ABSTRACT

Title of Document: SURVEY OF MARYLAND DENTISTS’ KNOWLEDGE, OPINIONS AND PRACTICES ABOUT ORAL CANCER PREVENTION AND EARLY DETECTION

Catherine Maybury, MPH, 2010

Directed By: Assistant Professor Kerry Green,
Department of Public and Community Health

To reduce the morbidity and mortality associated with oral cancer, dentists must have oral cancer prevention and early detection knowledge and skills, and they must perform routine screening examinations. Maryland dentists were surveyed to assess their knowledge, opinions and screening practices relating to oral cancer prevention and early detection. Thirty-eight percent of dentists had a high level of knowledge of oral cancer risk factors, thirty-nine percent had a high level of knowledge of oral cancer diagnostic procedures, and thirty-eight percent received a high score for provision of oral cancer examinations. Dentists who strongly agreed or agreed that their oral cancer knowledge is current were more likely to receive a high score for knowledge of oral cancer diagnostic procedures and knowledge of risk factors and diagnostic procedures combined. Deficiencies exist in dentists’ knowledge and practices relating to oral cancer. Actions are needed in education, policy and research to address these deficiencies.
SURVEY OF MARYLAND DENTISTS' KNOWLEDGE, OPINIONS AND PRACTICES ABOUT ORAL CANCER PREVENTION AND EARLY DETECTION

By

Catherine Maybury

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Advisory Committee:
Assistant Professor Kerry Green, Chair
Research Associate Professor Alice M. Horowitz
Professor Min Qi Wang
My thesis is dedicated to Dr. Alice M. Horowitz

Thank you for freely sharing your knowledge, expertise and insights
and your endless edits, guidance, and encouragement.

Your dedication to the field of public health and
your passion are a constant source of inspiration.

I will be forever grateful to you.
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Chapter 1: Introduction

Section 1.1: Problem Statement

Oral cancer is cancer of the lips, oral cavity and pharynx. In the U.S., it is the eighth most common cancer (U.S. Cancer Statistics Working Group, 2010) accounting for approximately three percent of all cancers (Silverman, 2001). In 2009, it is estimated that there were 35,720 new cases and 7,600 deaths from oral cancer (American Cancer Society, 2010).

In 2007, the incidence of oral cancer in the U.S. was 10.4 percent with the rate in men more than twice that in women (15.4 vs. 6.1) (Altekruse et al., 2010). Maryland ranked 46th among the states and the District of Columbia with an incidence rate of 8.9 percent (National Cancer Institute, 2009). The rate in men was 2.5 times greater than that in women (13.2 vs. 5.3)(National Cancer Institute, 2009). For the period 2004-2006, the oral cancer mortality rate in the U.S. was 2.5 percent, with the rate in men more than twice that in women (3.8 vs. 1.4) (Horner et al., 2009). During this same period, Maryland’s oral cancer mortality rate was 2.8 percent, ranking it 20th among the states and the District of Columbia. The mortality rate was higher in men than in women (4.2 vs. 1.6), and in blacks than in whites (3.7 vs. 2.6) (Horner et al., 2009).

Although oral cancers are more clinically visible and accessible than most other cancers, they are detected and diagnosed at advanced clinical stages (Maryland Department of Health and Mental Hygiene, 2003). The three primary reasons for this are: First, there are gaps in knowledge and practices among dentists and other healthcare providers relating to oral cancer prevention and early detection (Yellowitz et al., 1998;
Horowitz et al., 2000; Yellowitz et al., 2000). Second, there is no standard screening recommendation for oral cancer, as there is for other cancers such as breast, cervical, and colorectal (American Dental Association, 2010; American Cancer Society, 2008; Rethman et al., 2010). And third, there is a lack of knowledge among the public of the risk factors for oral cancer, as well its signs and symptoms (Horowitz et al., 1998). Thus, the frequency at which patients are screened for oral cancer varies among dentists. The Healthy People 2010 recommendation is for adults 40 years and older and those at high risk to have an annual oral cancer screening (U.S. Department of Health & Human Services, n.d.). However, only 29 percent of U.S. adults 18 years and older and 40 percent of Maryland adults 40 years and older reported having had an oral cancer screening in the past year (Pleis et al., 2009; Maryland Department of Health & Mental Hygiene, 2009).

When oral cancers are found in early stages, the survival rate is greater than 80 percent, while cancers found in late stages have five- and ten-year survival rates of 60 percent and 49 percent, respectively (American Cancer Society, 2009). These long-term survival rates have not changed significantly in the last three decades (Horner et al., 2009). The five-year survival rate varies widely by stage at the time of diagnosis. It ranges from 81.8 percent for patients diagnosed at a localized (early) stage, to 52.1 percent for patients with regional lymph node involvement, to 26.5 percent for patients with distant metastasis (Horner et al., 2009). Only 33 percent of oral cancer lesions are diagnosed at a localized stage in the U.S., and the rate is even lower in Maryland (27.3 percent) (Maryland Department of Health & Mental Hygiene, 2003).

In the U.S., there are significant disparities in the five-year survival rates of blacks
and whites. For the period 1999-2006, the five-year survival rate was 64.4 percent for white men; 65.6 percent for white women; 40.1 percent for black men; and, 58.2 percent for black women (Horner et al., 2009). Much of the disparity in these survival rates was due to the greater proportion of tumors diagnosed at late stages among black men than among white men. In black men, only 17 percent of tumors were diagnosed at the local stage, compared with 31 percent in white men.

Research suggests that the pathogenesis of oral cancer has two distinct etiologies: one through tobacco and alcohol and another through the Human papillomavirus (HPV) (Kreimer et al., 2005; D’Souza et al., 2007). There is a growing recognition that HPV, HPV-16 in particular, plays a role in the etiology of a subset of oral cancers called oropharyngeal cancers. Oropharyngeal cancers appear on the tonsillar area, the base of the tongue and the oropharynx. A recent systematic review of the scientific literature found that approximately 35 percent of all oral cancers are positive for HPV DNA and 90 percent of HPV positive cancers were positive for HPV-16 (Kreimer et al., 2005). Of concern, is that the number of cases of cancer of the tonsil and the base of the tongue has increased in Maryland in recent years (Maryland Department of Health and Mental Hygiene, 2010).

In the past decade, Maryland has made progress to reduce the morbidity and mortality associated with oral cancer. However, key epidemiological data indicates that more must be done. These indicators are: an oral cancer mortality rate that is higher than the national average (especially among black men); less than one third of all oral cancer lesions are diagnosed at the earliest stage; only 40 percent of adults aged 40 years and older report having an oral cancer screening exam in the past year; and, increasing rates
of oral cancers associated with HPV. Dentists and dental hygienists are at the forefront of the state’s efforts to reduce the morbidity and mortality associated with oral cancer. Therefore, it is important to assess the knowledge and practices of dentists to determine if a deficiency in oral cancer prevention and early detection exists.
Section 1.2: Research Questions

This study examines what Maryland dentists’ know and do relating to oral cancer prevention and early detection. To assess their knowledge, opinions and practices, we evaluated the following research questions:

1. What are dentists’ reported practices relating to oral cancer? Specifically, whom do they screen, what risk factors do they assess when taking health histories, and what, if any, adjunctive procedures do they use in diagnosing oral cancer?

2. What is dentists’ knowledge of oral cancer diagnostic procedures? Specifically, do they know the signs, symptoms, and risk factors for oral cancer, do they know what to look for and where to look when examining a patient, and do they know the recommended oral cancer screening practices?

3. What are dentists’ opinions about oral cancer screening exams? Specifically, do they believe they are adequately trained to perform oral cancer screening exams, do they believe their knowledge is current, are they comfortable performing oral cancer screening exams, and do they agree with key aspects of the recommended screening practices?
Section 1.3: Rationale for this Project

In the past decade and a half, Maryland has made progress in its oral cancer prevention initiatives. Measures of this progress include a decrease in the oral cancer mortality rate, an increase in the number of adults age 40 and over that report having an oral cancer examination in the past year, and an increase in the number of adults age 40 and over that report ever having an oral cancer examination in their lifetime (Maryland Department of Health and Mental Hygiene, 2010).

However, there is still more work to be done in providing oral cancer education and oral cancer screenings. Dentists are in a unique position to screen patients for oral cancer signs and symptoms because they see their patients relatively frequently and regularly. Regular screening examinations increase the chances of detecting oral cancers early (Horowitz et al., 1996). They also provide practitioners the opportunity to discuss oral cancer risk factors and provide counseling about preventive measures, such as stopping tobacco use, limiting alcohol use, and oral sex (U.S. Department of Health and Human Services, n.d.). To determine if a deficiency in oral cancer prevention and early detection exists, it is important to assess the knowledge and practices of dentists.

This study is similar to a study conducted in 1995. The earlier study was part of a larger statewide study of healthcare providers (dentists, dental hygienists, physicians, nurses, and nurse practitioners) and the public (Horowitz et al., 1996). As a result of the previous study, several interventions were developed, including training dentists throughout Maryland on how to perform oral cancer screening examinations. One objective of this study is to assess dentists’ knowledge and practices relating to oral cancer prevention and early detection. It will also examine two new areas of interest:
HPV as a risk factor for oral cancer and the use of adjunctive procedures in detecting and diagnosing oral cancer. Questions about HPV were included because of the increasing evidence that HPV plays a role in the etiology of some oral cancers and the increasing incidence of the types of cancers associated with HPV. We asked about the use of adjunctive procedures because there are a large number of these devices available on the market and we wanted to investigate their use by dentists in Maryland.
Section 1.4: Definition of Terms

Oral Cancer. Oral cancer is cancer of the lips, oral cavity and oropharynx. The oral cavity includes the tongue, floor of mouth, the lining inside the lips and cheeks, gums, hard palate, and salivary glands. The oropharynx includes the back one-third of the tongue, the soft palate (back of the mouth), the tonsils, the back of the throat, and the walls of the pharynx (University of Maryland Medical Center, 2010).

Oral Cancer Risk Factors. The primary risk factors for oral cancer are: past and present use of tobacco and alcohol products; exposure to ultraviolet radiation (increases risk of lip cancer); exposure to viruses such as Human papillomavirus (HPV); low consumption of fruits and vegetables; and, age older than 45 years (American Cancer Society, 2010a). It is especially important to screen for tobacco and alcohol use, since 80 percent of oral cancers are attributable to these two risk factors.

Oral Cancer Signs and Symptoms. In early stages, oral cancer does not cause pain or discomfort and it may be difficult to see. The early signs and symptoms of oral cancer include a sore in the mouth that bleeds easily or does not heal (most common symptom) or a persistent white or red patch on the gums, tongue, tonsil, or lining of the mouth (American Cancer Society, 2010b). Leukoplakia is white patches that can form on the cheeks, gum or tongue. Leukoplakia is commonly seen in tobacco users, in people with ill-fitting dentures, and in those who have a habit of chewing on their cheek. This condition can progress to cancer. Erythroplakia is red patches in the mouth. Erythroplakia is less common than leukoplakia, but has a greater potential for being cancerous. It is important to see a physician or dentist if any of these conditions are present and lasts more than two weeks (American Cancer Society, 2010b).
Common indicators of later stages of the disease are: pain in the mouth that doesn't go away (also very common); a sore throat or a feeling that something is caught in the throat that doesn't go away; trouble chewing or swallowing; trouble moving the jaw or tongue; numbness of the tongue or other area of the mouth; swelling of the jaw that causes dentures to fit poorly or become uncomfortable; loosening of the teeth or pain around the teeth or jaw; voice changes; a lump or mass in the neck; weight loss; and, persistent bad breath. It is important to see a physician or dentist if any of these conditions are present and lasts more than two weeks (American Cancer Society, 2010b).

**Adjunctive Procedures.** A variety of diagnostic aids and adjunctive techniques used to assist in the screening of healthy patients or to assess abnormal lesions. The methods employed by these diagnostic aids are tissue staining or light-based detection systems. The most common systems are: Toluidine Blue, ViziLite Plus with TBlue, MicroLux DL, Velscope, OralCDx brush biopsy, and Sapphire Velscope (Patton et al., 2008).

**Dentists Knowledge.** The survey contains twenty-five questions related to the signs, symptoms and risk factors for oral cancer. These questions measure dentists’ knowledge of oral cancer diagnostic procedures.

**Dentists Opinions.** The survey contains twenty-four Likert-style questions about critical aspects of oral cancer screening practices and training. These questions measure dentists’ self-efficacy in providing oral cancer screening exams and tobacco and alcohol cessation education.

