

Population-based cancer screening through community participation: Outcome of a district wide oral cancer screening program from rural Kannur, Kerala, India

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Abstract

Background: Oral cancer is a major public health challenge, and about one-fifth of all oral cancer cases reported globally are from India. In spite of the potential for early detection by simple visual examination, the majority of patients report in later stages of the disease, especially in low and middle-income countries. We report the results from a district level population-based oral cancer screening program. **Methods:** A cross-sectional survey was carried out among people aged >15 years in 48 panchayats of Kannur district in Kerala, India. This comprehensive multi-stakeholder district-wide screening was carried out in six stages including planning, sensitization, recruiting of community volunteers and training, survey, organization of specialist camps and referring to cases to cancer center. The descriptive statistical analysis was performed using EpiData analysis software (Version 2.2.2.180). **Results:** Among the 1,061,088 people in 265,272 houses surveyed, 2507 of them attended the screening camps, and 13 oral cancers and 174 oral precancers were detected. Majority of the oral cancer patients were male (69%), with primary education or illiterate (62%) and low socioeconomic status (61%). Five of the patients diagnosed with early-stage cancer are alive and have good oral health-related quality of life. **Conclusion:** Detection of precancerous and early-stage cancers should be a priority of oral cancer screening programs. The possible key for addressing cancer screening needs of the rural population is to equip the primary health centers in cancer screening activities with available human resources while adapting to local context.

Key words: Cancer screening, community participation, early detection, oral cancer

Introduction

The International Agency for Research on Cancer (IARC) in 2012 estimated 14.1 million new cases of cancer including 8.2 million deaths worldwide. Oral cancer is the 11th most common cancer among men in the world with an incidence rate of 2.6%. India accounts for one-fifth of all oral cancer cases and one-fourth of all oral cancer deaths worldwide, which is estimated to be 1 million new cases and 0.77 million deaths, respectively.^[1] The common risk factors for oral cancers are tobacco use (smokeless and smoking), areca nut chewing, alcohol use, and poor nutrition. Other risk factors include genetic factors, mate drinking, viruses, and chronic trauma.^[2,3] Smokeless tobacco is widely used in Southeast Asia, and the prevalence of its use among the rural and socially disadvantaged population is alarmingly high.^[4] Smokeless tobacco use is strongly associated with oral cancer.^[5] The causal role of smoking and alcohol use in the incidence of oral cancer and oral epithelial dysplasia is well established.^[6] Oral cancer screening through visual examination helps in detection of malignant and potentially malignant lesions in early stages.^[7] Visual examination of the oral cavity is a cost-effective method of oral cancer screening when it is directed at high-risk population.^[8] A Cochrane review of the effectiveness of the current screening methods in decreasing oral cancer mortality concluded that a visual examination as a part of population-based screening programme reduces the mortality rate in high-risk individuals.^[9]

There are limited community-based screening programs in India, and only sporadic opportunistic camp-based screenings have been carried out. The National Cancer Control Program (NCCP) of India recommends secondary prevention by early

detection and diagnosis of cancers, for example, cancer of cervix, breast, and oral cavity by screening and patient education on self-examination. There is a need for local cost-effective cancer prevention and control strategy in India.^[10]

This paper evaluates the outcome of a district level cancer control strategy “ASWAS” in the detection of early-stage oral cancer and precancer. This cancer screening program was conducted with the cooperation of Local Self-Governments and the District Health Department with a Tertiary Cancer Centre.

We intend to describe the population-based oral cancer screening strategy in 48 panchayats of Kannur district from August 2013 to March 2014, with an objective to estimate the proportion of newly detected cancers and precancers.

Methods

Ethics considerations

All participants provided a written informed consent to participate in the study. Ethical approval to conduct the study was obtained from the Institutional Review Board and the Institutional Ethics Committee (IEC) of the Malabar Cancer Center (MCC). Additional ethics approval was also obtained from the Ethics Advisory Group of the International Union against Tuberculosis and Lung Disease (The Union), Paris, France.

Study Design

This was a cross-sectional study.

