A REVIEW OF SOCIAL AND BEHAVIORAL EFFORTS AT ORAL CANCER PREVENTIONS IN INDIA

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Abstract: Background. Oral cancer is a major public health problem in South-Central Asia, home to one fifth of the world’s population. In most regions of India, it is the most common cancer in men and the third most common cancer in women. Prevention is an effective tool to reduce disease burden on society and may offer particular advantages in developing countries.

Methods. The primary and secondary oral cancer prevention efforts in India were reviewed and presented. In addition, the scope of the oral cancer problem and the tobacco industry in India are discussed, and the chief etiologies in the region are summarized.

Results and Conclusions. The effectiveness of these prevention efforts provides an excellent social/behavioral model for similar programs in other developing countries. Furthermore, similar programs may also be applicable to certain populations in schools or industries in the developed world.

Keywords: oral cancer; head and neck neoplasms; cancer prevention; behavioral modification; India

SCOPE OF THE PROBLEM

Although head and neck cancer is relatively rare in the United States, it is the fifth most common cancer worldwide. Furthermore, in some parts of the world, these cancers represent the most common malignancies found in men. For example, in South-Central Asia (India, Pakistan, Bangladesh, Iran, Afghanistan, and the Central Asian Republics), home to one fifth of the world’s population, head and neck cancer accounted for approximately 155,400 new cases of cancer in 1990 (17% of all cancers and 25% of all cancers occurring in men). Although in most regions of the world, laryngeal and nasopharyngeal cancers account for between one third and one half of all head and neck malignancies, in South-Central Asia, 80% of head and neck cancers are found in the oral cavity and oropharynx. In most regions of India, cancer of the oral cavity is the leading malignancy diagnosed in men, accounting for up to 20% of cancers in men, and oral cavity cancer is the third most common cancer in Indian women. However, the incidence of oral cancer in India does seem to be gradually declining.

Reliable oral cancer prevalence and mortality data are unavailable for India. However, a review of the approximately 1.5 million cancer deaths in England and Wales from the years 1973 to 1985 has shown that Indian-born men and women had
greater than twofold and fivefold (respectively) higher relative risks of oral cancer mortality than native English and Welsh individuals. Furthermore, India has particularly poor survival rates for oral cancers compared with other regions of the world. Five-year relative survival rates for oral cavity cancer are in the 40% to 45% range and for oropharyngeal carcinoma in the 25% to 30% range. The chief reason for these poor survival rates is the late presentation for treatment, with only one third of patients with oral cavity cancer and approximately one in eight patients with oropharyngeal cancer being initially seen with localized disease. In a study from Southwestern India, only 20% of patients with oral cancer were initially seen with localized disease. In an environment of limited resources for such overwhelming public health problems, it is apparent that efforts at primary prevention and early detection will be critical in limiting the impact of oral cancer on Indian society.

India is the world’s third largest producer of tobacco, producing 7% of the world’s unmanufactured tobacco and 13.5% of the world’s manufactured tobacco products. Furthermore, India is a net exporter of tobacco, and in 1990, it had a $97.7 million dollar trade surplus in tobacco. In 1993, 900,000 people were employed in India in the growing and curing of tobacco, with an additional 3.4 million working in tobacco manufacturing. It has been estimated that smokeless tobacco–related products such as guthka or pan masala account for $1 billion annually in business, equivalent to 0.2% of India’s gross national product. Although it has been shown that in developed countries the costs of tobacco consumption outweigh the income that the industry generates, data regarding this issue in the developing world is limited. A cohort study in New Delhi of 342 patients with either head and neck or lung cancers has estimated the costs to the patient related to their cancer diagnosis to be approximately $423. From these calculations, the authors estimated that $56 million was spent by Indian patients with newly diagnosed cancers of the head and neck or lung in 1990. The patient costs for these malignancies alone was equivalent to approximately 13% of the annual revenue generated by tobacco. However, these estimates do not include the cost of the health care system, which is intensely subsidized; the cost of other tobacco-related cancers and diseases; the costs of prevalent cases; or the indirect societal costs. Although the total costs of oral cancer to Indian society remain unknown, it would seem obvious that the health benefits (including reductions in oral cancer incidence and mortality) gained with tobacco control efforts will outweigh the costs of the loss of the tobacco industry.

