An Academic Dental Center Grapples with Oral Cancer Disparities: Current Collaboration and Future Opportunities


Abstract: This article reviews the epidemiology of oral cancer in the United States, explores the complex reasons for its disproportionate burden in minority groups, and describes the efforts of New York University’s College of Dentistry to address these oral cancer disparities. These efforts include the development of state and regional consortia and networks, public education and community screening efforts, undergraduate dental curriculum development, professional education, intensive research efforts, and significant dental-medical collaborations. Future directions include the need to develop and assess oral cancer education/awareness programs, specifically customized to the various dental-medical professionals/trainees and to populations at risk. Improving the quality of life of patients during and following treatment for oral cancer is another important area that has great opportunity for dental-medical collaboration.

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The National Cancer Institute estimated that 27,700 new cases of oral cavity and pharyngeal cancer would be diagnosed in the United States in 2003 and that 7,200 individuals would die from this disease.1 Efforts to reverse these statistics through prevention and early detection are well under way, and the dental profession is playing a pivotal role. Although recently released data from U.S. cancer registries up to the year 2000 have shown a modest yet significant decreasing trend in overall incidence and mortality rates for oral cancer,2 there remains much work to be done in the areas of public awareness, early detection, prevention, and treatment of this devastating disease. The purpose of this review is to explore the disproportionate burden of oral cancer in minority groups and to discuss how these critical areas are being addressed by a consortium of institutions and entities in the New York area. Specifically, we provide an overview of disparities in oral cancer incidence, mortality, and treatment and their possible etiologies. This literature reveals the need for increased public and professional awareness as well as greater involvement of dental and medical professionals in early detection and prevention for oral cancer. Finally, we share our collaborative dental-medical experiences at New York University and discuss opportunities for more such collaborations.

Which Populations Have a Higher Burden of Oral Cancer?

Racial/Ethnic Groups

Evidence for ethnic/racial differences in the oral cancer burden in the United States comes primarily from the data collected by national cancer registries. The Surveillance Epidemiology and End Results Program (SEER) has been in existence since 1973; its purpose is to prospectively collect U.S. cancer data from twelve registries across the country. SEER separates ethnic data into five groups: blacks, whites (subdivided as white Hispanic and white non-Hispanic in some registries), Asian/Pacific Islanders, American Indians/Alaska Natives, and Hispanics. In a comparison of the incidence and mortality
rates and stage of disease at the time of diagnosis of oral cancer across these groups, blacks have consistently shown the highest rates and most advanced stage of disease. This is especially true for black males (see Figure 1A-C).\(^2\)

However, these figures may underestimate the incidence of oral cancer in the United States. Since the SEER data represents twelve registries but not all states, there may be geographic variability in ethnic rates. For instance, oropharyngeal cancer rates

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**Figure 1A.** SEER U.S. oropharyngeal cancer incidence rates, 1996-2000

**Figure 1B.** SEER U.S. oropharyngeal cancer mortality rates, 1996-2000
from the New York State Cancer Registry reveal an incidence for Hispanic males in New York City (18/100,000) almost twice that seen in the SEER data (9.9/100,000), although these higher rates are not reflected in the mortality rates. Second, ethnic sub-populations are growing rapidly. There is evidence of high rates of oral cancer in some immigrant populations, such as those from the Indian subcontinent.\(^3\) Compared to those in the United States, incidence rates for oropharyngeal cancer in India are high for men (>25/100,000) and women (>11/100,000).\(^4\) The mapping of oral cancer rates by country of origin has not been conducted in the United States. Immigrants from India, Bangladesh, Pakistan, and Sri Lanka comprise 18.6 percent (close to two million) of the Asian population residing in the United States, which is almost a 50 percent increase over the last decade.\(^5\) Over 14 percent (269,000) of these sub-groups live in New York City, making up 31 percent of its Asian population.

**Low Socioeconomic Groups**

Based upon overall oral cancer data obtained from 172 countries, socioeconomic status (SES) does not appear to be a factor in the worldwide incidence rates of oral cancer.\(^6\) However, SEER data does not presently include SES information for oral cancer, and a number of investigators have linked U.S. Census and SEER data for various SES-related variables (such as income, education levels, medical insurance, and others) and have shown an inverse relationship between oral cancer incidence and such SES-related variables.\(^7,8\) The National Cancer Institute is currently exploring the linkage of SES data through the National Longitudinal Mortality Study.