Study Setting

Kannur district in Kerala consists of 81 panchayats grouped under 11 blocks. In Kerala, cancer screening camps are routinely conducted by Governmental and Non-Governmental

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Organizations, utilizing the human resources from tertiary cancer centers. These camps are attended voluntarily by the general population. MCC is an autonomous institution under the Health and Family Welfare Department, Government of Kerala, providing oncology care to the population of Northern Kerala. Community Oncology Department of the institution regularly organizes early cancer detection camps and awareness programs.

Kannur District Panchayath and District Health Department with the help of MCC planned a district level cancer control program named “ASWAS.”

Study population and study period

Population aged >15 years in 48 panchayats of Kannur district from August 2013 to March 2014.

Program description

This multi-stakeholder program consisted of six stages [Figure 1]. The stakeholders include District Panchayath, District Health Department, and MCC.

Stage I

Preliminary discussion for program conception and feasibility assessment were held among stakeholders. Four meetings were held during this stage and matters related to program implementation, finance, coordination, and monitoring were planned. District Panchayath President, Director of MCC and District Medical Officer, were the chief participants in these meetings.

Stage II

An expanded stakeholder meeting comprising people's representatives from all three levels of local self-governing institutions (District, Block, and Grama panchayaths) was held. Medical officers and health inspectors from the primary health center (PHC) and community health centers participated in the meeting. An orientation session was conducted to emphasize the need and feasibility of early cancer detection at the community level with the utilization of limited resources existing in the PHCs. This was followed by an open discussion by the participants. Organizing committees were formed in each Panchayath comprising people from all walks of life.

Stage III

It consisted of three components: selection of community volunteers; training of trainers; and training of volunteers. At the panchayath level, volunteers were selected among Accredited Social Health Activist workers, Anganwadi workers,

self-help group members, and NGO members. Combining two and/or three blocks, we organized four programs for the training of trainers. Doctors from the community oncology department of MCC conducted the training program. Oral cancer screening methods were demonstrated using PowerPoint presentations and photographs. Information, education, and communication materials were given to all participants to facilitate their volunteer training program. The trained PHC doctors and health inspectors conducted volunteer training at their respective panchayaths. A total of 48 volunteer training programs were organized.

Stage IV

Trained community volunteer groups conducted a house-to-house survey and oral cavity examination. Depending on population and geographic area, each panchayath has 15–20 wards with 200–300 houses per ward. Two or three volunteer groups were assigned to a ward and asked to complete the survey within a month. Based on the criteria provided by MCC, those requiring further examination at panchayath level camps were selected and provided entry cards. People having the following signs, symptoms, or habits were invited to attend the camp.

1. A white patch or plaque in the oral cavity
2. A red patch or plaque in the oral cavity
3. A nonhealing oral ulcer of >2 weeks duration with or without pain
4. Burning sensation or dryness in the mouth
5. Inability to take hot or spicy food or restricted mouth opening or difficulty in tongue movements
6. An abnormal growth/swelling in the oral cavity with or without pain
7. Chronic tobacco and alcohol users (>20 years of use).

Stage V

Patients identified were invited to attend the panchayath level screening camp. Patients already diagnosed with oral cancer were excluded. All participants were examined by doctors, and suspicious cases were referred to MCC. All chronic tobacco users were given brief intervention on cessation and advised follow-up.

Stage VI

All patients suspected of oral cancer or potentially malignant disorders were referred to MCC for further evaluation and management. All presumptive oral cancer cases and suspicious precancerous cases were confirmed through biopsy. Panchayath members and health workers acted as patient navigators and ensured that all identified patients complied with advises given to them.

Data collection

Trained volunteers conducted a house-to-house survey to collect information on sociodemographic factors, tobacco, and alcohol use habits. Volunteers also examined the oral cavity for any suspicious cancerous and precancerous lesions and collected data. Information about the referred patients was collected from case records.

Oral health-related quality of life was recorded through the direct patient interview.

