lesions, etc.

The key element in poor prognosis is delay in the presentation of oral cancer and the reasons for the presentation in the advanced stage are lack of awareness

about the disease, lack of cancer screening, poor socio-economic status and self-negligence. Early detection of oral cancer offers a better survival rate. Rural areas of countries have inadequate access to medical facilities.^[5] In the present study, 22 per cent of patients reported that they do not have adequate screening and cancer treatment facilities in the nearby health care centres.

Self-neglect is an altered behavioural change in which an affected individual neglects to attend to their basic needs or not attending appropriately to their medical conditions.^[6] Old age, chronic smoking, alcoholism, functional and social dependency and financial constraints are the important causes of the self-neglect. The important causes of oral cancer like tobacco consumption, alcoholism and ageing are also predisposing factors for self-neglect.^[7,8] The present questionnaire study was carried out to assess the common causes of self-neglect (the individuals who have not taken appropriate treatment even after explaining the consequences of the disease) among oral cancer and pre-cancerous patients. Analysing the causes of self-neglect and awareness will serve as an adjuvant to the standard medical treatment model.

Aims and objectives

To assess the causes of self-neglect and awareness among pre-cancer and cancer patients.

MATERIALS AND METHODS

Study design: A cross-sectional questionnaire study was conducted among pre-cancerous and cancerous patients who were not under proper treatment regimen or missed their treatment module.

Type of study: The study group consisted of oral pre-cancerous and cancer patients not taking appropriate treatment even after explaining the consequence of the disease. A questionnaire with 16 closed-ended questions was framed. It was designed such that 11 questions were pertaining to self-negligence and 5 questions were relating to the awareness of the patients. The questionnaire was prepared in English and then translated to the regional language, Tamil. Both the language questionnaires were peer reviewed and suggestions of the reviewed expertise were incorporated into the questionnaire. The awareness of the study group was accessed by a few important questions like: What is cancer? What are the causes and risk factors of cancer? Is cancer curable? Is it transmissible, etc. Questions pertaining to causes of self-neglect were also included in the questionnaire. Approval from the Institutional review board and Institutional Ethical Committee (IEC) from SBV

University, Puducherry was obtained. A patient consent form was obtained from the study group. Necessary help was provided for illiterate persons.

Study area and duration of the study: The study was conducted in Puducherry and Cuddalore populations over a period of 2 months (August and September 2015).

Sample size: Patient data were retrieved from the institutional tumour board register. 45 patients were selected by convenient sampling technique. Of the 45 patients, 62 per cent were male patients and 38 per cent were female patients and 57 per cent were from rural and 43 per cent were from urban areas.

Inclusion criteria: Patients suffering from oral pre-cancerous and cancer lesions who have either neglected the treatment or missed the treatment follow-up.

Exclusion criteria:(I) Pre-cancerous and cancer patients under proper treatment.

(II) Those who did not wish to participate were excluded.

OBSERVATIONS AND RESULTS

Data analysis was done by using Statistical Package for Social Sciences (SPSS; version 10). Data regarding the age, sex and location (either from rural or urban areas) of the patients were included in the analysis. The results of the study are as follows:

Demographic factors: The three important demographic factors considered in the study were age, sex and location of the patients. The range of age was between 20–80 years. Among the study group, 62 per cent were males and 38 per cent were females and 57 per cent were from rural and 43 per cent were from urban areas [Graph 1].

Awareness about cancer, causes and risk factors, symptoms and early detection:

The questionnaire revealed that 40 per cent of the patients did not know about what is oral cancer, while 60 per cent of patients were aware of what is oral cancer. 83 per cent of the patients knew that oral cancer could be caused by deleterious habits and 40% were unaware of the causes of oral cancer. Four per cent of the patients were aware of the genetic causes of oral cancer. None of the study group was aware that ill-fitting dentures and altered lifestyle could cause cancer.

Causal role of smokeless and smoking tobacco was known to 80 per cent of patients. 89 per cent of the patients

used to consume tobacco (smokeless and smoking) and 21 per cent used to consume areca nut and pan. Most of the patients in the study group were unaware of the fact that the consumption of areca nut alone can produce cancer.