**ESTABLISHED RISK FACTORS**

The strength and consistency of the association between tobacco and oral cancer has been demonstrated in numerous case-control and cohort studies with significant relative risks or odds ratios in the threefold to 12-fold range. Furthermore, a dose-response effect is consistently shown in these studies between the duration and dose of smoking and the increasing risk of oral cancer and between the time since quitting and the decreasing risk of oral cancer. The specificity of the link between tobacco and oral cancer (and not the nonmucosal/unexposed head and neck malignancies), the coherence and analogy of the explanation of tobacco-induced oral cancer to lung carcinogenesis, and the biologic plausibility of the well-established tobacco-induced carcinogenesis model have all helped establish tobacco as the chief etiologic agent in oral cancer.

Studies within the Indian population have demonstrated similar associations between tobacco and oral cancer. Most tobacco consumed in India is in the form of unregulated tobacco products. “Bidis” account for at least 40% of all tobacco consumed in India; these are hand-rolled, filterless tobacco cigarettes produced at home mainly by millions of poor women and children. Other tobacco products common in India include “hookah” (traditional water pipe), “chutta” (clump of tobacco smoked with the lighted end inside of the mouth), “misri” (a powdered tobacco rubbed on the gums), and various other forms of smokeless tobacco products. Furthermore, “pano” (betel leaf, lime, catechu, and areca nut) is commonly chewed in India either mixed with tobacco or alone and is a strong risk factor independent of tobacco use for carcinoma of the oral cavity. Although consumption of manufactured cigarettes in India seems to be declining, the overall tobacco consumption continues to grow at 2% to 3% annually. Currently, approximately 65% of Indian men and one third of Indian women use some form of tobacco. Furthermore, elevated rates of pano use in Indian adolescents have been reported.

Tobacco, however, is not the only factor in the complex causality equation of these cancers. Al-
Alcohol is an important promoter of oral carcinogenesis and is a contributive factor in at least 75% of oral cancers in Western countries. Furthermore, alcohol seems to have an effect on risk of oral cancer independent of tobacco smoking, but these effects are consistently significant only at the highest level of alcohol consumption. Similar associations have been demonstrated in India as well. Other potential risk factors for oral cancer such as poor nutrition, laryngopharyngeal reflux, human papillomavirus, air pollution, and genetics have been greatly studied recently in the Western literature but, as of yet, have received little attention in the Indian population. However, indoor air pollution from wood stove use, a common form of cooking and heating in India, has been linked (independent of tobacco and alcohol) to oral cancer in other developing countries. Furthermore, human papillomavirus type-16, a sexually transmitted disease and the primary cause of cervical cancer, is strongly associated with oropharyngeal cancer. In fact, cervical cancer is the leading cancer in the women of South-Central Asia. This would suggest that human papillomavirus type-16 is likely a significant contributor to oropharyngeal cancer in India, as well. The public health challenge to control sexually transmitted diseases in India is obvious and impacts not only infectious disease prevention but also the control of such diseases as cervical and oropharyngeal cancer.

Primary Prevention Efforts

Because oral cancer is the leading cancer in Indian men and third most common cancer in Indian women and is likely related to the high rates of tobacco use, several behavioral intervention studies for tobacco cessation for oral cancer prevention have been performed in India. Although not formally stated, these researchers, as well as the Indian government, have used most of the categories of social influence in attempts at behavior modification to reduce tobacco use and prevent oral cancer. Many of these studies have also incorporated efforts to reduce oral cancer mortality by secondary prevention efforts for early cancer detection. This review will discuss these studies as two broad categories, those directed at cancer prevention (primary prevention) and those directed at early detection (secondary prevention).

Early work by Mehta and Gupta established the incidence of oral cancer and precancer in five districts of four states in India in 1966 to 1967. From their experiences with this study and in a 10-year follow-up study of the natural history of these lesions, they designed a tobacco cessation intervention study for more than 12,000 tobacco-using subjects in three of the districts in three states of the original study. Each subject’s mouth was examined by a dental surgeon, who provided professional advice as indicated for oral problems and tobacco risks. Immediately after such an examination, a social scientist counseled the subject regarding the risk of oral cancer and precancer related to tobacco use with an illustrated booklet for assistance. A film entitled Tobacco Habits and Oral Cancer was designed for each district and pretested to confirm its effectiveness to the target audience. The film was shown for groups of 20 to 25 and followed by a group discussion and subsequent re-showing to the same group. Furthermore, posters demonstrating the link between tobacco and oral cancer were displayed prominently in each village. One year after the initial intervention, a follow-up with the same format was carried out. Tobacco use was reduced or stopped in 3.1% to 21.1% of subjects, and this reduction was greater than the increase in tobacco use in two of the three districts. Furthermore, precancerous lesions regressed in a significantly greater number of individuals with such lesions who stopped or reduced tobacco use compared with those who continued or increased tobacco use. Although this study included no control group, it showed the feasibility of behavioral modification efforts and the effectiveness of reversing precancerous lesions by tobacco cessation in the Indian population. Elements of informative education, persuasive imagery, and social reinforcement were all used by these researchers.