Data variables

Information on the following variables such as age, sex, educational qualification, economic status, tobacco, and alcohol

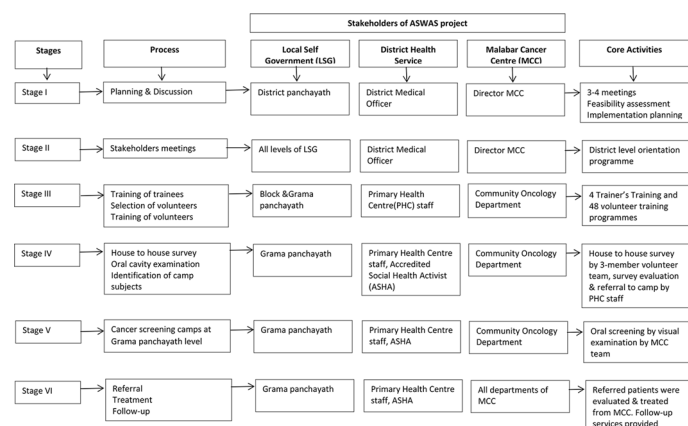


Figure 1: Program implementation strategy of oral cancer screening program in rural areas of Kannur district, Kerala, India in the year of 2014

use status were extracted from hospital case records into a pretested structured data collection form by investigators. Information on number of houses visited, total population, smoking, and alcohol use were extracted from survey compilation report. Posttreatment oral health-related quality of life of oral cancer patients on follow-up was assessed using the Oral Health Impact Profile (OHIP)-14. OHIP-14 is derived from OHIP-49 which measures the people's perception of the oral condition of their oral wellbeing.^[11] The OHIP-14 consists of seven domains, and each domain is assessed using a set of two questions. Scoring was done using a Likert-type five-point response. The scores 0, 1, 2, 3, and 4 correspond to the categories never, hardly never, occasional, very often, and often, respectively. The maximum OHIP score possible was 56, and the minimum score was zero. Higher the score, the higher the oral health impact, and lower the oral health quality of life. The Malayalam language version of the OHIP-14 questionnaire was prepared using back-translation method.

Data entry, data validation, and analysis:

The principal investigator of this study performed double data entry using EpiData entry software (Version 3.1, EpiData Association, Odense, Denmark). The two databases were compared and validated for discrepancies, which were resolved through referral to the original data source. This finalized database was securely locked. A duplicate version of the finalized database, after removing personal identifiers, was used for statistical analysis using EpiData analysis software (Version 2.2.2.180, EpiData Association, Odense, Denmark).

Results

1,061,088 people from 265,272 houses in 48 panchayaths were surveyed by 6325 volunteers. They identified a total of 3226 patients to attend the camps after initial evaluation, but only 2507 attended. On an average, 52 people attended each camp. The camps were conducted over a period of 8 months. We detected 13 oral cancers and 174 oral precancerous cases. Precancerous cases included leukoplakia ($n = 89$), oral submucous fibrosis ($n = 31$), and oral lichen planus ($n = 54$) [Figure 2]. Among the 13 detected oral cancer patients, majority were male (69%). They were either illiterate (31%) or had primary level education (31%), and none had higher secondary or college level education; and 61% belonged to below poverty line category.

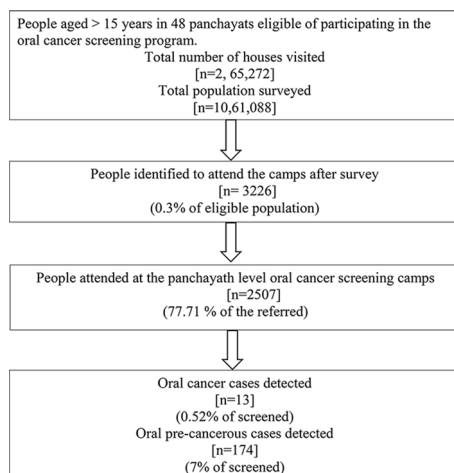


Figure 2: Impact of oral cancer screening program in rural areas of Kannur district, Kerala, India in the year of 2014

Tobacco smoking habit was identified in 62% of oral cancer patients, whereas 54% had the habit of chewing tobacco and 69% of patients were alcoholic. All patients on follow-up reported complete abstinence from tobacco and alcohol use. Among users, the mean duration of smoking was 36.87 years ($n = 8$, $SD = 17.5$). Among alcoholics, the mean duration of alcohol consumption was 41 years ($n = 9$, $SD = 15.86$) [Table 1].