Seventy-three per cent of the patients did not have any awareness of the symptoms. Most known symptoms among the patients were tissue growth (8%), non-healing ulcer (4%) and red patch (2%). Eleven per cent of the patients were aware of the fact that they can present any of the above-mentioned symptoms. But none of the patients knew that oral cancer can present as a white patch.

Forty-eight per cent of the patients were not aware whether cancer is curable or non-curable, while 28 per cent of the patients were aware that it may be cured if diagnosed at an early stage. The mean value for cancer awareness was at its peak in the age group between 41 – 60 years (43.58), followed by 61 – 80 years (41.4) and was least in the age group between 20 – 40 years (39.82). The mean values of awareness for cancer based on gender and region are presented in Graphs 2 and 3, respectively.

Causes of self-neglect among oral cancerous and pre-cancerous patients:

Five questions pertaining to causes of self-neglect were included in the questionnaire. The causes of the self-negligence were categorised as follows:

Category A: Not willing for treatment

Category B: Lack of medical facilities

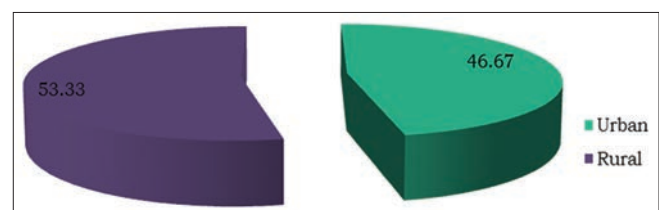
Category C: Lack of awareness about the disease

Category D: Low socio-economic status category

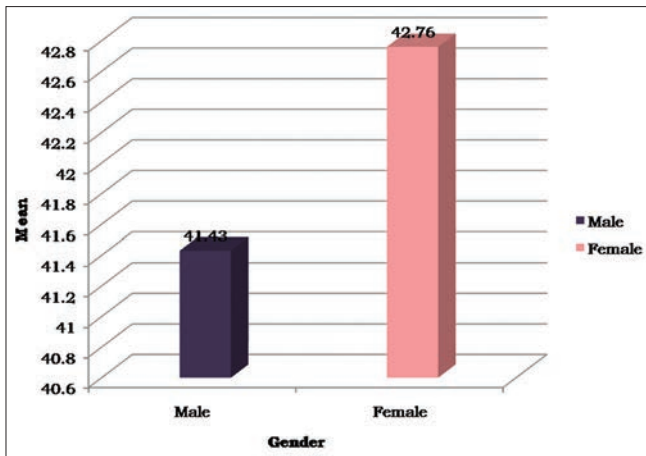
Category E: Pseudo confidence of well-being category

Category F: Fear of separation from society

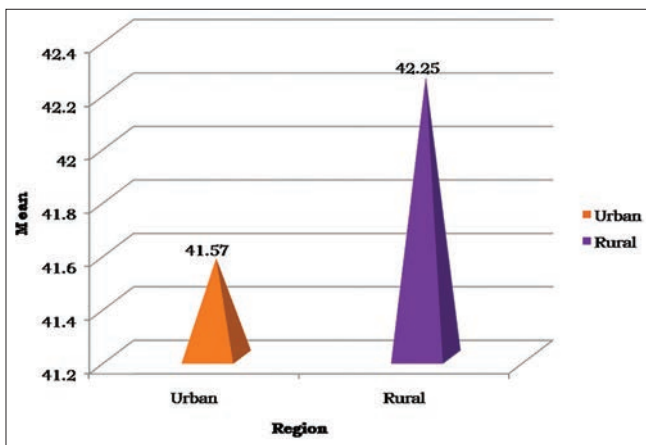
Frequency distribution of the causes is represented in Graph 4.