**Dentists Practices.** The survey contains ten questions to measure the comprehensiveness of oral cancer risk factors probed while taking medical histories and four questions to assess compliance with recommended oral cancer screening practices.
Chapter 2: Literature Review

This review of the oral cancer literature is organized as follows: 1) Introduction – What is Oral Cancer? – briefly describes oral cancer and the populations impacted by the disease; 2) Risk Factors – provides a high-level overview of the main factors that increase the risk for developing oral cancer; 3) Incidence Rates, Mortality Rates, and Trends – summarizes oral cancer incidence and mortality rates in the U.S. and Maryland and recent epidemiologic trends; 4) Stage at Diagnosis – describes the impact of the stage at diagnosis on long-term survival rates; 5) Health Disparities – identifies populations that bear the greatest burden for oral cancer; and 6) Prevention and Early Detection – summarizes previous research on the knowledge, opinions and practices of dentists; describes current oral cancer screening recommendations; provides information about the public’s knowledge of oral cancer; and describes the importance of health literacy to overall health and oral health.
Section 2.1: Introduction – What is Oral Cancer?

Oral cancer is cancer of the lips, oral cavity and oropharynx. The oral cavity includes the tongue, floor of mouth, the lining inside the lips and cheeks, gums, hard palate, and salivary glands. The oropharynx includes the back one-third of the tongue, the soft palate (back of the mouth), the tonsils, the back of the throat, and the walls of the pharynx (University of Maryland Medical Center, 2010). The most common sites for oral cancer are: the tongue (30 percent), the lip (17 percent), and the floor of the mouth (14 percent) (Silverman, 2001).

Oral cancer accounts for approximately three percent of all cancers in the U.S. (Silverman, 2001). The mortality rate for oral cancer is higher than that of several other cancers that we commonly hear about, such as cervical cancer, Hodgkin’s lymphoma, and malignant melanoma (Stahl et al., 2004). It is estimated that one American dies from oral cancer every hour (Kademani, 2007). More than 90 percent of people diagnosed with oral cancer are older than 45 years, with the average age at diagnosis 60 years (Silverman, 1998). Oral cancer is more common in men than in women and more frequent among black men than white men (Shiboski et al., 2000).

Historically, oral cancers were associated with men aged sixty years and older who used tobacco and alcohol products (Johnson, 2001; Blot et al., 1988). However, the epidemiological data indicates that the patient demographic is changing. The male-to-female ratio of oral cancers has changed from 10:1 to 2:1 in the last four decades. The incidence of oral cancer in women has increased significantly, largely due to an increase in women smoking (Shiboski et al., 2000). There has been a steady increase in the incidence of oral cancers in patients younger than 40 years of age (from 0.4 to 4.0
percent) and in those without risk factors (Llewellyn et al., 2001; Schantz and Yu, 2002; Ries et al., 2006).
Section 2.2: Risk Factors

The primary risk factors for oral cancer are: past and present use of tobacco products; excessive use of alcohol; exposure to viruses such as HPV; exposure to ultraviolet radiation; low consumption of fruits and vegetables; and, age older than 45 years (American Cancer Society, 2010a). Each of these risk factors is briefly described below.

**Tobacco.** All forms of tobacco, including cigarettes, cigars, pipes and smokeless tobacco, have been established as causal for oral cancer. Smokers are six times more likely than non-smokers to develop oral cancer, and tobacco usage of any kind accounts for more than 75 percent of oral cancer deaths in the U.S. (Tomar, 2001). Patients who continue to smoke after diagnosis of an initial tumor have up to a six-fold greater risk of developing a second primary tumor than patients who stop smoking after diagnosis (Johnson, 2001; Blot et al., 1988). After three to five years of smoking cessation, a fifty percent reduction of risk for oral cancer risk has been observed, and within ten years of cessation, the risk returns to normal (U.S. Department of Health and Human Services, 2004; Blot et al., 1988).

**Alcohol.** Alcohol is the second greatest risk factor for developing oral cancer (Altieri et al., 2004; Goldstein et al., 2010). Oral cancers are six times more common in drinkers than in non-drinkers and 75-80 percent of all oral cancer patients consume alcohol frequently (American Cancer Society, 2006). Studies have shown that excessive alcohol use (defined as more than twenty-one standard drinks in a week) is associated with nutrient deficiency, which is an independent risk factor for oral cancer (Blot et al., 1988). When you combine tobacco with excessive alcohol use, the risk for developing
oral cancer increases by 15-fold (Tomar, 2001). This increased risk is due to the synergistic effect of alcohol and tobacco (alcohol increases the permeability of mouth tissues to tobacco carcinogens). It has been difficult to distinguish the separate effects of tobacco and alcohol because people who consume alcohol tend to use tobacco and vice versa (Blot et al., 1988). Research shows that the risk of developing oral cancer increases with both the dosage and the length of time that tobacco and alcohol products are used (Franchesi et al., 2000; Tomar, 2001).

**HPV.** Approximately 20-25 percent of all oral cancers occur in people who do not smoke and who only drink alcohol occasionally (Llewellyn et al., 2003). Research suggests that the pathogenesis of oral cancer has two distinct etiologies: one through tobacco and alcohol, and another through HPV (Blot et al., 1988; D’Souza et al., 2007; Frish et al., 2000). There is a growing recognition that HPV, HPV-16 in particular, plays a role in the etiology of a subset of oral cancers called oropharyngeal cancers (D’Souza et al., 2007; Falkry and Gillison, 2006; Gillison, 2007; Frish et al., 2000). Oropharyngeal cancers appear on the tonsillar area, the base of the tongue, and the oropharynx (Falkry and Gillison, 2006). While incidence rates for most cancer sites in the oral cavity declined or remained constant in the past three decades, those for tonsillar and base-of-tongue cancers increased significantly, predominantly for Caucasian men under the age of 65 years (Frisch et al., 2000). Although the trends in incidence rates for oral cancers have mainly been attributed to population fluctuations in the use of alcohol and tobacco, the use of alcohol and tobacco in the US has largely declined since 1964, and thus cannot explain the recent increase in the incidence of tonsillar and base-of-tongue cancers (Sturgis and Cinciripini, 2007).
A recent review of the literature found that approximately 35 percent of all oral cancers are positive for HPV DNA and 90 percent of HPV positive cancers were positive for HPV-16 (Kreimer et al., 2005). Current data indicate that oral HPV-16 infection is primarily sexually acquired and is a strong risk factor for oral cancer (Gillison, 2007; Gillison, 2008). In a recently reported case–control study, after adjustment for age, gender, alcohol, tobacco, oral hygiene, and family history of head and neck cancers, individuals seropositive for HPV-16 had a 15-fold increase in risk for oropharyngeal cancer when compared with seronegative individuals (D’Souza et al., 2007).

HPV infection may be altering the demographics of oral cancer patients, as these patients tend to be younger, nonsmokers, and nondrinkers. Patients with HPV-positive tumors appear to have an improved prognosis, at least half the risk of death, when compared with patients with HPV-negative tumors (Falkry et al., 2008). The HPV etiology of these tumors may have future clinical implications for the diagnosis, therapy, screening, and prevention of oral cancers (Falkry and Gillison, 2006). A prophylactic vaccine capable of preventing oral HPV-16 infection could likely prevent HPV-associated oral cancers. However, for vaccination against oncogenic HPV infection to have the greatest benefit it should be administered prior to the onset of sexual behavior (Gillison, 2008). Currently, vaccines targeted against oncogenic HPV infection have been indicated for use in women only. Vaccinating males against oncogenic HPV infection may be an important approach for the prevention of oral cancer, given the incidence is higher in men (Falkry and Gillison, 2006). Clinical trials are in progress to determine the efficacy of such vaccines in preventing genital oncogenic HPV infection in men and clinical trials to evaluate the potential for vaccines to prevent oral HPV 16
infection are in the developmental stages (Falkry and Gillison, 2006).

**Ultraviolet Radiation.** Exposure to sunlight is the major risk factor for lip cancer. Other factors that increase risk for lip cancer include smoking, smokeless tobacco products, and excessive alcohol use (Perea-Milla et al., 2003). The vast majority of lip cancers occur on the lower lip. Those at greater risk for lip cancer are: men (two to three times more likely to be diagnosed with lip cancer than women), fair-skinned individuals, and individuals with viruses such as HPV, herpes simplex, and acquired immunodeficiency syndrome (AIDS) (Perea-Milla et al., 2003). Vitamin deficiency may also be a contributing factor to lip cancer. Studies indicate that the vitamins found in fruits and vegetables, particularly carotene, seem to play a role in decreasing the risk for lip cancer (Pavia et al., 2006).

**Low consumption of fruits and vegetables.** Poor dietary practices and nutritional deficiencies have been linked to a risk of developing oral cancer, while diets rich in fruits, vegetables, and vegetable fats are inversely related to oral cancer risk (Edefonti et al., 2010; Winn, 1995). Pavia et al. (2006) conducted a meta-analysis of sixteen studies examining the effect of fruit and vegetable consumption on oral cancer and concluded that the consumption of fruits and vegetables is associated with a reduced risk of oral cancer. They found that each portion of fruit consumed per day significantly reduced the risk of oral cancer by 49 percent and that vegetable consumption showed a significant reduction in the overall risk of oral cancer by 50 percent. A second recent meta-analysis of forty case-control studies, by Lucenteforte and colleagues (2009) found that fruits and vegetables, beta-carotene, vitamin C, selected flavonoids, and whole grains were inversely related to the risk of oral cancer.
**Age.** Age is a risk factor for oral cancer. Ninety-five percent of oral cancers are diagnosed in people older than 45 years, with the average age at diagnosis 60 years (Llewellyn et al., 2003).

While age is not a modifiable risk factor, the previously described risk factors are modifiable lifestyle factors. Studies report that up to 75 percent of oral cancers could be prevented by modifying behaviors (Blot et al., 1988). Quitting tobacco and limiting alcohol use significantly lowers the risk of developing oral cancers, even after many years of use. Avoiding unprotected sun exposure, as well as pipe and cigar tobacco can prevent lip cancers. Lastly, research shows that eating a healthy, balanced diet with at least five servings of fruits and vegetables every day may provide some protection against oral cancer (Pavia et al., 2006; Lucenteforte et al., 2009).
Section 2.3: Incidence Rates, Mortality Rates and Trends

Section 2.3.1: Incidence and Mortality Rates

In 2009, it is estimated that there were 35,720 new cases and 7,600 deaths from oral cancer in the U.S. (American Cancer Society, 2009). In 2007, the incidence rate of oral cancer in the U.S. was 10.4 percent with the rate in men more than twice that in women (15.4 vs. 6.1) (Altekruse et al., 2010). Maryland ranked 46th among the states and the District of Columbia with an incidence rate of 8.9 percent. The rate in men was 2.5 times greater than that in women (13.2 vs. 5.3) (National Cancer Institute, 2007).

For the period 2004-2006, the oral cancer mortality rate in the U.S. was 2.5 percent, with the rate in men more than twice that in women (3.8 vs. 1.4) (Horner et al., 2006). During this same period, Maryland’s oral cancer mortality rate was 2.8 percent, ranking it 20th among the states and the District of Columbia. The mortality rate was higher in men than in women (4.2 vs. 1.6), and in blacks than in whites (3.7 vs. 2.6) (Horner et al., 2006).

Section 2.3.2: Trends in Incidence, Mortality and Five-Year Survival Rates

U. S. Trends

Oral cancer incidence rates and mortality rates have declined over the past three decades in the U.S. However, these decreases have not been consistent or uniform within the U.S. population (Kingsley et al., 2008; Reis et al., 2000). Recent studies have shown statistically significant differences in oral cancer incidence rates and mortality rates among population subgroups, including minorities, various age groups, and between genders (Swango, 1996). For example, a study by Shiboski et al. (2000) demonstrated
that although incidence rates of oral cancer have been steadily decreasing among white males, incidence rates among older black males (65 years and older) have been increasing. This study also found that oral cancer rates among females have increased.