Nearly half of the patients were detected in early stages (stage 1 = 38% ($n = 5$) and stage 2 = 8% ($n = 1$). The detected cases treated at MCC underwent surgery (31%), radiation (23%), supportive care (23%) or a combination of all these (8%) [Table 2]. All early-stage patients on follow-up were disease free. The total OHIP score of patients ranged from 2 to 27 with a mean score of 13. The maximum OHIP score possible is 56 and the minimum score is zero. Lower score represents higher oral health-related quality of life. Patients detected with late stages of cancer had a poor outcome as 86% of them died within a period of 2 years [Table 3].

Table 1: Sociodemographic characteristics and health behavior of oral cancer patients detected by cancer screening program in rural areas of Kannur district, Kerala, India in the year of 2014

Patient characteristics	Variables	n (%)
Sex	Male	9 (69)
	Female	4 (31)
Education	Illiterate	4 (31)
	Primary	4 (31)
	Secondary	3 (23)
	Not recorded	2 (15)
Occupation	No job	4 (31)
	Manual worker	6 (46)
	Self employed	1 (8)
Income*	Not recorded	2 (15)
	APL	1 (8)
	BPL	8 (61)
Health behavior	Not recorded	4 (31)
	Smoking	8 (62)
	Chewing tobacco	7 (54)
	Alcoholic	8 (62)

*APL=Above poverty line, BPL=Below poverty line

Table 2: Clinical staging, type of treatment and outcome of oral cancer patients detected by cancer screening program in rural areas of Kannur district, Kerala, India in the year of 2014

Patient characteristics	Variables	n (%)
Clinical staging	Stage1	5 (38)
	Stage2	1 (8)
	Stage3	5 (38)
	Stage4	2 (16)
Type of treatment	Surgery	4 (31)
	Radiation	3 (23)
	Combination	1 (8)
	Supportive care	3 (23)
Outcome	Not willing for treatment	2 (15)
	On follow-up	5 (39)
	Lost to treatment	2 (15)
	Death	6 (46)

Table 3: Profile of oral cancer patients detected by cancer screening program in rural areas of Kannur district, Kerala, India in the year of 2014 (n=13)

Age	Sex	Duration smoking (years)	Duration SLT (years)	Duration alcohol (years)	Clinical staging	Patient outcome	OHIP-14 score [‡] (maximum=56)
75	Female	0	42	0	Stage 1	Alive	14
60	Male	35	0	35	Stage 1	Alive	2
59	Male	39	0	39	Stage 1	Alive	2
65	Female	0	0	0	Stage 1	LFU	
75	Female	0	0	0	Stage 1	LFU	
65	Female	0	45	0	Stage 2	Alive	20
70	Male	0	40	40	Stage 3	Alive	27
90	Male	61	70	70	Stage 3	Death	
49	Male	5	3	17	Stage 3	Death	
64	Male	49	0	49	Stage 3	Death	
52	Male	22	0	22	Stage 3	Death	
64	Male	34	34	48	Stage 4	Death	
79	Male	50	0	50	Stage 4	Death	

SLT=Smokeless tobacco, LFU=Lost to follow-up, [‡]OHIP-14=Oral Health Impact Profile-14: Higher the OHIP score lower will be the oral health-related quality of life and vice versa

Discussion

In this population-based cancer screening program, nearly half of oral cancer patients identified were in the early stages of the disease. Either tobacco or alcohol was used by all patients for varying duration. The socioeconomic status of the patients considering education, income and occupation were low. All five oral cancer patients who were detected in early stage and undergone treatments are alive and having a minimal oral health impact.