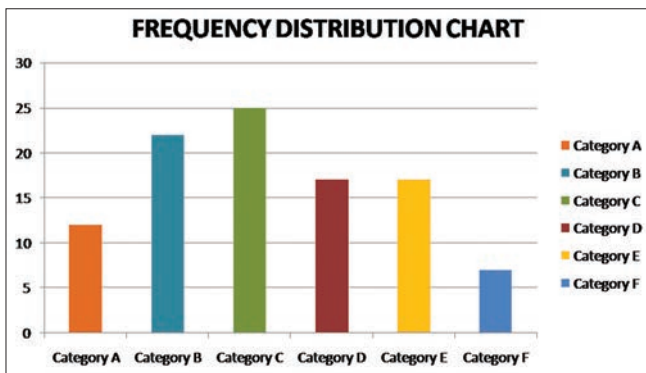
Graph 1: Distribution of the respondents on the basis of region



Graph 2: Mean value for awareness of cancer based on gender



Graph 3: Mean value for awareness of cancer based on region



Graph 4: Categories illustrating the causes of the self-negligence

DISCUSSION

Oral cancer is a major health problem in Indian subcontinent, and it is one of the top three cancers in India. World health organization in the year 2010 stated that 55,000 Indians die because of cancer. The incidence of cancer has increased in recent decades. In this study, tobacco-related cancers represented around 18 per cent of

female and 42 per cent of male cancer deaths. In men, two of the most common fatal cancers were oral cancer and lung cancer.^[9] There are three most important reasons for high mortality rate with the first being the diagnosis at a later stage that leads to poor prognosis. The second reason is inadequate access to medical facilities especially in the rural areas of India. The third cause is low socio-economic status; the low socio-economic group is more vulnerable to common high-risk factors like consumption of tobacco and poor dietary habits. And lastly, the occurrence of the lesion in inaccessible areas is also a reason for the late reports.

Most cancer patients report at the advanced stage due to a lack of awareness about the disease, inadequate access to medical facilities mainly in the rural areas of India, low socio-economic status and the occult nature of the disease. Various public awareness surveys conducted worldwide in developed and developing countries showed a significant lack of awareness among the general public. Warnakulasuriya KA *et al.*^[10] (1999, in Great Britain), Powe BD *et al.*^[11] (2004 in African American), Peker I *et al.*^[12] (2010, in Turkey) and Srikanth Reddy B^[13] (2012, in South India), highlighted the general lack of awareness among the public about mouth cancer, lack of knowledge about its causation and also the excess risk associated with alcohol.

In this present questionnaire study, there was a significant lack of awareness about oral cancer among the patients of rural and urban populations with no significant difference between the two populations. A low level of awareness was evident mainly about what is oral cancer, the importance of its early detection and management. Forty per cent of the patients did not know what oral cancer is, and 9 per cent of the patients had a false belief that it is a contagious and transmissible disease.

Seventy-three per cent of the patients knew that oral cancer could be caused by deleterious habits. The causal role of smokeless and smoking tobacco was known to 80 per cent of the patients. These findings were similar to the findings of the study done by Hertrampf K *et al.*^[14] in the year 2012. Few patients were aware of the genetic causes and none of the study group was aware of the fact that ill-fitting dentures and altered lifestyle including diet could also cause oral cancer. Lack of awareness also existed that consumption of areca nut alone can also produce cancer.

Seventy-three per cent of the patient did not have awareness of the symptoms. The commonly appreciated symptoms are tissue growth, non-healing ulcers and red patch. Most of the patients did not know that it can present

as a white patch. These findings were similar to Tadbir AA *et al.*^[15] (2013, in Iran).

Early detection and prevention is the only way to increase the survival rate and decrease the incidence rate. Creating the awareness among general public plays a significant role in it. The present study revealed that only 28 per cent of the patients were aware that cancer is curable if it is diagnosed at an early stage.

Self-neglect is an altered behavioural change of an individual who neglects to attend to their basic needs including their medical conditions. The important causes like old age, chronic smoking, alcoholism, functional and social dependency and financial constraints are also predisposing factors for cancer. All the participants of the study group had one or more deleterious habits. The present study revealed that the common causes of self-neglect are lack of awareness about the disease, lack of medical facilities, low socio-economic status and pseudo confidence. Twelve per cent of the patients were not willing for the treatment. Lack of appropriate medical facilities for cancer screening and management is noticed in both urban and rural areas of the study population. In reviewing the literature, there were numerous studies conducted to analyse the causes of self-neglect. Burden of Disease of India – 2005 released by the National Commission on Macroeconomics and Health Ministry of Health and Family Welfare, Government of India also stated that cancer screening and management programme and medical management facilities have to be increased in rural and urban health care centres to reduce the cancer incidence and cancer death.