Only a few studies have looked at the relationship between ethnicity/race and SES factors and oral cancer. Arbes et al., linking U.S. Census and SEER, demonstrated that, by ethnicity alone, the hazard of death from oral cancer for blacks was 1.7 times that of whites, but that this effect was reduced to 1.3 by controlling for SES.\(^9\)

### Why Are These Populations Disproportionately Affected?

**Incidence**

Higher incidence rates of oral cancer in these minority populations in the United States are likely due to the complex interplay of both avoidable and non-avoidable risk factors. Avoidable risk factors for
oral cancer in the general U.S. population primarily include tobacco use, heavy alcohol consumption, poor diet, and sunlight exposure (lip cancer); non-avoidable factors include age and genetic predisposition.10

**Tobacco and alcohol.** Because 75 percent of the cases of oral cancer in the United States are associated with tobacco smoking and heavy alcohol use,11 a higher prevalence of these habits within these minority populations may help explain their higher incidence rates of oral cancer. Descriptive data collected from the Centers for Disease Control and Prevention’s Behavioral Risk Factor Surveillance System (BRFSS) in 2002 does show an inverse relationship between income/education levels and rates of current cigarette smoking and heavy alcohol use in the United States. However, there are no clear trends for smoking and alcohol use by race/ethnicity that mirror oral cancer incidence rates.12

On the other hand, adherence rates to a composite of positive health-related behaviors (exercise, tobacco use, alcohol consumption, percent fat in the diet, and fruit/vegetable consumption) show that, compared to non-Hispanic whites and Mexican Americans, non-Hispanic blacks have higher rates of total non-adherence and lower rates of total adherence.15

The use of smokeless tobacco is a risk factor for oral cancer and precancer. This habit is far less prevalent than smoked tobacco, although there are states, such as West Virginia, where current use prevalence in men is greater than 30 percent.14 Low SES levels and rural residence are predictive of use,15 although increased incidence rates of oral cancer have not been apparent in these populations.16,17 Smokeless tobacco consumption in South Asia in various forms is an important cultural tradition. The most popular form of smokeless tobacco consumed is the betel quid, known as “Paan,” a mixture of areca nut, slaked lime, spices, seeds, and tobacco wrapped in a betel leaf. “Gutkha” is a powdered or granulated mixture of tobacco, areca nut, limes, and spices, available in handy foil sachets. Introduced over two decades ago, gutkha is immensely popular across all socioeconomic strata of the Indian society and with both genders, and it is believed to be a harmless “mouth freshener.” The risk of oral cancer due to paan and gutkha use has been clearly demonstrated.18 In India alone, approximately 30 percent of oral cancers in India are attributable to smokeless tobacco and areca nut use, and an additional 50 percent to the combined use of smokeless tobacco/areca nut use and smoking.19 Gutkha is especially threatening because of the ease and low expense of obtaining it, along with its youth appeal and convenience and the lack of social stigma to using it. The mass production and marketing of gutkha has been implicated in a rise of oral cancer, particularly in a younger population.20 As South Asian people have emigrated to various countries, they have continued using these products,21 and this could be happening in the United States.

**Diet.** Of all the dietary patterns studied, diets high in fruits and vegetables have been shown to confer protection,22,23 most likely because of the putative antioxidant activities of the micronutrients contained within these foods, particularly beta-carotene, but also vitamins A, C, E, and selenium.24 There are disparities in dietary intake in the United States, and data from the BRFSS concerning average daily intake of fruits and vegetables show that a higher percentage of low SES Americans (measured by income and education) consume suboptimal amounts of fruits and vegetables daily.12 By ethnicity/race, the percentages of blacks and Hispanics with suboptimal daily intake of fruits and vegetables is higher than for whites and “Others.” Furthermore, oral cancer case control studies have suggested that diets lower in fruits and vegetables were predictive of the higher oral cancer incidence rates in blacks.25,26 How oral carcinogenesis is affected by micronutrients in health and in states of deficiency or is modulated by the effects of smoking and drinking is presently unclear.