Kingsley et al. (2008) examined incidence and mortality data from the National Cancer Institute’s Surveillance, Epidemiology and End Results (SEER) Program, for each year between 1975 and 2004, to identify specific populations within the U.S. that may be at greater risk for oral cancer, as well as trends over the past three decades. They found an overall declining trend in oral cancer incidence rates over the past 30 years, with the most significant declines observed over the past ten years. Short-term trend analysis of the past five years indicates a reversal of this decline, which may signify an important development in the epidemiology of this disease. Over the past 30 years, oral cancer incidence has declined among white males (-1.21 percent), white females (-0.66 percent), black males (-1.53 percent) and black females (-1.38 percent), although these observed declines have not been uniform across time. For example, while the incidence of oral cancer among black males declined over the past 30 years, temporal stratification of these data revealed that this decline was greatest over the past five years (-6.64 percent). This stratification also revealed the incidence of oral cancer among black females rose from -1.38 percent over the entire 30 year period, to +3.18 percent during the most recent five-year period. Their analysis showed that incidence rates are continuing to decline in all states, except four (Nevada, Idaho, North Dakota and North Carolina) in which the rates are increasing.

Mortality rates also declined over the past 30 years for all groups. The rates of decline were: white males (-2.16 percent), white females (-1.62 percent), black
males (-1.92 percent) and black females (-1.71 percent). More specific temporal analysis of the data revealed two distinct trends. First, decreases in mortality rates were greatest over the last ten-year period compared to the last 30 years, and the decreases were much less pronounced over the more recent five-year period. The second trend, found only among white males, revealed that mortality rates, although still declining, were declining by ever-smaller amounts over each time period: 30 years (-2.16 percent), 10 years (-1.83 percent), and five years (-0.33 percent).

The five-year survival rate is another important measure of the burden of oral cancer. Overall, 60 percent of people with oral cancer survive for five years after diagnosis, an increase of approximately 15 percent since the 1960’s (Reis et al., 2006). While the increase in the five-year survival rate is measurable progress against this disease, this rate is still very low and significant disparities remain between some population groups. See Section 2.5 for a discussion of disparities among different groups.

There are a few other epidemiological trends to note. From 1973 through 1996, white men and women showed an overall decrease in age-adjusted incidence rates of cancer of the lip and floor of the mouth (Shiboski et al., 2000). This is likely due to the increased awareness of the damaging effects of prolonged exposure to sunlight and the use of sunscreens for protection (Reis et al., 2000). However, there was a significant increase in age-adjusted incidence rate of tongue cancer over the same period, especially among whites aged 35 to 39 years (Shiboski et al., 2000).
Maryland Trends

In Maryland, the incidence of oral cancer decreased an average of 5.4 percent per year from 2002 to 2006. Males consistently had higher oral cancer incidence rates than females. Over the five-year period, oral cancer incidence rates declined for all groups (white males, white females, black males, and black females). The largest declines in incidence rates were seen among black males (7.1 percent), black females (6.4 percent), and white males (5.2 percent)(Maryland Department of Health & Mental Hygiene, 2009).

Mortality rates for oral cancer declined an average of 0.2 percent per year from 2002 to 2006. During this period, mortality rates were consistently higher for males than females. Rates for black males increased an average of 7.2 percent per year, while rates for white males and white females declined slightly. Mortality rates for black females were not included due to low death counts that resulted in unstable rates (Maryland Department of Health & Mental Hygiene, 2009).
Section 2.4: Stage at Diagnosis

Like most other cancers, the prognosis for those diagnosed with oral cancer depends largely on the clinical stage of the tumor at diagnosis. The American Joint Committee on Cancer (2010) describes cancers according to tumor size, cancer location, and cancer extent (how far it has spread). Oral cancers are categorized as follows:

- **Stage I.** The cancer is less than two centimeters in size, and has not spread to lymph nodes in the area.

- **Stage II.** The cancer is more than two centimeters in size, but less than four centimeters, and has not spread to lymph nodes in the area.

- **Stage III.** Either of the following may be true: The cancer is more than four centimeters in size, or the cancer is any size but has spread to only one lymph node on the same side of the neck as the cancer. The lymph node that contains cancer measures no more than three centimeters.

- **Stage IV.** Any of the following may be true: The cancer has spread to tissues around the lip and oral cavity. The lymph nodes in the area may or may not contain cancer. The cancer is any size and has spread to more than one lymph node on the same side of the neck as the cancer, to lymph nodes on one or both sides of the neck, or to any lymph node that measures more than six centimeters. The cancer has spread to other parts of the body.

Stage I and Stage II cancers are at a localized stage, Stage III cancers are classified as tumors with regional metastasis and Stage IV cancers are classified as tumors with distant metastasis.
Although oral cancers are more clinically visible and accessible than most other cancers, they are detected and diagnosed at advanced clinical stages (Stages III and IV) (Maryland Department of Health & Mental Hygiene, 2003). In the U.S., only one third of oral cancers are diagnosed at a localized stage (Reis et al., 2009). For 2000-2007, 34.7 percent of oral cancers were diagnosed at a localized stage, 44 percent were diagnosed at a regional stage, 13.9 percent were diagnosed at a distant stage, and 7.4 percent were diagnosed at an unknown stage (Altekruse et al., 2010). In Maryland, 28.1 percent of oral cancer cases were diagnosed at a localized stage and 44.4 percent were diagnosed at a regional stage (Maryland Department of Health & Mental Hygiene, 2009).

When oral cancers are found in early stages, the survival rate is greater than 80 percent, while cancers found in late stages have five- and ten-year survival rates of 60 percent and 49 percent, respectively (American Cancer Society, 2009). These long-term survival rates have not changed significantly in the last three decades (Reis et al., 2009). The five-year survival rate varies widely by stage at the time of diagnosis. It ranges from 81.8 percent for patients diagnosed at a localized stage, to 52.1 percent for patients with regional lymph node involvement, to 26.5 percent for patients with distant metastasis (Horner et al., 2009).

The location of oral cancers also affects the five-year survival rates. In the U.S., for 1988-2006, the relative five-year survival rate by oral cancer site is as follows: Lip (93.9 percent), Tongue (74.6 percent), Salivary Gland (74.6 percent), Floor of mouth (53.2 percent), Gum/Other Mouth (60.3 percent), and Oropharynx and Tonsil (54.2 percent). The ten-year survival rate is significantly lower for cancers of the Tongue, Floor of mouth and Oropharynx and Tonsil: Lip (88.0 percent), Tongue (46.6 percent), Salivary
Gland (70.5 percent), Floor of Mouth (38.7 percent), Gum and Other Mouth (49.0 percent), and Oropharynx and Tonsil (44.2 percent) (Fast Stats, 2010).
Section 2.5: Health Disparities

In the U.S., oral cancer incidence, mortality and relative survival rates, as well as trends in these rates, vary substantially for blacks and whites and males and females. Morse and Kerr (2006) examined data from the National Cancer Institute’s Surveillance, Epidemiology and End Results (SEER) Program from 1975 through 2002 to quantify oral cancer rates and trends for black and white Americans. Their results provide evidence of racial disparities, as well as significant changes in oral cancer incidence and mortality rates over this 28-year period. There is no consensus on the causes of these racial differences, but they may include differences in access to care, stage at diagnosis, insurance status, and attitudes of health providers (Settle et al, 2009).

During the 1975-2002 period, Age Adjusted Incidence Rates (AAIRs) were notably higher for males than for females, with black males having the highest rates (Morse and Kerr, 2006). For black males, AAIRs rose sharply from the mid-1970s through the mid-1980s before beginning a sharp decline that continued through 2002. For white males, AAIRs declined from the mid-1970s into the early 2000s. For black females, there was a general downward trend over the entire period. For white females, rates increased modestly from the mid-1970s into the early 1980s, and then decreased thereafter. A comparison of AAIRs for 1975 with those for 2002 showed a net decline for black males (17 percent), white males (26 percent), black females (22 percent), and white females (5 percent). For the most recent five-year period (1998-2002), AAIRs were more than twice as high in white men as in white women (15.7 vs. 6.6 percent) and more than three times as high in black men as black women (19.5 vs. 6.0 percent).
During the 1975-2002 period, males had higher Age Adjusted Mortality Rates (AAMRs) than did females; black males had the highest rates, while white females had the lowest rates. For black males, AAMRs increased sharply from 1975 through 1980, before showing an equally marked decline throughout the rest of the period. For white males, AAMRs declined throughout the 28-year period. For black females, there was a modest decrease in rates from the mid-1970s into the mid-1990s before declining more sharply through the rest of the period. Rates for white females fell during most of the period. A comparison of AAIRs for 1975 with those for 2002 showed a net decline for black males (22 percent), white males (29 percent), black females (15 percent) and white females (16 percent). For the most recent five-year period (1998-2002), mortality rates were more than twice as high in white men as in white women (3.9 vs. 1.6 percent) and more than three times as high in black men as black women (7.1 vs. 1.9 percent).

The authors also found disparity in the relative survival rates between blacks and whites, and virtually all ages, anatomical sites, and stages at diagnosis. For both blacks and whites, five-year relative survival was related to the age at diagnosis, with younger patients generally having higher relative survival rates than older patients. The five-year relative survival rate is also related to the anatomical site of the primary cancer, with cancers of the lip and major salivary glands having the highest rates for survival, and cancers of the pharynx having the lowest rates. Blacks have a higher incidence of cancers of the pharynx than whites (38 vs. 26 percent). Lip cancer, which is associated with a high relative survival rate, was more common in whites (11 percent) and very rare in blacks (1 percent). This difference in lip cancer is attributed to the higher pigmentation levels of blacks, which protect the lips from radiation.
For oral cancer cases diagnosed during the period 1995-2001, the overall five-year relative survival rates were highest for white females (63 percent) and white males (61 percent), intermediate for black females (52 percent) and lowest for black males (34 percent). Relative survival rates declined with each successively higher stage at diagnosis. The highest five-year relative survival rates were seen in whites (males and females) and black females who were diagnosed at a localized stage (>80 percent), while black males who were diagnosed with distant metastases or un-staged disease had the lowest rates (23 percent). A higher proportion of white females (42 percent) and white males (35 percent) were diagnosed at a localized stage than were black females (31 percent) and black males (17 percent).

As mentioned in the previous section, the stage at which a cancerous lesion is diagnosed is an important predictor of survival. Thus, oral cancer examinations are an opportunity to identify pre-cancerous lesions and early-stage cancers. However, in 1998, only 13 percent of U.S. adults (14 percent of whites, 7 percent of blacks) reported having received such an examination within the preceding 12 months (U.S. Department of Health and Human Services, n.d.). Blacks were 1.5 times less likely to have had an oral cancer examination than whites (10.3 vs. 15.5 percent). This lower rate of oral cancer examinations may be a contributing factor to late stage diagnosis. In addition, adults with less than 12 years of education were 2.5 times less likely than those with 13 or more years of schooling to ever have had an oral cancer examination.

Patterns of exposure to oral cancer risk factors, particularly tobacco and alcohol, are likely responsible for most of the observed differences in oral cancer rates across race and sex groups (Day et al., 1993). Several studies have shown increased incidence and
mortality rates of oral cancers among certain demographic groups, which may have resulted from increased risks or risk behaviors (Levi et al., 2001; Morse and Kerr, 2006; Ries et al., 2006). Analysis of data from a large U.S. population-based case-control study of oral cancer conducted in the mid-1980s found that most of the difference in oral cancer incidence rates between blacks and whites was attributable to racial differences in patterns of alcohol intake, especially among current smokers, as well as to higher oral cancer risks associated with alcohol intake among blacks (Day et al., 1993; Gridley et al., 1990).

A growing body of evidence suggests that HPV plays an etiologic role in oropharyngeal cancer and recent studies indicate that these cancers may account for some of the observed racial differences in incidence and mortality rates (Settle et al., 2009). Settle and colleagues (2009) conducted a prospective analysis of patients (n=539) with oropharyngeal cancers. They found a significant decrease in overall survival rate in black versus white patients (52.1 months vs. 23.7 months) that was driven by the overall survival rates in those with oropharyngeal cancer. White patients were nine times more likely to have HPV-positive oropharyngeal tumors than black patients. HPV-positive tumors respond better to treatment with combined chemotherapy and radiation than HPV-negative tumors. HPV-positive and HPV-negative tumors have different behavior, and the study results indicate that the majority of black patients have HPV-negative tumors that did not respond optimally to the combined chemotherapy and radiation therapy.