CONCLUSION

Oral cancer is one of the most common cancers prevailing in India. There is an increase in the incidence and mortality rate even after so much of advancements in treatment modalities. Late diagnosis is an important cause of poor prognosis and cancer deaths. The present study concluded that the patients had adequate awareness that deleterious habits could lead to cancer and had a low level of awareness about the causes of cancer, symptoms and management options available to treat cancer. In analysing the causes of self-negligence, study revealed that most of the patients were addicted to one or more deleterious habits. The lack of awareness, inaccessibility to health care centres, lack of medical facilities in health care centres and low socio-economic status are the most important causes

for self-negligence. The study result emphasizes that the government should plan for more cancer screening camps in order to prevent the progression of cancer and to increase awareness. It should be looked upon that adequate cancer screening and management facilities are available in healthcare centres.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

REFERENCES

1. Coelho KR. Challenges of the oral cancer burden in India. *J Cancer Epidemiol* 2012;2012:701932.
2. Villa A, Kreimer AR, Pasi M, Polimeni A, Cicciù D, Strohmenger L, *et al.* Oral cancer knowledge: A Survey administered to patients in dental departments at large Italian Hospitals. *J Cancer Educ* 2011;26:505–9.
3. Kingsley K, O'Malley S, Ditmyer M, Chino M. Analysis of oral cancer epidemiology in the US reveals state-specific trends: Implications for oral cancer prevention. *BMC Public Health* 2008;8:87.
4. van der Waal I. Are we able to reduce the mortality and morbidity of oral cancer; some considerations. *Med Oral Patol Oral Cir Bucal* 2013;18:e33-7. doi: 10.4317/medoral. 18486.
5. Kumar S, Heller RF, Panday U, Tewari V, Bala N, Oanh KTH. Delay in presentation of oral cancer: A multifactor analytical study. *Natl Med J India* 2001;14:13-7.
6. Gibbons S, Lauder W, Ludwick R. Self-neglect: A proposed new NANDA diagnosis. *Int J Nurs Terminol Classif* 2006;17:10-8.
7. Gupta B, Johnson NW. Systematic review and meta-analysis of association of smokeless tobacco and of betel quid without tobacco with incidence of oral cancer in South Asia and the Pacific. *PLoS One* 2004;9:e113385. doi: 10.1371-journal.pone. 0113385.
8. Shanmugham JR, Zavras AI, Rosner BA, Giovannucci EL. Alcohol-folate interactions in the risk of oral cancer in women: A prospective cohort study. *Cancer Epidemiol Biomarkers Prev* 2010;19:2516-24.
9. Dikshit R, Gupta PC, Ramasundarahettige C, Gajalakshmi V, Aleksandrowicz L, Badwe R, *et al.* Cancer mortality in India: A nationally representative survey. *Lancet* 2012;379:1807–16.
10. Warnakulasuriya KA, Harris CK, Scarrott DM, Watt R, Gelbier S, Peters TJ, *et al.* An alarming lack of public awareness towards oral cancer. *Br Dent J* 1999;187:319-22.
11. Powe BD, Finnie R. Knowledge of oral cancer risk factors among African Americans: Do nurses have a role? *Oncol Nurs Forum* 2004;31:785-91.
12. Peker I, Alkurt MT. Public awareness level of oral cancer in a group of dental patients. *J Contemp Dent Pract* 2010;11:049-56.
13. Srikanth Reddy B, Doshi D, Padma Reddy M, Kulkarni S, Gaffar A, Ram Reddy V. Oral cancer awareness and knowledge among dental patients in South India. *J Craniomaxillofac Surg* 2012;40:521-4.
14. Hertrampf K, Wenz HJ, Koller M, Wiltfang J. Public awareness about prevention and early detection of oral cancer: A population-based study in Northern Germany. *J Craniomaxillofac Surg* 2012;40:e82-6. doi: 10.1016/j.jcms. 2011.04.007.
15. Tadbir AA, Ebrahimi H, Pourshahidi S, Zeraatkar M. Evaluation of levels of knowledge about etiology and symptoms of oral cancer in southern Iran. *Asian Pac J Cancer Prev* 2013;14:2217-20.