**Mortality**

The reasons for ethnic disparities in oral cancer survival and mortality rates are highly complex. Most of the studies in the United States have focused on ascertaining the reasons for the high mortality rates in blacks. Factors include the late stage and larger tumor size at the time of diagnosis and inequalities in the type and timing of treatment.2,9,27

**Late Stage/Large Tumor Size at Diagnosis.** A precancerous, or potentially precancerous, lesion generally precedes oral cancer, often by a matter of years.28 This should provide ample opportunity to allow for interception of this disease. The reasons underlying late-stage diagnosis are key and likely involve a complex interplay between professional and patient factors. Because oral cancer is usually asymptomatic in the early stages, patients are less likely to recognize a problem and seek evaluation.
Indeed, a recent survey and chart audit of patients with newly diagnosed oropharyngeal squamous cancers showed that symptom-driven examinations yielded a significantly higher chance of late-stage disease compared to non-symptom-driven opportunistic screenings.29

**Lack of Patient Awareness and Access to Care.** Unfortunately, individuals at high risk are often the least aware of this disease and have lower access to and use of health care services, which reduces the opportunity for screening. Data from the National Health Interview Survey show that approximately 64 percent of the U.S. population reported visiting the dentist in 1999.30 The habit of not visiting the dentist is associated with race, income, and education (see Figure 2).31 Data from the Cancer Control Supplement to the 1992 National Health Interview Survey (NHIS) show that the utilization of dental and medical services reported by individuals with a history of current smoking was approximately 50 percent and 70 percent, respectively, and that these rates also are associated with race, income, and education (see Figure 3).32 Interestingly, the difference in percentages between dentists and physicians visits is greater for the “lowest utilization” groups and suggests that physicians are more likely to see those at highest risk for oral cancer. A study on the use of health services before diagnosis of head and neck cancers supports this suggestion by showing that there was a greater opportunity for early detection by physicians—an important fact for future medical training initiatives.

**Lack of Screening by Dental and Medical Professionals.** Only a fraction of Americans receive an oral cancer examination. A recent study based upon the 1998 NHIS survey indicates that only 20.1 percent of adults have ever received such an examination,34 and blacks,35,36 Hispanics,37 and patients with low education35,36 were significantly less likely to have had such an examination.

Horowitz and Goodman reported that dentists were more likely to perform oral cancer screenings

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**Figure 2. Percentage with visit to dentist, 1996**

than physicians.\textsuperscript{35,38} In contrast, physicians are more likely to provide risk factor counseling such as tobacco cessation,\textsuperscript{32} which suggests that the two professions have something to learn from each other. Responses from the Cancer Control Supplement to the 1992 NHIS indicated that individuals with a history of current smoking who had seen a dentist or physician in the last year were twice as likely to be advised to quit by their physician (51.6 percent) compared to their dentist (24.1 percent).\textsuperscript{32} Interestingly, there was no apparent trend by ethnicity or SES for advising patients to quit. A recent survey of family physicians in Maryland showed that, despite appropriate risk factor assessment for oral cancer, only 14.8 percent performed an oral cancer examination for patients over the age of forty at the initial appointment and that the performance was even lower for recall appointments (10.8 percent). Although 62 percent of physicians felt adequately trained to perform oral cancer examinations according to this survey, the main reason cited by those physicians who didn’t perform such examination was lack of training.\textsuperscript{39}

Other Health Care Provider-Related Factors. There is evidence that patients who experience signs and symptoms of more advanced oral cancer are more likely to seek initial contact with medical health care professionals than dentists\textsuperscript{29,40} and that patients with asymptomatic early stage disease are more likely to be detected by oral health care providers.\textsuperscript{29} However, a recent study showed that delay in diagnosis of patients with oral cancer was shorter compared to other aerodigestive tract cancers. Allison has reviewed the literature about factors predicting delay of the diagnosis of oral cancer.\textsuperscript{41} The presence

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\caption{Comparison of percentage utilization of dental versus medical services in current smokers, 1992}
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of another previously diagnosed medical problem requiring stabilization or ongoing care was the strongest predictor for professional delay in oral cancer diagnosis.42

Other Factors. There are other factors potentially influencing late-stage diagnosis. In surveys where adults were asked if they had heard of oral cancer, affirmative response rates ranged from 66 percent25 to 85 percent.35 However, their awareness of oral cancer’s signs and symptoms, its risk factors, or of an oral cancer examination to detect this disease was low, and this awareness appeared to be lower in groups at risk for disparities.35,36

In addition, ethnicity/racial patterns of treatment care for oral cancer have recently been explored by Shavers et al. who demonstrated, in a multivariate analysis controlling for numerous factors, that blacks were significantly less likely to receive cancer surgery for advanced oral cancer and early treatment for oral cancer compared to whites and Hispanics.27 Oral cancer therapies, including radiotherapy, were found to be associated with an increased risk of mortality in blacks as compared to whites.43 Factors related to post-cancer treatment recovery and care have not been adequately studied.