In a follow-up to the preceding study, the cohorts from each of the three districts continued to be examined on an annual basis. In addition, a control cohort was identified in each district by random selection of villages that were included in the previous epidemiologic study of oral cancer but were not included in the behavioral modification trial. Furthermore, additional educational interventions were included: radio broadcasts, newspaper articles, and in one district, folk theater. Again, all materials were pretested for format and content and restructured as needed on the basis of the annual review. After 5 years, the tobacco habits were stopped or reduced by 33% to 66% of the intervention cohorts but only 12% to 30% of the control cohorts. Furthermore,
the 5-year age-adjusted incidence of oral precancers was reduced in the intervention group. This study demonstrated in a controlled fashion the effectiveness of such a behavior modification strategy in a more long-term setting. It also expanded the educational and persuasive efforts of the program through mass media (radio and newspaper) and more traditional forms of entertainment (folk plays). Another publication by this group provided some additional information regarding the two cohorts. First, the two cohorts seemed very similar with respect to demographic characteristics, as well as initial tobacco habits. Second, the authors elaborated on their behavioral modification methods. Some degree of educational training did occur through the interaction between the individual and the social scientist. Subjects were encouraged to contemplate their addiction and were given strategies for quitting, including coping with withdrawal symptoms. Furthermore, an element of motivational reward was applied by discussing the financial benefits of tobacco cessation. Social reinforcement was given to those who quit, and it was suggested to these individuals that they become a model and leader for such efforts. Finally, the formats and contexts of the mass media campaigns were extensively pretested and retested with focus groups for effectiveness.

As the population became aware of the link between tobacco use and oral cancer and precancer, the education and persuasion efforts switched from one of mainly information presentation to help with strategy development for tobacco cessation. By the eighth year of follow-up, an additional film regarding the link between tobacco and oral cancer and precancer and the importance of tobacco cessation was made. The education materials and strategies continued to be reviewed with the target population. By the eighth year of the study, 9.5% and 30.8% of the men in the intervention cohorts had stopped or reduced tobacco use, respectively, whereas only 2.2% and 20.0% of the control cohorts had done so. For women the results were even more dramatic; 19.0% and 37.6% of women in the intervention cohorts stopped or reduced tobacco use, respectively, whereas only 6.1% and 33.4% of the women in the control cohorts did so. Furthermore, only 11.4% of men and 2.3% of women increased their tobacco use compared with 30.8% and 14.1% of the control men and women, respectively. The greatest success at stopping tobacco use was seen in men using primarily cigarettes and in women using primarily bidis, whereas the mixed use group seemed more resistant to stopping in both men and women. Finally the age-adjusted oral precancer incidence rates were lower for the intervention cohorts than control cohorts; in fact, only 41% and 28% of expected oral precancer cases were identified in the intervention cohorts for men and women, respectively.

In the 10-year follow-up, additional information was provided regarding the annual educational talk given to individuals or small groups immediately after their oral examination. Pre-designed formats (annually updated) were used for these discussions, and standardized responses were developed for frequently asked questions. Before the education program was designed, focus groups demonstrated little awareness of the association between tobacco use and oral cancer and had many misconceptions regarding the health effects of tobacco use. The educational films were approximately 20 minutes in length and were made in color and in the local language for the particular intervention cohort. The initial films were designed to educate the audience to the link between tobacco use and oral cancer and precancer, whereas the follow-up film was designed to provide tobacco cessation and withdrawal symptom coping strategies to the audience. In addition to educational posters, radio health broadcasts and newspaper special articles, and lantern slides with similar information were displayed at local cinemas. After 10 years of follow-up, the study was successful in achieving a tobacco cessation rate of 14.3% in the intervention cohorts compared with only 4.5% in the control cohorts. Greater success was seen in women (20.5% stopped) than men (11.7%) and for those using primarily cigarettes (38.3% stopped). Furthermore, the stoppage rate continued to climb throughout the follow-up period for the intervention cohorts, whereas it remained stagnant for the control cohorts. The relapse rates for men in the intervention cohorts were approximately half that of the control cohorts for those having quit 1 or 2 years, and were one third that of the controls for men having quit 3 years. Although not as dramatic, similar findings were found for women. The annual age-adjusted incidence rates of oral precancer in the intervention cohorts after 10 years of follow-up were lower than that of the control cohorts for both men and women and for all tobacco use groups, and the risk ratio for oral precancer was only 0.40. The authors point out that the intervention and control cohorts were not concurrent in time and that a
greater number of the control cohorts were lost to follow-up. However, they assert that the similar baseline prevalence of oral precancer and tobacco use suggests that the two groups were comparable. Clearly, these researchers have used the educational and persuasive forms of classic behavior modification. Little motivation or facilitation was used with the exception of praise for stopping tobacco use from the annual examiner, interviewer, or group and the access to routine annual oral examinations and counseling. Both manipulative and empowering efforts were demonstrated, and, as whole, the intervention was clearly effective. The cost and time investment were not discussed but were likely significant.