Evidence also shows that racial disparities may exist in the treatment received by patients with oral cancer, with whites more likely than blacks to receive cancer-directed surgery, even after data are stratified on the anatomical site affected and stage at
diagnosis (Tomar et al., 2004). The reasons for such treatment differences are not clear. Furthermore, although treatment can affect survival, survival analyses that include the type of treatment received and adjusted for other relevant factors, such as age, sex, measures of socioeconomic status, cancer site and stage, do not account completely for the observed differences in survival between blacks and whites (Tomar et al., 2004). It is likely that additional characteristics, including lifestyle habits (for example, smoking, drinking and diet), cultural factors and co-morbid conditions also play a role in survival differences between black and white Americans with oral cancer (Day et al., 1993; Moore et al., 2006; Murdock and Gluckman, 2001).
Section 2.6: Prevention and Early Detection

A comprehensive oral cancer examination is the primary method used to detect oral cancer. During the examination, which can be completed in less than five minutes, the healthcare provider inspects and palpates the head, neck and oral cavity (American Cancer Society, 2008). The American Cancer Society (2008) recommends that primary care doctors and dentists examine the mouth and throat as part of a routine cancer-related checkup. Routine checkups provide the opportunity to see abnormal tissue changes and to detect cancer at a localized stage.

Only one third of all oral cancers are detected and diagnosed at a localized stage (Altekruse et al., 2010). There are three principal reasons for this low rate of early diagnosis. First, there are gaps in knowledge and practices among dentists and other healthcare providers relating to oral cancer prevention and early detection (Yellowitz et al., 1998; Horowitz et al., 2000; Yellowitz et al., 2000). Second, there is no standard screening recommendation for oral cancer, as there is for other cancers such as breast, cervical, and colorectal (American Cancer Society, 2008; American Dental Association, 2010; Rethman et al., 2010). And third, there is a lack of knowledge among the public of the risk factors for oral cancer, as well its signs and symptoms. The public also lacks knowledge that an oral cancer exam exists, and therefore they do not even know to ask for one (Horowitz et al., 1998).

Each factor is discussed in the following sections: 2.6.1: Dentists’ Knowledge, Opinions and Practices Relating to Oral Cancer; 2.6.2: Oral Cancer Screening Recommendations; and 2.6.3: The Public’s Knowledge of Oral Cancer. Section 2.6.4: Health Literacy discusses the impact of health literacy on oral health.
Section 2.6.1: Dentists’ Knowledge, Opinions & Practices Relating to Oral Cancer

Knowledge

To conduct comprehensive oral cancer screening examinations and provide patients with appropriate information about oral cancer risk factors, dentists’ knowledge must be accurate and current. Previous studies indicate that there are gaps in dentists’ knowledge of the risk factors and signs and symptoms of oral cancer (Yellowitz et al., 1998; Horowitz et al., 2000; Yellowitz et al., 2000). A national study by Yellowitz et al. (2000) found that almost all dentists correctly identified patients’ tobacco use (99.7 percent), having a prior oral cancer lesion (96.4 percent) and alcohol use (92.7 percent) as risk factors for oral cancer. However, only one-third of the dentists knew that oral cancers are most often diagnosed in patients 60 years of age or older and that low consumption of fruits and vegetables is a risk factor. Their assessment of dentists’ knowledge of oral cancer diagnostic procedures found that 83 percent of dentists knew that squamous cell carcinoma is the most common type of cancer, 81 percent identified all of the procedures for examining the tongue for oral cancers, and 80 percent recognized that an early oral cancer lesion usually is a small, painless red area. But, only 54 percent knew the two most common sites of intraoral cancer are the tongue and floor of the mouth, and only 37 percent knew that the two lesions most likely to be associated with oral cancer are erythroplakia and leukoplakia. If dentists do not know what to look for or where to look, their ability to detect and diagnose oral cancers at an early stage is diminished (Horowitz et al., 2000).

To measure dentists’ knowledge, the researchers created two indices (Horowitz et al., 2000; Yellowitz et al., 2000); one measured knowledge of oral cancer risk factors and
the other measured knowledge of oral cancer diagnostic procedures (Horowitz et al., 2000). Based on the number of correct responses to survey questions, dentists were categorized into one of three categories: high score, medium score or low score. To identify patterns of knowledge of oral cancer risks and diagnostic procedures, they cross-classified dentists on each of these two indices. They found that only 12 percent of dentists had a high score on both indices. With only 12 percent of dentists having a high knowledge of both oral cancer risk factors and diagnostic procedures, it is possible that a significant percentage of dentists may not recognize or find potentially cancerous lesions (Horowitz et al., 2000).

The authors also evaluated the effects of four background characteristics on dentists’ levels of knowledge about oral cancer risk factors and diagnostic procedures. The four background characteristics were: gender, type of practice, year of dental school graduation and the interval since their last oral cancer Continuing Education (CE) course. Many of their findings are not surprising. Recency of graduation had a consistent effect on the likelihood of getting a high score on each knowledge index. Compared with dentists who graduated before 1970, each of the three younger graduate cohorts was increasingly more likely to get a high score on each knowledge index. Dentists who had never taken an oral cancer CE course were two times less likely to get a high score on both knowledge indices than were dentists who had taken an oral cancer CE course within the past 12 months. Increased emphasis on oral cancer in dental school curricula, an outcome of this early research, may be in part responsible for this increased knowledge of oral cancer among more recent graduates (Horowitz et al., 1998; Horowitz et al., 2000; Maryland Department of Health & Mental Hygiene, 2003). The authors
concluded that the correlation between the recency of graduation and dentists’ levels of knowledge of risk factors and diagnostic procedures for oral cancer suggested that dental schools provide adequate coverage of oral cancer. However, they suggested CE courses were needed to help earlier graduates update their knowledge of oral cancer risk factors and diagnostic procedures.

**Practices**

This same national survey also evaluated dentists’ practices relating to screening for risk factors when taking a medical history and the provision of oral cancer examinations (Horowitz et al., 2000; Yellowitz et al., 2000). The researchers found that when assessing a patients’ risk for oral cancer, 91 percent of dentists asked about the patients’ cancer history, and 65 percent asked about the patient’s family history of cancer. Ninety percent asked about present tobacco use, 77 percent asked about past tobacco use and 72 percent asked about the types and amount of tobacco products used. With regard to alcohol, 60 percent of dentists asked about present alcohol use, 50 percent asked about past alcohol use, but only 33 percent asked about the types and amounts of alcohol used. On average, dentists assessed about five of the eight health history factors.

With regard to the provision of oral cancer screening examinations, 81 percent reported that they provided an oral cancer examination for 100 percent of their patients 40 years of age and older at their initial appointment, and 78 percent said they provided this examination at recall appointments. Only 35 percent reported that they palpated lymph nodes of patients 18 years of age or older 80 percent or more of the time. Even fewer dentists (14 percent) reported providing oral cancer examinations for edentulous patients 18 years of age and older. The low numbers of dentists palpating lymph nodes in
patients is troubling because palpation is a crucial component of the oral cancer examination. If dentists are not performing this step, they are not providing the best possible care to their patients and they may miss detecting some oral cancers. It is also disturbing that so few dentists report providing exams for edentulous patients because these patients have many of the characteristics (older age, being a current or former tobacco user) that may place that at high risk for developing oral cancer (Horowitz et al., 2000).

To measure dentists’ oral cancer screening practices, the researchers created two indices (Horowitz et al., 2000; Yellowitz et al., 2000); one measured the number of risk factors screened when taking a medical history and the other measured provision of oral cancer examinations (Horowitz et al., 2000). Based on the number of correct responses, dentists were categorized into one of three categories: high score, medium score or low score. To examine the associations between dentists’ screening practices and provision of examinations, they cross-classified dentists on each of these two indices. They found that only 15 percent of dentists had a high score on both indices. If only 15 percent of dentists are performing the recommended screening practices, many patients are not receiving oral cancer examinations, which may lead to cancers being detected and diagnosed at later stages (Horowitz et al., 2000). In addition, if dentists do not assess their patients’ risks for oral cancer, they may miss the opportunity to identify high-risk patients, such as those who smoke or drink, who should be screened regularly for oral cancer.

The authors (Horowitz et al., 2000; Yellowitz et al., 2000) evaluated the effects of the four background characteristics on key aspects of oral cancer screening practices.
Dentists who were graduated from 1980-1989 or 1990-1995 were 1.5 to 2.0 times, respectively, more likely to get a high score for their screening practices. Dentists who had never taken an oral cancer CE course or who had not taken one in the past five years were 2.6 or 1.7 times, respectively, less likely to get a high score. Dentists who were graduated between 1980 and 1995 were 1.5 times more likely to score high on the index measuring provision of oral cancer examinations, while dentists who had never taken an oral cancer CE course or had not take one within the past five years were 2.2 and 1.5 times, respectively, were less likely to get a high score.

**Opinions**

The researchers assessed dentists’ opinions as to whether their knowledge of oral cancer was current, if they were adequately trained to perform oral cancer screening exams, if they were comfortable performing oral cancer screening exams, and the quality of their training on oral cancer in dental school (Horowitz et al., 2000; Yellowitz et al., 2000). Sixty-eight percent of dentists reported that their knowledge of oral cancer was current, but only four percent strongly agreed with this statement. Eighty-eight percent of dentists agreed or strongly agreed that they were adequately trained to examine patients for oral cancer. Seventy-two percent agreed or strongly agreed that they were adequately trained to palpate lymph nodes. However, only 25 percent strongly agreed or agreed that they were adequately trained to perform oral cancer examinations. Twenty-nine percent of dentists rated their education in oral cancer as very good, 49 percent rated it good, and 20 percent rated it as poor. These wide ranging opinions indicated that interventions were needed to decrease the deficiencies in dentists’ self-efficacy and skills
relating to oral cancer prevention and early detection.

It is important to note that the survey instrument developed and used in these initial studies, the National Oral Cancer Survey of Dentists (NOCSD), has been widely used in the U.S. and other countries, yielding similar results (Patton et al., 2005; Applebaum et al., 2009). The NOCSD is discussed in Section 3.2: Survey Instrument.
Section 2.6.2: Oral Cancer Screening Recommendations

There is no standard screening recommendation for oral cancer, as there is for other cancers such as breast, cervical, and colorectal (American Cancer Society, 2008; American Dental Association, 2010; Rethman et al., 2010). The leading medical, professional and governmental organizations make different recommendations about the need for and frequency of oral cancer screening examinations. For example, the Healthy People 2010 recommendation is for adults 40 years and older and those at high risk to have an annual oral cancer screening (U.S. Department of Health & Human Services, n.d.). Unfortunately, only 29.4 percent of U.S. adults 18 years and older reported ever having an oral cancer examination (Pleis et al., 2009). In Maryland, 50 percent of adults 40 years and older report ever having an oral cancer screening exam, and 40 percent report they had an exam in the past twelve months (Maryland Department of Health & Mental Hygiene, 2009). While the percent of Maryland adults who report having had an oral cancer examination is significantly greater than the percent of adults in the U.S., overall these numbers are very low.

The American Dental Association (2010) states that an oral cancer screening is a routine part of the dental examination, but it does not specify a frequency for the examinations. Many dental and health organizations recommend twice-yearly visits to the dentist for preventive checkups, but exam rates vary by healthcare provider. A third recommendation, by the American Cancer Society (2008), is for people aged 20 or older to have periodic health exams, and depending on a person's age and gender, exams for cancers of the thyroid, oral cavity, skin, lymph nodes, testes, and ovaries, as well as for some non-malignant (non-cancerous) diseases. The American Cancer Society’s
recommendation is a cause for concern in the fight against oral cancer because the oral cancer screening recommendation is buried in a paragraph that describes other cancer-related checkups, or it is a footnote in a table (Smith et al., 2010).

A fourth organization, the U.S. Preventive Services Task Force (USPSTF) concluded that the evidence was insufficient to recommend for or against routinely screening adults for oral cancer (USPSTF, 1996). In 2004, the USPSTF revised its criteria to rate the strength of the evidence and thus revised their recommendation for oral cancer examinations to the following:

“The USPSTF found no new good-quality evidence that screening for oral cancer leads to improved health outcomes for either high-risk adults (i.e., those over the age of 50 who use tobacco) or for average-risk adults in the general population. It is unlikely that controlled trials of screening for oral cancer will ever be conducted in the general population because of the very low incidence of oral cancer in the United States. There is also no new evidence for the harms of screening. As a result, the USPSTF could not determine the balance between benefits and harms of screening for oral cancer.”

The current USPSTF (2004) recommendation statement regarding oral cancer is as follows:

- Direct inspection and palpation of the oral cavity is the most commonly recommended method of screening for oral cancer, although there are little data on the sensitivity and specificity of this method. Screening techniques other than inspection and palpation are being evaluated but are still experimental.
Tobacco use in all forms is the biggest risk factor for oral cancer. Alcohol abuse combined with tobacco use increases risk.

Clinicians should be alert to the possibility of oral cancer when treating patients who use tobacco or alcohol.