In summary, those of low SES or minority status have higher incidence and mortality rates for oral cancer. The reasons for this are complex, and there are many discrepancies in our understanding. Modifiable risk factors include patient habits, public awareness, treatment differences, and dental and medical professional involvement in screening and patient education. More subtle factors, such as provider attitudes towards patients of differing ethnic and cultural background, may be additional factors.44 In this article, we will focus on early detection and prevention as two key issues for reducing incidence rates.

How Can the Critical Problem of Early Detection and Prevention Be Solved?

Public awareness can be enhanced by mass media, community efforts, and education by health care providers across the nation. The work of numerous oral cancer advocacy groups and organizations, particularly the American Dental Association’s nationwide oral cancer campaign, has undoubtedly led to an increase in public awareness, although the impact on the awareness of populations at greatest risk remains unknown. It is hypothesized that an increase in public awareness will also drive professional awareness through demand for oral cancer screenings and the use of emerging diagnostic testing.

In addition, there is a unique opportunity to foster medical-dental collaborations to maximize the impact of this disease. While both professions need a heightened awareness of the epidemiology of oral cancer, it appears that oral health care providers need to increase risk factor counseling, while medical professionals need to increase screening for disease. Early training of both medical and dental professionals to perform oral cancer screenings and risk factor assessments is key. Better coordination among medical and dental professionals of short-term and long-term care may also help to reduce the morbidity and mortality of cancer survivors.

The 2000 U.S. Surgeon General’s Report on Oral Health recognized ethnic disparities in access to dental care and ways to increase the opportunities for underserved and at-risk communities to receive oral cancer screenings are needed.

Attempts to Solve These Issues: NYU College of Dentistry’s Story

In March 1999, New York University’s College of Dentistry Dean Michael Alfano met with a group of dental leaders in the New York/New Jersey area, and together they laid the groundwork for the creation of a consortium dedicated to the prevention and early detection of oral cancer, known as the Oral Cancer Consortium.45 Thanks to Dean Alfano’s vision and energy, oral cancer was adopted as an important initiative by our college, and faculty and staff formally endorsed this oral cancer initiative as part of the college’s new strategic plan.

Over the last four years, the oral cancer initiative has been augmented by major grants from the National Institute of Dental and Craniofacial Research (NIDCR). In 2000, New York State was awarded an NIDCR-funded Phase I grant for a state model for oral cancer control, now known as the Oral Cancer Awareness Program for New York. The college has had a major involvement in this statewide effort. In 2001, the college was awarded a seven-year
health disparities center grant, known as the NYU Oral Cancer Research for Adolescent and Adult Health Promotion Center, Principal Investigator, Dr. Ralph Katz. A number of our basic science researchers have also been awarded grants to study oral carcinogenesis. Dr. Ananda Dasanyake has recently formed an international workgroup of dentists, physicians, and oral cancer epidemiologists to address the rising incidence of cancer of the tongue and mouth in different parts of the world. The college has also developed and disseminated oral cancer-related educational programs directed towards practicing dentists and dental hygienists at the local and national level.

**Oral Cancer Consortium**

In 1999, New York University College of Dentistry, the University of Medicine and Dentistry-The New Jersey Dental School, the State University of New York at Stony Brook, Columbia University, and New York City Health and Hospitals Corporation formed the Oral Cancer Consortium (OCC) with a mission focused on motivating health care professionals and the public to the need for comprehensive oral examination. Since its inception, OCC membership has increased from five to twenty-three members and now spans four states. OCC has organized annual oral cancer screening events that have served thousands of citizens. Contributions by CDX Laboratories, Zila Pharmaceuticals, and some of the dental schools have supported captivating advertisements, including in popular Spanish and English dailies, in an attempt to reach disparity populations. A highly interactive OCC website, designed and hosted by the college (www.oral-cancer.org/), and a dedicated toll-free number have facilitated dissemination of screening information and oral cancer educational links to both the public and professionals. In addition, for three years the weather anchorman for the ABC-TV station in New York, Sam Champion, has recorded and aired multiple public service announcements and made live appearances during prime-time on the night before the screening event.