Others have found similar tobacco cessation rates with trials in India designed for general tobacco cessation and not specifically directed toward oral cancer prevention. In the state of Karnataka, systematic surveys were carried out in three areas to assess the prevalence and type of tobacco use. The first survey represented a baseline and was followed by a repeat survey in 2 years and a final survey in 5 years. In one area (intervention area), extensive anti-tobacco community education was conducted. Primary health workers were involved in anti-tobacco education to individuals or small groups weekly and to larger discussion groups on a monthly basis. In addition, several printed educational materials were distributed throughout the community, and films on tobacco cessation were shown at least twice during the intervention period. Tobacco cessation rates were clearly improved in the intervention area, and these findings were true for both men and women and for both smoking tobacco and smokeless tobacco.

Other efforts at tobacco reduction in India have focused on the use of mechanisms of motivation and facilitation to modify behavior. Several Indian states have banned the sale, display, manufacture, and distribution of smokeless tobacco and similar products such as gutka and paan masala. Tobacco advertising is banned in all state-controlled electronic media, and warning labels are required on cigarette packets; however, tobacco advertising is not restricted in print media, on billboards, or in video cassettes of Indian films. Although taxes represent approximately 75% of the cost of a packet of cigarettes, taxes are much lower on packaged chewing tobacco and rarely collected on unpackaged products. Smoking is prohibited in many public places such as government offices, hospitals, and airlines. Although additional efforts at tobacco control are ongoing, there is lack of leadership at a national level.

SECONDARY PREVENTION

Treatment of oral cancer is often debilitating, disfiguring, and relatively ineffective in advanced-stage disease; furthermore, in India, patients tend to be initially seen at higher stages than in the developed world. Therefore, several studies have investigated the usefulness of early detection to reduce oral cancer morbidity and mortality. Because primary medical and dental care for the oral cavity in India is lacking, these studies have chiefly involved efforts at education of basic health workers and the general public for oral cancer and precancer screening. In a study in Southwestern India, 53 basic health workers were trained at both tobacco cessation counseling and oral examinations. In 1 year, the group examined more than 39,000 high-risk subjects, identifying 523 requiring referral to a dentist, with 40% and 5% having an oral precancerous lesion or oral cancer, respectively. This study demonstrated the possibility of incorporating oral cancer and precancer detection and smoking cessation training into the Indian rural public health system.

After an initial baseline study of tobacco use, cancer incidence, and cancer extent at presentation patterns in the state of Kerala in Southwestern India, Mathew et al established a plan to improve secondary prevention through the early detection of oral cancers and precancers. Two hundred eighty-two primary health workers in 14 primary health centers were trained to educate their patients about the harmful effects of tobacco and the link between tobacco and oral cancer and to properly examine the oral cavity and identify oral cancer and precancer. Two initial 8-hour training sessions were conducted and were followed semiannually by two 3-hour additional sessions. In the control area of the state, primary health workers did not receive such training. During the initial 3-year period, there was no difference in the percent of oral cancer patients with localized disease registered in the cancer registry between the intervention and control areas. In fact, primary health workers referred only 10 of the 302 patients with oral cancers diagnosed from the intervention area. In a subset of 14 trained health workers, the authors did later demonstrate a very strong correlation between the findings of the health worker and those of three physicians ($r = .85$, sensitivity 94.3%, and specificity 99.3%).
However, in a study conducted during the same time frame and in the same state, the feasibility of empowering people to self-examine their mouth was demonstrated. Fifty college students distributed 10,000 copies of a brochure describing the risk factors for oral cancer and the appearance of oral cancer and precancer. All subjects older than 30 who used tobacco were asked to carefully read the information and report to the local clinic on certain days for oral cancer screening if they identified a lesion of concern on examination of their own mouth. Of the 247 subjects who reported to the clinics, 3% had an incident oral cancer, 3% had a recurrent oral cancer, and 34% had precancerous lesions. Furthermore, six of the seven individuals seen with incident cancers had stage I (localized) disease. Clearly, this study demonstrated that empowering individuals to understand the etiology of oral cancer and to examine themselves for oral cancer may enhance secondary prevention efforts and ultimately lead to decreased oral cancer mortality.