This district-level oral cancer screening program was a multi-stakeholder program which utilized the population mobilizing capacity of local self-governing institutions, institutional infrastructure, and dedicated manpower of District Health Department and cancer screening expertise of tertiary cancer center. A population-based cancer screening program among women conducted in Mumbai used similar strategy for cancer screening, but the involvement of local self-governing institutions and public health department in program planning and implementation was minimal.^[12] They were planning to cover a population of 125,000 women over a period of 5 years. In this study, we were able to cover a population of 1,061,088 people over a period of 8 months. The active participation of people's representatives and health service staff made this possible. Community participation and community ownership of the intervention are necessary for the success of community-based projects.^[13]

Health worker's effectiveness in detecting oral cancers and precancers were widely studied.^[14,15] A recent study from Sri Lanka has re-evaluated the utilization of primary health care staff in early detection of potentially malignant disorders and cancers. They pointed out the need for further training as the poor agreement was observed in identifying these lesions. Hence, identifying individuals based on risk and referring them to the dental department at the local government hospital was recommended as an alternative.^[16] In our study, volunteers selected 3226 patients for further evaluation at the screening camp, of which 13 were cancer cases, and 173 were precancer cases. Community volunteers were trained to identify any deviation from normal and not specific lesions. This may explain the wide difference between the cases screened and those detected. This shows that community volunteers can

be effectively used for preliminary screening of oral cancer. These cases should be further confirmed by a trained dental surgeon through secondary screening. This two-tier strategy will effectively scale down the patient load and ensure diagnostic accuracy. The results from a population-based opportunistic cancer screening program in New Delhi has identified 18 oral cancer patients over a period of 2 years by screening 3503 people. Higher yield of cases reported in this center-based screening strategy may be due to increased referrals from the peripheral rural centers or due to the longer duration of the program.^[17] The population-based oral cancer screening strategy used in our program largely conforms to the screening and management algorithm for oral cancer in the operational framework put forward by the Ministry of Health, Government of India.^[18] We included an oral cavity examination by community volunteers during the house-to-house survey, and there was no option of self-referral to the screening program. The oral cancer patients identified in our program belonged to the lower socioeconomic strata of the population. A 10-year retrospective study from Brazil also agrees with our finding that oral cancer patients have low socioeconomic status.^[19] A study from Tamil Nadu, India also showed that risk of oral cancer was inversely proportional to education, income, and occupation.^[20] Male gender, tobacco use in all forms, and duration of risk habits are significantly associated with oral cancer.^[21] Low socioeconomic status is also associated with treatment delay.^[22] We also found that 54% of the study participants were in the late stages and this late stage reporting may be attributed to lower socioeconomic status and poor health seeking behavior associated with tobacco and alcohol habits.

Strengths

The strength of this study was its multi-stakeholder involvement and community participation. Apart from the cases detected, this program resulted in house-to-house awareness generation about oral cancer signs, risk factors and oral cavity self-examination methods for identifying changes.

Limitations

It was a large population-based cancer screening program, implemented in a relatively short duration of time which may have resulted in increased workload on the District Health

Department. Lack of centralized survey monitoring, data evaluation and documentation are other limitations of this study.

Implications

Implementation of similar programs in rural areas will meet the much-required cancer screening needs of the rural population through awareness raising and capacity building at a primary care level. The house-to-house survey will help to disseminate cancer-related information in rural households. This study also demonstrated that lay volunteers, if trained, can be effectively used in oral cancer screening programs. The PHC health workers had hands-on experience in cancer screening which was not yet a part of the primary level activities in India. This program will be a stepping stone for upcoming nation level cancer control programs envisaged at primary care level. It also demonstrated the relevance of community participation in improving the reach of health programs in rural areas.

Conclusion

This district wide cancer control program with multi stakeholder participation resulted in identification of substantial number of oral cancers in early stages. The reliance of the program on the existing health system at no additional infrastructural or manpower costs makes it an ideal one for national level implementation. The exemplary role played by Accredited Social Health Activists and other community volunteers in the implementation of the program highlights the prospect of community participation for the success of similar large-scale programs.

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Conflicts of interest

There are no conflicts of interest.

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