At the college, screening events are organized months in advance, with students and faculty members eagerly volunteering to participate. An oral cancer screening training and calibration module has been developed to educate screeners about oral cancer and teach them how to survey, examine, and offer health promotion services, including appropriate referrals for oral lesions or tobacco cessation counseling. Local volunteer dentists participating in the screening on our dental van service a constant lineup of screenees and report this to be a very positive experience. Recently, the OCC has developed a relationship with the Yul Brynner National Head and Neck Cancer Foundation in an attempt to enhance collaboration with our medical counterparts and to foster awareness for this disease on an even larger scale.

**NIDCR Phase I Grant: Oral Cancer Awareness Program for New York (OCAAP/NY)**

As part of this state-model grant, the most comprehensive assessment ever of the oral cancer burden and control needs was conducted in New York State. Oral cancer incidence and mortality rates (by ethnicity/race) and stage of disease at diagnosis have been mapped by county in an attempt to identify high rate areas. Prevalence of risky behaviors (smoking and alcohol) have also been mapped by adding oral cancer-specific questions to the state’s BRFSS telephone survey. Surveys, focus groups, and interviews have been conducted to assess the oral cancer-related knowledge, attitudes, and practices of the public, multiracial community leaders, health educators, and health care providers (dentists, dental hygienists, primary care practitioners, and nurse practitioners). Simultaneous web-based broadcasts to over 200 regional community-based health centers and an educational segment on Spanish television have been presented.

As a result of advocacy efforts on the part of the members of the grant team, there was a significant policy change in New York State: a mandate for dentists to undertake continuing dental education in oral cancer early detection and prevention that includes tobacco cessation counseling. The New York State Dental Association, with the help of a grant from the State Health Department, implemented a continuing education program at no cost to participants. This policy and regulatory change is an example of a successful coalition effort to bring about changes in New York State and leverage funds. More than 10,000 dentists and hygienists across the state have taken the two-hour mandated lecture. Furthermore, focus groups of oral cancer survivors have been conducted, and an assessment of hospitalization costs from oral and pharyngeal cancers has been made.
However, the most important outcome of the Phase I grant has been the building of a state network of partnerships, including both dental and medical organizations and institutions. Indeed, the diligence of the Phase I grant has led to the recognition and support of the larger New York State Comprehensive Cancer Control Plan for further research on oral cancer early detection, including clinical trials.

NYU Oral Cancer Research for Adolescent and Adult Health Promotion Center (RAAHP)

The overall goal of this center is to conduct studies and promote activities that will reduce ethnic disparities in oral cancer incidence in the United States. The RAAHP center has been in operation for two years with four major studies and a number of pilots currently in the data-collection phase. The aim of study #1 is to develop our understanding of the indications for current and emerging technologies in the detection of early oral cancer and precancerous lesions. The results of this research will hopefully translate to the clinical setting and optimize the screening patterns and yield of all health care providers. The aim of study #2 is to estimate the association between oral epithelial dysplasia (OED) and the use of smoking tobacco and alcoholic beverages and nutritional intake in a Hispanic population living in Puerto Rico. The results from this study will further our understanding of the etiology of OED, provide possible explanations for the high rates of oral cancer in Puerto Rico, and suggest opportunities for primary prevention. The aim of study #3 is to test the effect of personalized risk communication on smoking cessation in the dental setting. It represents an important translational, multidisciplinary strategy for tobacco-related cancer prevention. The aim of study #4 is to assess whether minorities’ knowledge, attitudes, and practices related to oral cancer screening affect their willingness to participate in research.