Patients should be encouraged to not use tobacco and to limit alcohol use in order to decrease their risk for oral cancer as well as heart disease, stroke, lung cancer, and cirrhosis.

More recently, the American Dental Association Council on Scientific Affairs, with support from the Centers for Disease Control and Prevention, convened a panel to address the benefits and limitations of oral cancer screening and the use of adjunctive screening aids to visualize and detect malignant and potentially malignant oral lesions (Rethman et al., 2010, pg. 514). The Council’s key conclusions are:

1) While stage of cancer at diagnosis has an impact on treatment decisions and resultant health outcomes, community-based screening by means of visual and tactile examination in the general adult population intended to detect early and advanced oral cancers may not alter disease-specific mortality.

2) Community-based screening by means of visual and tactile examination may decrease oral cancer–specific mortality among people who use tobacco, alcohol or both.

3) Screening by means of visual and tactile examination may result in detection of oral cancers at early stages of development (Stages I and II).

4) In asymptomatic patients seeking dental care, there is insufficient evidence to determine whether screening by means of visual and tactile examination to detect potentially malignant and malignant lesions alters disease-specific mortality.
5) There is insufficient evidence that commercial devices based on autofluorescence or tissue reflectance enhance visual detection of potentially malignant lesions beyond that achieved through a conventional visual and tactile examination.

The authors note that it is important to remember that a conclusion of "insufficient evidence" does not necessarily mean that the intervention is or is not effective, but means that the panel did not find sufficient evidence to support a recommendation for screening (Rethman et al., 2010, pg. 514). Differing recommendations regarding the need for and frequency of oral cancer screening examinations, along with the absence of a recommendation to screen asymptomatic patients for oral cancer by both the USPSTF and the American Dental Association Council on Scientific Affairs, may result in some dentists not screening all of their patients for oral cancer. This in turn may result in oral cancers being detected at more advanced stages. It may also result in patients not asking their dentist or healthcare provider about the need for an oral cancer examination (Macek et al., 2003).
**Section 2.6.3: The Public’s Knowledge of Oral Cancer**

The third reason that oral cancer is diagnosed at advanced stages is a lack of knowledge among the public of the risk factors for and signs and symptoms of oral cancer. The public also lacks knowledge that an oral cancer exam exists, and therefore they do not even know to ask for one (Horowitz et al., 1998). In the past 20 years, studies conducted at both the national and state levels have investigated the public’s knowledge of oral cancer. The annual National Health Interview Survey (NHIS) first included questions about oral cancer in 1990 (Dental, Oral, and Craniofacial Data Resource Center, n.d.). Questions assessed knowledge of risk factors for and signs and symptoms of oral cancer, as well as oral cancer exams. Follow-on studies conducted in states such as Maryland included questions about oral cancer similar to those on the NHIS, which allows for comparison of state and national data.

In the first study of the public’s knowledge of oral cancer, Horowitz and colleagues (1995) analyzed the data from the 1990 NHIS. They found that only 25 percent of adults surveyed correctly identified one early sign of oral cancer, while 44 percent responded that they did not know one early sign of oral cancer. Sixty-seven percent of respondents knew that tobacco use was a risk factor for oral cancer, but only 13 percent knew that alcohol use was associated with an increased risk for oral cancer. Respondents were also misinformed about risk factors for oral cancer, incorrectly believing that hot spicy foods or frequently biting the cheek or lip causes cancer. The authors concluded that the public was not well informed about oral cancer.

As part of an overall needs assessment for use in developing a state model of oral cancer education, prevention and early detection, Horowitz and colleagues (1998)
investigated Maryland adults’ knowledge of oral cancer. Similar to the NHIS, they assessed knowledge of oral cancer risk factors, signs and symptoms, and factors associated with having an oral cancer exam. Their results were similar to those of the 1990 NHIS study. Eighty-five percent of those surveyed said they had heard of oral cancer. However, only 23 percent could correctly indentify one early sign of oral cancer, and 39 percent replied that they did not know of an early sign of oral cancer. Individuals that were more likely to know one early sign of oral cancer were 40 to 64 years of age and had 12 years of education. Individuals who used smokeless tobacco were 4.6 times more likely to know one sign of oral cancer than nonusers. Individuals with the highest level of knowledge of oral cancer risk factors were females, with some college education, and a belief that personal behaviors cause more cancers.

Only 21 percent of respondents had ever heard of an examination for oral cancer. However, when the oral cancer examination was described to these respondents, 28 percent said they had heard of an oral cancer examination. Similarly, other studies have shown an increase in the number of respondents that say they have ever had an oral cancer examination once it is described to them. This may indicate that dentists are providing oral cancer examinations without telling their patients that they are doing so (Horowitz et al., 2001; Macek et al., 2003). Those more likely to have ever had an oral cancer exam were 40-64 years of age, white, having 12 years of education or more, and a higher level of knowledge about oral cancer risk factors.

These initial studies, as well as more recent studies, indicate that the public is not appropriately aware of the risk factors for oral cancer, the existence of examinations, and the importance of early detection (Stahl et al., 2004). Without accurate knowledge about
oral cancer, people cannot make informed decisions about their health (Horowitz et al., 1995). Many of the risk factors for oral cancer, such as tobacco and alcohol use, are behaviors that can be modified. Therefore the dissemination of information about oral cancer through health education and health promotion efforts may lead to a reduction of risk factors associated with the disease, as well as early detection. Interventions should be directed at individuals that are less educated, young adults, the elderly and tobacco and alcohol users (Horowitz et al., 1998). Dentists and family physicians are positioned to lead the effort to raise awareness about oral cancer because they see their patients relatively frequently. Therefore, they should ask all patients about their high-risk behaviors, educate patients about oral cancer prevention, and provide oral cancer examinations on a regular basis (Horowitz et al., 1998).
Section 2.6.4: Health Literacy

Definition

One definition of health literacy is “the ability to access, understand, appraise and communicate information to engage with the demands of health contexts to promote health” (Rootman et al., 2005). Health literacy encompasses a number of skills, including reading, writing, numeracy, listening, oral communication, computer literacy, media literacy, and navigating the health care system (Schwartzberg et al., 2005; pg 3-14). As such, it is a complex interaction between social and individual factors including: communication skills of consumers and providers; consumers and providers knowledge of health topics; culture and societal impact; demands of the healthcare system; and demands of the situation or context of the encounter (IOM, 2004; pg 3-16). The Institute of Medicine (IOM) estimates that 90 million people, 47 percent of U.S. adults, have difficulty understanding and acting upon health information (IOM, 2004; pg 1-3).

Individuals and Health Literacy

The 2003 National Assessment of Adult Literacy (NAAL) assessed the English literacy and health literacy of adults in the United States. Approximately 43 percent of adults function at a basic or below basic level of health literacy (Kurtner et al, 2006). Of concern is the mismatch between these individuals’ literacy skills and the demands and assumptions of the increasingly complex healthcare system (Rudd and Keller, 2009; Horowitz and Kleinman, 2008). This mismatch may affect their ability to take action for health promotion and protection, for disease prevention and chronic disease management, and for access and follow-up to care (Rudd, 2003; Horowitz and Kleinman, 2008).
Research indicates that adults with limited health literacy have less knowledge of disease management and health promoting behaviors, report poorer health status, and are less likely to use preventive services (IOM, 2004; pg 83). Limited health literacy is greater in older adults, those with limited education, minorities, the poor, and those with limited English proficiency (Kurtner et al, 2006). For example, adults with less than 12 years of education were 2.5 times less likely than those with 13 or more years of schooling to ever have had an oral cancer examination (U.S. Department of Health and Human Services, n.d.). Since a comprehensive examination is the primary means to detect oral cancer, these adults with less education are more likely to develop oral cancers that are detected at advanced clinical stages. Limited health literacy contributes to increased consumer, health provider and healthcare system costs (IOM, 2004; pg 100-103); costs estimated at $106 to $238 billion annually (Vernon et al., 2007).

**Healthcare Providers**

Health literacy is typically defined and discussed in terms of an individual's ability to read, understand, and use healthcare information to make decisions and follow instructions for treatment (IOM, 2004, pgs 3-16). However, healthcare providers also play a pivotal role in health literacy. Clear health communication is increasingly recognized as essential for patient safety, but communication problems among health care providers, patients, and families are common and a leading root cause of adverse outcomes (The Joint Commission, 2007). Much of the scientific literature related to healthcare providers focuses on provider communication skills and how to assess patients’ health literacy in order to communicate more effectively (Rudd et al., 2003;
Castro et al., 2007; Schwartzberg et al., 2007; Apter et al., 2008; Horowitz and Kleinman, 2008). A key aspect of clear communications is *plain language*. Plain language is patient-centered communication that the patient is able to understand the first time they read it or hear it, and as such it is a critical component of efforts to reduce the impact of low health literacy (Plainlanguage.gov, n.d.). To address issues associated with poor health literacy and help clinicians better communicate with patients and families, a number of best practices have been recommended by the American Medical Association, American College of Physicians Foundation, and the Joint Commission (The Joint Commission, 2007).

Provider knowledge is also a critical aspect of health literacy (Horowitz et al. 2000; Yellowitz et al, 2000). Providers must keep current with the latest scientific research and incorporate this knowledge into their practice in a timely manner for prevention, diagnosis, risk assessment and treatment of diseases (U.S. Department of Health & Human Services, n.d.). If they do not have the knowledge and skills to properly screen for and treat a health condition, they cannot provide accurate information and evidence-based care to their patients, which can result in poorer patient health outcomes (Horowitz et al., 2000; Yellowitz et al., 2000). For example, if a dentist is not aware that HPV is a risk factor for oral cancer, they would probably not assess this risk factor when taking a medical history, would not counsel the patient about reducing risk for HPV, and may not look for lesions in the area of the oral cavity typically associated with HPV-associated lesions. Understanding existing deficiencies in provider knowledge and skills is essential for developing interventions to minimize the deficiencies.
**Oral Health Literacy**

Oral health literacy is defined as “the degree to which individuals have the capacity to obtain, process and understand basic oral health information and services needed to make appropriate health decisions” (U.S. Department of Health and Human Services, 2000). Oral health literacy, like health literacy, is a function of the individual patient’s skills, the provider’s knowledge, skills and ability to communicate effectively, and the demands placed on patients by the healthcare system (IOM, 2004; pg 3-16; Jones et al., 2007). As with health literacy, effective communication is essential to delivery of quality care and it can contribute to successful oral health outcomes (Horowitz and Kleinman, 2008).

Low literacy and low health literacy present several barriers that must be overcome to achieve optimal oral healthcare. The main barriers, described in the report *The Invisible Barrier: Literacy and Its Relationship with Oral Health*, are:

1) many health-care providers are not trained to assess and address the literacy needs of their patients, so they present information without making sure the patient understands what has been communicated; 2) many healthcare providers use readily available materials that are difficult to understand; 3) patients are reluctant to admit they do not understand something a healthcare provider says or are reluctant to ask questions for more information; and 4) many low literacy patients either do not perceive that they have a problem or 5) they recognize they have a problem and work to conceal it due to shame or embarrassment (U.S. Department of Health and Human Services, 2005). To overcome these barriers, dental professionals must become more knowledgeable about literacy, work to assess the abilities of their patients, and learn to use plain-language approaches.
when communicating health information to their with patients (Horowitz and Kleinman, 2008). Additional research should be conducted to understand the prevalence of oral health literacy and how it might be addressed in dental practice settings.
Chapter 3: Methods

Section 3.1: Background Information

This study is a collaboration between the Maryland State Dental Association and the Herschel S. Horowitz Center for Health Literacy at the University of Maryland, School of Public Health. The Maryland State Dental Association provided a list of randomly selected dentists at no cost. The survey cover letter was printed on the Association’s letterhead and signed by their president. This study was funded by a grant from the Friedman Family Dental Research Project.