In a follow-up study of the effectiveness of the education of primary health workers at oral examination and counseling, the authors found a seemingly dramatic impact in secondary prevention. In a community-based cluster-randomized, controlled trial, the authors found a higher incidence rate, lower stage at presentation, and better survival for oral cancer in the intervention clusters than the control clusters. More than 50,000 subjects were in each arm of the study, and the two groups were similar with respect to age, sex, occupation, education, income, and tobacco/alcohol use. Of the 59,894 subjects in the intervention arm, 82.1% were screened, and 36 oral cancers and 1310 oral precancers were identified. The unadjusted incidence of oral cancer was 56.1 and 20.3 cases/100,000 person-years for the intervention and control groups, respectively. Second, 72.3% of the oral cancers in the intervention group were initially seen with localized disease compared with only 12.5% of the control group, and this was reflected in a survival rate of 85.1% versus 43.8%.

SUMMARY

Drs. Gupta, Mehta, Mathew, and Sankaranarayanan have been instrumental in advancing the primary and secondary prevention of oral cancer in India through tobacco cessation and early detection efforts. Their work has primarily focused on the education and empowerment of the individual to make healthy choices but has also incorporated manipulative and persuasive aspects of behavior modification. Regulatory efforts to motivate and facilitate tobacco cessation through methods such as advertising bans, higher taxes, and banning sales are partially in place, but a national push toward greater national regulation is needed. Other efforts such as facilitating access to cessation treatment and counseling, access to simple routine oral examinations and dental care, and incentives to tobacco farmers to produce other crops are areas of potential change. Given the economic problems of the Indian state, it is unlikely that significant additional services will become available. However, national campaigns directed at educating the public about the harmful effects of tobacco and its link with oral cancer, at empowering the public to oral self-examination, and at facilitating tobacco cessation efforts could be done with confidence that these strategies work and will impact oral cancer incidence and mortality in the Indian population.

For the developing world at large, where resources for medical care are limited, lessons from this review are seemingly clear. Where general knowledge of the etiology and presentation of oral cancer is lacking, edification of the populous about the association with tobacco and about the nature of presentation may be effective in reducing oral cancer incidence and mortality. With regard to other diseases with clear behavioral risk factors, it is likely that such efforts at mass education and behavioral modification to empower individuals to make healthy choices are effective in reducing the burden of disease on society, as well as often cheaper than advanced medical and surgical care of such diseases.

With regard to the developed world, where resources for medical care may be greater but the ability to effectively reach the masses is more challenging, lessons are less clear. For example, in the United States, efforts at reducing the use of tobacco have had success, and the incidence and mortality of oral cancer is now declining. However, survival rates from oral cancer have not improved, and major racial disparities have persisted in oral cancer incidence and mortality over the past three decades. The complexity and cost of media coverage, as well as the lack of centralized medical care, consistent use of primary care providers, or a tradition to disease prevention all represent impediments to the use of population-based oral cancer prevention in the United States. Although such intensive prevention efforts used
in India specifically for the prevention of oral cancer might not be cost-effective in the United States, aggressive general anti-tobacco messages targeting "captive" or specific groups might prove effective in addressing some oral cancer's persisting public health problems. For instance, educational and behavioral modification strategies to avoid the initiation of tobacco use by adolescents could be used in the captive environment of school to ultimately prevent tobacco-induced malignancies such as oral cancer. Similarly, groups such as South-Central Asian immigrants could be targeted with campaigns similar to those used in India in hopes of reducing morbidity by encouraging early detection. Finally, one of the chief public health problems concerning oral cancer in the United States is the disparity in incidence and mortality rates for oral cavity cancer for African-Americans. African-American men have approximately twice the oral cancer mortality rate of Americans. African-American men have approximately twice the oral cancer mortality rate of white men in the United States, and it would seem that programs of behavioral modification to prevent tobacco initiation in school children would be particularly effective in schools with large African-American populations.

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