Over the past year, the RAAHP disparities center and the Phase I NIDCR grant have formed a close working relationship with the Cancer Awareness Network for Immigrant Minority Populations on several research projects. This network runs out of the Center for Immigrant Health at New York University School of Medicine and was established in response to disparities in the utilization of and participation in cancer prevention, detection, and treatment services in immigrant and minority communities. This collaboration has led to increased awareness of the growing problem of paan and gutkha chewing in South Asian immigrants. Given the very limited research on South Asians in the United States, this network has now developed a “Smokeless Tobacco, Oral Pathology Prevention And Awareness Network” (STOP PAAN) supported by the National Cancer Institute (NCI), New York State Department of Health Office of Minority Health, the RAAHP center, and NYU School of Medicine International Student Program. STOP PAAN is currently engaged in increasing awareness about the risk of cancer posed by paan and gutkha in the South Asian immigrant communities in New York City, screening for associated oral lesions, and developing a campaign of culturally appropriate interventional messages on prevention. This medical/dental collaboration has resulted in the development of a survey instrument to assess the demographics, knowledge, attitudes, and practices of these immigrant populations with respect to use of paan and gutkha. The survey was translated into three languages, initially piloted in India, and subsequently piloted in New York City South Asian communities (Gujarati Indian, Pakistani, and Bangladeshi) in conjunction with oral cancer screenings. Recently, oral cancer has been included in the New York University School of Medicine’s Cancer Institute, an NCI-funded cancer center, and four of the NYU College of Dentistry’s faculty members have been formally inducted as members of the institute. Collectively, these medical collaborations have heightened awareness about oral cancer in the medical community and opened the door for future collaborations.

Educational Programs and Curricular Activities

Over the last four years the college has developed and instituted a number of new oral cancer-related educational programs. The first of these was a novel and highly interactive web-based oral cancer course for oral health care providers known as “Oral Cancer, Practicing for Life.” There are three main teaching modules: oral cancer screening rationale and techniques, assessment of patients with identified lesions, and the dental/oral management of oral cancer survivors.

An oral cancer-related curriculum begins in the dental student freshman year, beginning with the epidemiology of oral cancer and health promotion
awareness. In the second year, students must develop an oral cancer health promotion plan for their dental practice. They learn about the pathogenesis of oral cancer and precancer and take an intensive and interactive four-hour workshop on tobacco cessation, which includes a live patient interview. Before being promoted into the clinics, they must complete a hands-on oral cancer screening training module, which includes a mock oral brush biopsy. In the third year, students receive specific didactic material about the diagnosis and management of patients with lesions suspicious for oral cancer and precancer, and they must fulfill competency requirements in both this area and tobacco cessation to be eligible for promotion to the senior year. The diagnosis and treatment planning of every new patient presenting for dental care include risk factor assessments and customized preventive plans for oral cancer. Beginning early in 2003, thanks to an educational grant from CDX laboratories, senior students received lunchtime interactive seminars, authored by the Department of Oral Medicine, on the use of assessment tools to facilitate the diagnosis of epithelial oral lesions with possible malignant potential. Subsequently, the clinical program has mandated that all students perform a brush biopsy procedure before graduation.

The focus of the college on oral cancer education has extended beyond the student population. In addition to the aforementioned online oral cancer course, a number of oral cancer courses have been offered. In an attempt to heighten the awareness of our large alumni population, the college conducted a free oral cancer course in 1999 that included a hands-on component to teach alumni dentists how to perform an oral cancer screening. Oral cancer courses have been on the continuing dental education schedule ever since. Off-site, faculty members from the Department of Oral Medicine have been selected as lecturers for the New York State-mandated oral cancer course for dentists and oral cancer screening for medical practitioners. Developing strategies to improve the quality of life of patients during and following treatment for oral cancer is another important area that provides opportunity for dental-medical collaboration.

Summary and Conclusions

This article has reviewed the epidemiology of oral cancer and described the NYU College of Dentistry’s efforts to address oral cancer disparities in ethnic populations. Outcomes include the development of state and regional consortia and networks, public education and community screening efforts, undergraduate dental curriculum development, professional education, and intensive research efforts. Significant dental-medical collaboration is now developing.

Future directions include the need to develop and assess education/awareness programs customized for the various dental-medical professionals/trainees and for populations at risk. An example might be a program with greater focus on risk factor counseling for dentists and oral cancer screening for medical practitioners. Developing strategies to improve the quality of life of patients during and following treatment for oral cancer is another important area that provides opportunity for dental-medical collaboration.

REFERENCES