This research project is based on a 1995 survey of Maryland dentists. The earlier study was part of an overall needs assessment used to develop a state model of oral cancer education, prevention and early detection. Dentists, dental hygienists, physicians, nurses, nurse practitioners, and the public were surveyed as part of the needs assessment. Researchers at the National Institute of Dental and Craniofacial Research (NIDCR) conducted the initial survey of dentists that serves as a baseline for Maryland (Canto et al., 2001; Horowitz et al., 2000b). As a result of the previous study, several interventions were developed, including Continuing Education (CE) courses that provided hands on training of dentists throughout Maryland on how to perform oral cancer screening examinations (Canto et al., 2001; Horowitz et al., 2000b; Maryland Department of Health & Mental Hygiene, 2003).
Section 3.2: Survey Instrument

This study uses a 39-item questionnaire to assess dentist’s knowledge, opinions and practices concerning oral cancer. This instrument, *2009 Maryland Survey of Dentists: Oral Cancer*, is based on the National Oral Cancer Survey of Dentists (NOCSD). The NOCSD was developed, pilot tested and revised by NIDCR scientists, Dr. Alice Horowitz and colleagues, in 1995 (Horowitz et al., 2000). The NOCSD has been widely used in many studies in the U.S. and other countries since the initial study was conducted, yielding similar results (Clovis et al., 2002; Cruz et al., 2002; Patton et al., 2005; LeHew et al., 2007; Applebaum et al., 2009).

The *2009 Maryland Survey of Dentists: Oral Cancer* instrument was developed from the NOCSD instrument. Our survey instrument was modified minimally for layout and readability. It contains questions about two new areas of interest: HPV as a risk factor for oral cancer and the use of adjunctive procedures in diagnosing oral cancer. Because of the increasing evidence that HPV plays a role in the etiology of some oral cancers, we wanted to assess if dentists were aware of HPV as a risk factor for oral cancer and if they inquire about HPV when taking a medical history. The survey contains questions about adjunctive procedures used to detect and diagnose oral cancers because there are a large number of these devices available on the market. While the USPSTF and the American Dental Association Council on Scientific Affairs do not feel that the evidence is strong enough to support a recommendation for the use of these procedures in detecting and diagnosing oral cancers, there is some evidence in the scientific literature that these procedures are effective (Patton et al., 2008). Thus, we wanted to know if dentists were aware of these adjunctive procedures and if they used
them. Experts reviewed the new questions and we modified the questions based on their feedback.
Section 3.3: Description of the Study Population

The study population consisted of general practice dentists practicing in Maryland on September 1, 2009. Dentists not currently in clinical practice and dental specialists, such as oral surgeons, orthodontists and pedodontists, were excluded from the study.

Of the 463 dentists in the sample, 76 percent were men and 24 percent were women. Sixty-two percent were owners of a solo practice, 36 percent practiced in partnerships, and one percent practiced in community health centers. Thirty-four percent of the dentists graduated from dental school between 1970 and 1979, 35 percent graduated between 1980 and 1989, 15 percent graduated between 1990 and 1999, and 14 percent graduated between 2000 and 2009. Eighty-six percent of respondents were white, eight percent were Asian/Pacific Islander, three percent were black, and less than one percent were Hispanic. Twenty nine percent of respondents reported having taken an Oral Cancer Continuing Education (CE) Course in the past 12 months and 54 percent reported doing so in the past two to five years. Fifteen percent indicated it had been more than five years since they had taken an oral cancer CE course and less than one percent reported having never taken a course. See Table 3.3.1 – Selected characteristics of general practice dentists.
Table 3.3.1 – Selected characteristics of general practice dentists.

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<tr>
<th>Background Characteristics</th>
<th>N</th>
<th>Percentage*</th>
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<tr>
<td>Male</td>
<td>349</td>
<td>76</td>
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<tr>
<td>Female</td>
<td>107</td>
<td>24</td>
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<td><strong>Time of Graduation</strong></td>
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<td></td>
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<tr>
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<td>2</td>
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<tr>
<td>1970 to 1979</td>
<td>152</td>
<td>34</td>
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<tr>
<td>1980 to 1989</td>
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<td>35</td>
</tr>
<tr>
<td>1990 to 1999</td>
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<td>15</td>
</tr>
<tr>
<td>2000 to 2009</td>
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<td>14</td>
</tr>
<tr>
<td><strong>Type of Practice</strong></td>
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</tr>
<tr>
<td>Solo Practice</td>
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<tr>
<td>Group Private Practice</td>
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</tr>
<tr>
<td>Community Health Center</td>
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<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td><strong>Interval Since Last Oral Cancer Continuing Education Course</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within the Past 12 Months</td>
<td>102</td>
<td>29</td>
</tr>
<tr>
<td>Two to Five Years</td>
<td>190</td>
<td>54</td>
</tr>
<tr>
<td>Five or More Years</td>
<td>54</td>
<td>15</td>
</tr>
<tr>
<td>Never Taken a Course</td>
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<td>Asian/Pacific Islander</td>
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<td>.5</td>
</tr>
<tr>
<td>Other</td>
<td>9</td>
<td>2</td>
</tr>
</tbody>
</table>

*Some groups of percentages do not equal 100 due to rounding.*
Section 3.4: Description of the Sampling Procedure

The University of Maryland, College Park Institutional Review Board approved the Initial Application for Research Involving Human Subjects on September 2, 2009 without requiring any changes to the application. See Appendix A: IRB Application for a copy of the application. Measures to protect subject confidentiality are described in this document.

There were 1,169 dentists in the sample population (n). Because non-responses (including refusals) were expected, we sampled 60 percent more than the needed sample size. The sample size was determined using the following parameters:

- The sampling frame (N) was the total number of general practice dentists in Maryland on September 1, 2009. N = 2,500.
- Expected response rate = 40 percent
- Error rate = 3 percent
- Confidence Interval of 95 percent
- \( P\)-value = .05

The initial file from the MSDA contained 1,169 records of study subjects. Twelve duplicate records were deleted from the file, resulting in a sample population of 1,157. A copy of the original file was used as a master list to record all returned surveys. We assigned a unique numeric code to each subject. The code was used to track whether study subjects returned the survey. It was also used to generate a list of non-respondents for subsequent mailings. For each of the three mailings, the subject’s code was printed.
on the materials they received – the cover letter, survey, and envelope containing these two items.

The initial mailing was sent out on December 16, 2009. All subjects in the sample population (n = 1,157) received an envelope containing the survey instrument and a cover letter explaining the purpose of the survey. The cover letter was on MSDA stationary and signed by the current president. Subjects were requested to return the survey within two weeks. The survey was designed to be completed in approximately fifteen minutes. No incentives were provided to subjects. See Appendices C and D (Appendix C: Survey; Appendix D: Recruitment Letter #1).

The second mailing was sent to all non-respondents (n = 859) on January 12, 2010, four weeks after the initial mailing. As with the first mailing, each subject received an envelope containing the survey instrument and a cover letter. Subjects were requested to return the survey within two weeks. The project plan specified that the second mailing be to be sent out three weeks after the first mailing. However, the mailing was delayed due to the holidays and printer scheduling. See Appendices C and E (Appendix C: Survey; Appendix E: Recruitment Letter #2).

Within one week of the second mailing, we discovered problems with our survey process. When attempting to record surveys as “returned” on the master list, we found that some codes were already marked as returned, indicating that we had duplicate records. We confirmed the existence of duplicates by locating the first survey returned with that same code. We compared the lists used for the first and second mailings. We found that the unique code associated with each subject was not the same on the two lists. Printer staff inadvertently changed the codes on the second mailing list when they
modified the list to remove duplicates. They found and removed eleven duplicate records, resulting in the codes shifting in eleven places in the file. We spent considerable time trying to map the records from the first and second mailing lists so we could create a valid list of non-respondents for the third mailing. We also hoped that a correct mapping of the two lists would allow us to use the responses from the second mailing in the results analysis.

However, during the two weeks that it took to identify and confirm the problem with duplicate records, we also discovered that the surveys sent out in the second mailing were incomplete. The survey is eight pages and the four inside pages were missing. During printing and assembly of the survey, the inside pages of the survey were inadvertently left out and quality control did not catch this error. After consulting with experts, we decided we could not go back to subjects that returned the “incomplete survey” from the second mailing and ask them to complete the additional pages of the survey. Thus, responses from the second mailing (n = 222) could not be used in the results analysis.

To adjust for these issues, we changed the format of the third mailing. Instead of sending only a postcard reminder as planned, we sent a complete mailing (envelope containing the survey and cover letter) to all subjects that received the second mailing (n = 859). The list used for the third mailing had the same subjects as the second mailing list, but the codes were corrected and an additional code (“C”) was added to the survey, cover letter and envelope to distinguish it from the first two mailings. The cover letter asked subjects to use the enclosed survey and not a previous version if they had not yet returned the survey. Subjects that completed the second survey (n = 222) were included
in the third mailing in hopes that they would also fill out the full version of the survey. The third mailing was sent out five weeks after the second mailing, on February 16, 2010. See Appendices C and F (Appendix C: Survey; Appendix F: Recruitment Letter #3). Survey responses were accepted until April 16, 2010, two months after the third recruitment letter was mailed.

We received 619 completed surveys, for a response rate of 53.6 percent. This response rate is similar to previously published results using this instrument (Yellowitz et al., 1998; Horowitz et al., 2000; Yellowitz et al., 2000). We received 222 surveys from the second mailing in which incomplete surveys were mailed out. These surveys were deemed invalid and therefore were not be used in the analysis. Sixty-six subjects completed surveys from both the second and third mailings, reducing the number of invalid surveys from 222 to 156. Deleting the 156 invalid surveys from the total number of surveys returned (619), resulted in 463 usable surveys, for an effective response rate of 40.1 percent.

After a survey was recorded as returned on the master list, the survey data was entered into the worksheet that was created using SPSS v17 software. We used two-person teams to record the data in the following manner: one individual read the survey responses and a second individual entered the responses into the worksheet. The person reading the responses also verified that the data entry person correctly keyed the data. After data from all surveys was recorded, 20 percent of surveys were double checked for accuracy. Only three data entry errors were found during the verification process, and they were corrected. This sampling procedure is based on procedures used in previous studies at the University of Maryland School of Public Health.
The initial project plan specified that we would call ten percent of non-respondents to assess whether their background characteristics were similar to those of respondents. As a result of project delays and problems with the survey mailings, we decided not to call non-respondents. Therefore, we do not have information on the background characteristics of the non-respondents, preventing us from comparing respondents to non-respondents.
Section 3.5: Data Analysis

Section 3.5.1: Measures – Knowledge, Practices and Opinions Indices

Dentists’ knowledge, practices and opinions relating to oral cancer were categorized into four indices for analysis, which are described below.

Knowledge

The survey used ten questions to assess knowledge of oral cancer diagnostic procedures. Each correct answer received a score of “1” point. We summed the ten items to create an index called knowledge of oral cancer diagnostic procedures. Index values ranged from one to ten. Based on the number of correct answers, dentists were classified into one of three approximately equal categories of knowledge of oral cancer diagnostic procedures: low (1-5 items), medium (6-7 items) and high (8-10 items).

The survey used fifteen questions to assess knowledge of oral cancer risk factors. Eight questions asked about real risk factors, those supported by scientific evidence. The eight real-risk factors are: tobacco, alcohol, prior oral cancer lesion, age, lip cancer related to sun exposure, most oral cancers are diagnosed at age 60 and older, HPV, and low consumption of fruits and vegetables. The other seven questions asked about non-real risk factors, i.e., risk factors that are not supported by research and are common myths among the public and the dental profession. The non-real risk factors are: use of spicy food, obesity, use of hot foods and beverages, poor fitting dentures, familial clustering of cancer, poor oral hygiene, and family history of cancer. Each correct answer received a score of “1” point. We summed the fifteen items to create an index.
called *knowledge of oral cancer risk factors*. Index values ranged from one to fifteen. Based on the number of correct answers, dentists were classified into one of three approximately equal categories of knowledge of oral cancer risk factors: low (1-8 items), medium (9-10 items) and high (11-15 items).

*Practices*

The survey used ten questions to measure the comprehensiveness of oral cancer risk factors probed while taking medical histories. Each correct answer received a score of “1” point. We summed these ten items to create an index called *comprehensiveness of medical history*. Index values ranged from one to ten. Based on the number of correct answers, dentists were classified into one of three approximately equal categories measuring comprehensiveness of medical histories taken: low (1-5 items), medium (6-7 items) and high (8-10 items).

The survey used four questions about the provision of oral cancer examinations to measure compliance with provision of recommended screening examinations. Dentists received a score of “1” point for each different examination they reported providing to 100 percent of their patients. These four items were combined to create an index called *provision of oral cancer examinations*. Index values ranged from zero to four. Based on the number of examinations provided, dentists were classified into one of three approximately equal categories measuring compliance with recommended screening examinations: low (0-2 exams), medium (3 exams) and high (4 exams).
Opinions

The survey contained twenty-four Likert-style questions about critical aspects of oral cancer screening practices and training. These questions measured dentists’ opinions of how current their training was, their self-efficacy in providing oral cancer screening exams, and their self-efficacy in providing tobacco and alcohol cessation counseling. We also asked them to rate their oral cancer training in dental school. Opinions were recorded by selecting from one of five response categories: “Strongly Agree”, “Agree”, “Disagree”, “Strongly Disagree” and “Don’t Know”. Opinions related to how current their knowledge is, adequacy of training, and comfort in performing oral cancer examinations were selected for reporting purposes. In addition, we looked at potential associations among dentists’ opinions of how current their oral cancer knowledge is and levels of knowledge of risk factors and diagnostic procedures.
Section 3.5.2: Validity and Reliability

Validity. Content validity of the 2009 Maryland Survey of Dentists: Oral Cancer instrument was determined by submitting a draft instrument to known experts in the field of oral cancer. The instrument was revised based on their feedback.

Reliability. Reliability has been established over the years, with similar results obtained in the many studies that have used the NOCSD (Clovis et al., 2002; Cruz et al., 2002; Patton et al., 2005; LeHew et al., 2007; Applebaum et al., 2009). Many of our findings are similar to those of the Maryland pilot study and the 1995 nationwide study.
Section 3.5.3: Analysis Plan

The survey data was analyzed as follows:

Analyze the distribution. For each question, we looked at the frequency distribution of the responses.

Response Coding. For each question, we coded the data so it could be summarized. The types of recoding included the following:

- For a multiple-choice question with one correct answer, but five possible responses, we coded the correct answer as “1” point, and the other 4 responses as “0”. This allowed us to combine the answers from several related questions to create an index, such as the knowledge of oral cancer risk factors index.

- For questions with continuous data, the responses were grouped into categories. For example, responses to the question asking for year of graduation from dental school were grouped into the following categories: before 1970, 1970-1979, 1980-1989, 1990-1999, and 2000-2009.

- For questions using a five-point Likert item, the response categories of “Strongly Agree”, “Agree”, “Don’t Know”, “Disagree” and “Strongly Disagree” were recoded with the following values “1”, “2”, “3”, “4” and “5”, respectively. Recoding these responses supported the analysis that looked at the relationships between opinions of currency of training and the knowledge indices.

- For fill-in-the-blank questions, values were recorded as entered.
**Missing Data.** For each question, we looked at the frequency distribution to evaluate missing data. Missing data is defined as a question with no response or the “Don’t Know/Not Sure” response is selected. Missing data was evaluated to determine if the lack of data should be considered non-random. The results of this analysis are:

- 30 percent of the total survey questions had “Missing values” of less than one percent;
- 39 percent of the total survey questions had “Missing values” of 1 to 3 percent;
- 19 percent of the total survey questions had “Missing values” of 4 to 5 percent;
- 9 percent of the total survey questions had “Missing values” of 6 to 8 percent;
- Question 20b was missing 10 percent of the responses. The question asks respondents to enter two items. Most likely they misread the question. This question was intended to be a component of the *knowledge of oral cancer diagnostic procedures index* and it was included in the index.
- Question 29 was missing 11 percent of the responses. The question asks respondents to select two items. While some may have misread the question, others may not have had a second choice for preferred educational approaches. This question was not part of an index.
- Question 15b was missing 74 percent of the responses. The question asks respondents to check two items. Most likely they misread the question. This question was intended to be a component of the *knowledge of oral cancer diagnostic procedures index*. Due to the high number of missing values, it was not included in the index because it skewed the data and index categories.
**Statistical tests.**

Descriptive statistics (frequency distribution and mean) were used to describe the study population. The chi-square test was used to determine if there was a relationship between oral cancer knowledge and opinions about currency of knowledge. The chi-square test was selected to examine the relationship between two categorical variables (independent and dependent variables). The dependent variables are the knowledge indices: *knowledge of risk factors, knowledge of diagnostic procedures*, and the *combined knowledge index*. The independent variable is dentist’s opinions of how current their knowledge is. There are three levels of opinions – Strongly Agree/Agree, Don’t Know, and Disagree/Strongly Disagree. The *p*-value from chi square test tells us whether the association is statistically significant. Furthermore, we wanted to know the distributions of knowledge scores at each level of opinion. By conducting the chi-square test, we were able to look at the percentage of score distribution at each opinion level. A *p* < .05 level of significance was used in evaluating all statistical results. Results from this test should be interpreted with caution because three of the cells contain values lower than the recommended frequency of 5. These cells are: type of practice-community health center, type of practice-other, and interval since last oral cancer CE course-never taken a course. All statistical analyses were conducted using SAS version 9.2 (SAS Institute Inc., Cary, NC). Results of this analysis are shown in Section 4.3.
Section 3.6: Project Plan

See Appendix B.
Chapter 4: Results

Table 3.3.1 (Selected characteristics of general practice dentists) is placed in this section for easy reference when reviewing results.

<table>
<thead>
<tr>
<th>SELECTED CHARACTERISTICS OF GENERAL PRACTICE DENTISTS (N= 463)</th>
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<tbody>
<tr>
<td><strong>Background Characteristics</strong></td>
</tr>
<tr>
<td>Sex</td>
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<td>Male</td>
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<tr>
<td>Female</td>
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<tr>
<td><strong>Time of Graduation</strong></td>
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<td>Before 1970 (1968 &amp; 1969)</td>
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<td>1990 to 1999</td>
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<tr>
<td>2000 to 2009</td>
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<td><strong>Type of Practice</strong></td>
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<td><strong>Interval Since Last Oral Cancer Continuing Education Course</strong></td>
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<tr>
<td>Within the Past 12 Months</td>
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<td>Two to Five Years</td>
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<tr>
<td>Hispanic</td>
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<td>Other</td>
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*Some groups of percentages do not equal 100 due to rounding.
Section 4.1: Knowledge – Oral Cancer Risk Factors

We assessed dentists’ responses to 15 questions relating to knowledge of oral cancer risk factors. Eight questions pertain to real oral cancer risk factors, i.e., risk factors that are supported by scientific research. More than 95 percent of respondents knew that use of tobacco products, a prior oral cancer lesion and use of alcohol are risk factors for oral cancer. Knowledge of three risk factors, HPV, older age and lip cancer related to sun exposure, was moderate (response rates of 88 percent, 71 percent and 64 percent, respectively). While only one third of respondents knew that low consumption of fruits and vegetables is a risk factor, and fewer knew that the majority of oral cancers are diagnosed in people 60 years of age and older (29 percent). On average, dentists knew six of the eight real risk factors for oral cancer. See Figure 4.1.1 Knowledge of real risk factors for oral cancer.

![Graph: Real Risk Factors]

**REAL Risk Factors**
- Use of Tobacco: 99%
- Prior Oral Cancer Lesion: 98%
- Use of Alcohol: 96%
- HPV: 88%
- Older Age: 71%
- Lip Cancer Related to Sun Exposure: 64%
- Low Consumption of Fruits and Vegetables: 33%
- Majority of Oral Cancers Diagnosed at 60 Years of Age and Older: 29%

**Percentage of Dentists Correctly Identifying Real Risk Factors**

Figure 4.1.1 Knowledge of real risk factors for oral cancer.
Seven survey questions pertain to non-real risk factors, i.e., risk factors that are not supported by research and are common myths among the public and the dental profession. Seventy-six percent of dentists knew that consuming hot beverages and foods is not a risk factor for oral cancer. Sixty-nine percent knew that obesity and use of spicy foods are non-real risk factors. Approximately fifty percent correctly identified familial clustering and poor oral hygiene as non-real risk factors. Thirty-nine percent knew that poor-fitting dentures is not a risk factor, while only six percent knew that family history of cancer is a not a risk factor. On average, dentists knew four of the seven non-real risk factors. See Figure 4.1.2 Knowledge of oral cancer non-real risk factors.

![Figure 4.1.2 Knowledge of non-real risk factors for oral cancer.](image-url)
These fifteen questions about risk factors were combined to create an index (knowledge of oral cancer risk factors) that summarizes dentists’ knowledge of oral cancer risk factors. The number of correct answers ranged from 2 to 15. On average, dentists correctly identified nine of the fifteen risk factors. Figure 4.1.3 shows the number of questions answered correctly and the percentage of dentists with each score. Based on the number of correct answers, dentists were classified into one of three approximately equal categories: low (1-8 correct answers), medium (9-10 correct answers) and high (11-15 correct answers). These categories are discussed in Section 4.3. Background Characteristics and Knowledge of Oral Cancer.

Figure 4.1.3 Frequency distribution for Index: Knowledge of oral cancer risk factors.
Section 4.2: Knowledge – Oral Cancer Diagnostic Procedures

We assessed dentists’ responses to 11 questions relating to knowledge of oral cancer diagnostic procedures. One question (#15) asks respondents to check two items. Only 26 percent of respondents checked two items. Most likely they misread the question. Due to the low response rate on the second part of this question, we eliminated it from the analysis and used ten questions to assess knowledge of oral cancer diagnostic procedures instead of eleven.

More than 80 percent of dentists knew that squamous cell carcinoma is the most common form of oral cancer, the patient is asymptomatic in early stages of oral cancer, early oral cancer lesions usually appear as small, painless red areas, and the steps for examining the tongue for oral cancer. Over seventy percent knew that a lymph node most characteristic of oral cancer metastasis is hard, painless and mobile or fixed when palpated (77 percent), and that the area of the tongue most likely to develop oral cancer is the ventral-lateral border (72 percent). Fifty-nine percent knew that excluding the lip, the tongue is the most common site of oral cancer. Less than half of respondents (42 percent) knew the two lesions most commonly associated with oral cancer (erythroplakia and leukoplakia), and only 28 percent knew that oral cancer lesions are most often diagnosed in later stages. See Figure 4.2.1 Knowledge of oral cancer diagnostic procedures.
Figure 4.2.1 Knowledge of oral cancer diagnostic procedures.

Oral Cancer Diagnostic Procedures

- Patient sticks out tongue; posterior dorsum is examined; tongue pulled out, checked on both sides and underside: 85%
- Squamous cell carcinoma is the most common form of oral cancer: 83%
- Early oral cancer lesions usually appear as small, painless red areas: 81%
- The patient is asymptomatic in early stages of oral cancer: 80%
- When palpated, a lymph node most characteristic of oral cancer is hard, painless, fixed or mobile: 77%
- Area of the tongue most likely to develop oral cancer - ventral-lateral border: 72%
- Excluding the lip, the tongue is the most common site of oral cancer: 59%
- Erythroplakia and Leukoplakia are the two lesions most likely to be associated with oral cancer: 42%
- Oral cancer lesions are most often diagnosed at advanced stages: 28%

Percentage of Dentists Responding Correctly
These ten questions about diagnostic procedures were combined to create an index (*knowledge of oral cancer diagnostic procedures*) that summarizes knowledge of oral cancer diagnostic procedures. The number of correct answers ranged from 1 to 10. On average, dentists correctly identified seven of the ten oral cancer diagnostic procedures. Figure 4.2.2 shows the number of questions answered correctly and the percentage of dentists with each score. Based on the number of correct answers, dentists were classified into one of three categories: low (1-5 correct answers), medium (6-7 correct answers) and high (8-10 correct answers). These categories are discussed in Section 4.3 Background Characteristics and Knowledge of Oral Cancer.

![Figure 4.2.2 Frequency distribution for Index: Knowledge of Oral Cancer Diagnostic Procedures](image)

*Figure 4.2.2 Frequency distribution for Index: Knowledge of oral cancer diagnostic procedures.*
Section 4.3: Background Characteristics and Knowledge of Oral Cancer

Patterns of Knowledge

To investigate the relationships between dentists’ knowledge of oral cancer risk factors and diagnostic procedures, we cross-classified them by the three categories (low, medium and high) of the two oral cancer knowledge indices (risk factors and diagnostic procedures). Table 4.3.1 shows the percentage of all dentists by their joint distribution of these two characteristics. Our analysis focused on the likelihood of getting a high score on each index independently of the other, and in combination. Thirty-nine percent of dentists had consistent levels of knowledge on both indices: approximately 17 percent had a consistently high score; approximately 12 percent had a consistently medium score, and, approximately 10 percent had a consistently low score. For the sixty-one percent of dentists with inconsistent levels of knowledge, approximately 38 percent had better levels of knowledge of risk factors than diagnostic procedures, while approximately 40 percent had better levels of diagnostic procedures.
Table 4.3.1 Classification of general practice dentists by scores on diagnostic procedures and risk factors indices.

<table>
<thead>
<tr>
<th>Index: Knowledge of Oral Cancer Risk Factors</th>
<th>Index: Knowledge of Oral Cancer Diagnostic Procedures</th>
<th>All Dentists</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Low Score (1-5 items)</td>
<td>Medium Score (6-7 items)</td>
</tr>
<tr>
<td>Low Score (1-8 items)</td>
<td>37 (10.1%)</td>
<td>37 (10.1%)</td>
</tr>
<tr>
<td>Medium Score (9-10 items)</td>
<td>29 (7.9%)</td>
<td>43 (11.8%)</td>
</tr>
<tr>
<td>High Score (11-15 items)</td>
<td>31 (8.5%)</td>
<td>45 (12.3%)</td>
</tr>
<tr>
<td>All Dentists</td>
<td>97 (26.6%)</td>
<td>125 (34.2%)</td>
</tr>
</tbody>
</table>

Percentage of All Dentists
Levels of Knowledge and Opinions About Currency of Knowledge

We analyzed potential relationships among levels of knowledge of oral cancer risk factors, diagnostic procedures and the combination of the two knowledge indices and dentists’ opinions about the currency of their oral cancer knowledge. The combined knowledge index categorized responses to the 25 questions about oral cancer into three approximately equal categories: low (1-14 items), medium (15-18 items) and high (18-25 items).

Results of our analysis indicated that there was a statistically significant association between dentists’ opinions of the currency of their oral cancer knowledge and knowledge of oral cancer diagnostic procedures and the combined knowledge index. Dentists who strongly agreed or agreed that their knowledge is current were more likely to receive a high score on the knowledge of oral cancer diagnostic procedures index and the combined knowledge index. Additionally, dentists who strongly disagreed or disagreed that their knowledge about oral cancer is current were more likely to receive a low score on both of these indices. Our analysis did not indicate a statistically significant association between dentists’ opinions of the currency of their oral cancer knowledge and the knowledge of oral cancer risk factors index. See Tables 4.3.2, 4.3.3 and 4.3.4.
Table 4.3.2 Associations between opinion of knowledge currency and high scores on knowledge of oral cancer risk factors.

<table>
<thead>
<tr>
<th>Opinion of Knowledge Currency</th>
<th>Knowledge of Oral Cancer Risk Factors</th>
<th>Chi square test $p$-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Low Score (1-8 items)</td>
<td>Medium Score (9-10 items)</td>
</tr>
<tr>
<td>Strongly Agree and Agree</td>
<td>105 (31.6%)</td>
<td>100 (30.1%)</td>
</tr>
<tr>
<td>Don’t Know</td>
<td>6 (35.3%)</td>
<td>5 (29.4%)</td>
</tr>
<tr>
<td>Strongly Disagree and Disagree</td>
<td>23 (40.4%)</td>
<td>22 (38.6%)</td>
</tr>
</tbody>
</table>

$P$-value for the chi square test was .177, indicating that there was no statistically significant association between dentists’ opinions of the currency of their oral cancer knowledge and their levels of knowledge of oral cancer risk factors. For example, there were 31.6 percent dentists in the low score group, 30.1 percent dentists in the medium score group, and 38.3 percent dentists in the high score group who agreed (or strongly agreed) that their knowledge about oral cancer is current. Similar distributions were found for dentists in low score (40.4 percent), medium score (38.6 percent), and high score (21.1 percent) groups who disagreed (or strongly disagreed) that their knowledge about oral cancer is current.
Table 4.3.3 Associations between opinion of knowledge currency and high scores on knowledge of oral cancer diagnostic procedures.

<table>
<thead>
<tr>
<th>Opinion of Knowledge Currency</th>
<th>Knowledge of Oral Cancer Diagnostic Procedures</th>
<th>Chi square test</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Low Score (1-5 Items)</td>
<td>Medium Score (6-7 items)</td>
</tr>
<tr>
<td>Strongly Agree and Agree</td>
<td>81 (25.0%)</td>
<td>113 (34.9%)</td>
</tr>
<tr>
<td>Don’t Know</td>
<td>2 (14.3%)</td>
<td>6 (42.9%)</td>
</tr>
<tr>
<td>Strongly Disagree and Disagree</td>
<td>24 (45.3%)</td>
<td>19 (35.8%)</td>
</tr>
</tbody>
</table>

Results from the chi square test indicated that there was a statistically significant ($p=0.01$) association between dentists’ opinions of currency of their oral cancer knowledge and their levels of knowledge of oral cancer diagnostic procedures. For example, dentists who agreed (or strongly agreed) that their knowledge about oral cancer is current, were more likely to be in the high score group (40.1 percent) than in the medium score group (34.9 percent) or in the low score group (25 percent). Dentists who disagreed (or strongly disagreed) that their knowledge about oral cancer is current, were more likely to be in the low score group (45.3 percent) than in the medium score group (35.8 percent) or in the high score group (18.9 percent).
Table 4.3.4 Associations between opinion of knowledge currency and high scores on combined knowledge index.

<table>
<thead>
<tr>
<th>Opinion of Knowledge Currency</th>
<th>Combined Knowledge Index: Risk Factors and Diagnostic Procedures</th>
<th>Chi square test p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Low Score (1-14 Items)</td>
<td></td>
</tr>
<tr>
<td>Strongly Agree and Agree</td>
<td>71 (23.6%)</td>
<td></td>
</tr>
<tr>
<td>Don’t Know</td>
<td>2 (16.7%)</td>
<td>2 (16.7%)</td>
</tr>
<tr>
<td>Strongly Disagree and Disagree</td>
<td>24 (51.1%)</td>
<td>13 (27.7%)</td>
</tr>
<tr>
<td></td>
<td>114 (37.9%)</td>
<td>116 (38.5%)</td>
</tr>
</tbody>
</table>

Results from the chi square test indicated that there was a statistically significant ($p<.001$) association between dentists’ opinions of currency of their oral cancer knowledge and their levels of knowledge about oral cancer risk factors and oral cancer diagnostic procedures combined. For example, for dentists who disagreed (or strongly disagreed) that their knowledge about oral cancer is current, more were in the low score group (51.1 percent) than in the medium score group (27.7 percent) or in the high score group (21.3 percent).
Section 4.4: Practices – Screening Patients for Oral Cancer Risk Factors

We assessed dentists’ responses to ten questions relating to the comprehensiveness of oral cancer risk factors probed while taking medical histories. Ninety-nine percent of dentists ask patients about their history of cancer and 70 percent ask about family history of cancer. Regarding a patient’s tobacco use, 98 percent assess present tobacco use, 90 percent assess previous tobacco use, and 78 percent assess the type and amount of tobacco used. With regard to alcohol use, 76 percent ask about present alcohol use, 67 percent ask about past alcohol use, and 38 percent ask about the type and amount of alcohol used. Fifty percent ask about a patient’s history of HPV and 21 percent assess if the patient is a HPV vaccine recipient. See Figure 4.4.1 Percentage of dentists assessing oral cancer risk factors when taking a medical history.
Figure 4.4.1 Percentage of dentists assessing oral cancer risk factors when taking a medical history.

<table>
<thead>
<tr>
<th>Medical History: Risk Factors Probed</th>
<th>Percentage of Dentists Assessing Risk Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient's history of cancer</td>
<td>99</td>
</tr>
<tr>
<td>Patient’s present tobacco use</td>
<td>98</td>
</tr>
<tr>
<td>Patient's previous tobacco use</td>
<td>90</td>
</tr>
<tr>
<td>Type and amount of tobacco used</td>
<td>78</td>
</tr>
<tr>
<td>Patient's present alcohol use</td>
<td>76</td>
</tr>
<tr>
<td>Family history of cancer</td>
<td>70</td>
</tr>
<tr>
<td>Patient's past alcohol use</td>
<td>67</td>
</tr>
<tr>
<td>Patient's history of HPV</td>
<td>55</td>
</tr>
<tr>
<td>Type and amount of alcohol used</td>
<td>38</td>
</tr>
<tr>
<td>HPV vaccine recipient</td>
<td>21</td>
</tr>
</tbody>
</table>

Figure 4.4.2 shows the number of risk factors probed and the percentage of dentists with each score. Based on the number of correct answers, dentists were classified into one of three approximately equal categories: low (1-5 correct answers), medium (6-7 correct answers) and high (8-10 correct answers). These categories are discussed in Section 4.6 Background Characteristics and Oral Cancer Screening Practices.
Figure 4.4.2 Frequency distribution of risk factors probed when taking a medical history.
Section 4.5: Practices – Provision of Oral Cancer Examinations

We assessed dentists’ responses to four questions relating to the provision of oral cancer examinations to their patients. Eighty-five percent of dentists reported providing oral cancer examinations to 100 percent of their patients 40 years of age and older at both initial and recall visits. They provided oral cancer examinations at a slightly lower rate for 100 percent of their patients 18 to 39 years of age at both initial and recall visits (81 and 80 percent respectively). Eighty-eight percent of dentists provided oral cancer exams to their edentulous patients. However, only forty-three percent of dentists routinely palpated the lymph nodes of patients 18 years of age or older. See Figure 4.5.1.

Percentage of dentists performing recommended oral cancer screening practices for 100 percent of their patients.

Figure 4.5.1 Percentage of dentists performing recommended oral cancer screening practices for 100 percent of their patients.
These four questions were combined to create an index (provision of oral cancer examinations) that summarizes compliance with recommended oral cancer screening practices. The scores ranged from 0 to 4 depending on the number of different examinations that a dentist provides for 100 percent of their patients. On average, dentists performed three of the four recommended exams. Figure 4.5.2 shows the number of different examinations and the percentage of dentists with each score. Based on the number of examinations performed, dentists were classified into one of three approximately equal categories: low (0-2 exams), medium (3 exams) and high (4 exams). These categories are discussed in Section 4.6 Background Characteristics and Oral Cancer Screening Practices.

Figure 4.5.2 Frequency distribution for provision of recommended oral cancer examinations.
Section 4.6: Background Characteristics and Oral Cancer Screening Practices

Patterns of Screening Practices

To investigate the relationships between dentists’ comprehensiveness of medical history and provision of oral cancer examinations, we cross-classified them by the three categories (low, medium and high) of the two screening practices indices (comprehensiveness of medical history and provision of oral cancer examinations). Table 4.6.1 shows the percentage of all dentists by their joint distribution of these two characteristics. Our analysis focused on the likelihood of getting a high score on each index independently of the other, and in combination. Thirty-six percent of dentists had consistent levels of knowledge on both indices; approximately 19 percent had a consistently high score, approximately 12 percent had a consistently medium score, and approximately five percent had a consistently high score on both indices. For the 64 percent of dentists with inconsistent levels of knowledge, approximately 42 percent received a high score for screening patients for oral cancer risks when taking a medical history, while 38 percent received a high score for their provision of oral cancer examinations.
Table 4.6.1 Classification of general practice dentists by scores on provision of oral cancer examinations and comprehensiveness of medical history indices.

<table>
<thead>
<tr>
<th>Index: Provision of Oral Cancer Exams</th>
<th>Index: Comprehensiveness of Medical History</th>
<th>All Dentists</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Low Score (1-5 items)</td>
<td></td>
</tr>
<tr>
<td>Low Score (0-2 Exams)</td>
<td>19 (4.8%)</td>
<td>71 (17.9%)</td>
</tr>
<tr>
<td>Medium Score (3 Exams)</td>
<td>60 (15.1%)</td>
<td>175 (44.1%)</td>
</tr>
<tr>
<td>High Score (4 Exams)</td>
<td>31 (7.8%)</td>
<td>151 (38.0%)</td>
</tr>
<tr>
<td>All Dentists</td>
<td>110 (27.7%)</td>
<td>397 (100.0%)</td>
</tr>
</tbody>
</table>

Percentage of All Dentists

All Dentists 110 (27.7%) 121 (30.5%) 166 (41.8%) 397 (100.0%)
Section 4.7: Opinions – Knowledge, Practices and Training

We assessed dentists’ opinions regarding their oral cancer training in dental school, how current their oral cancer knowledge is, how comfortable they are performing oral cancer screening examinations, and if they agree with key aspects of the recommended screening practices.

We asked dentists to rate their undergraduate training in oral cancer as either “very good”, “good”, “poor” or “very poor”. Thirty-five percent rated their oral cancer education as “very good”, 48 percent rated it as “good” and 13 percent rated their training as poor. When asked if their dental school treated oral cancer examinations of patients similar to other procedures in terms of clinical requirements and credits received, 48 percent replied that their dental school’s treatment of oral cancer examinations was similar to other procedures. Thirty-nine percent said it was not treated similar to other procedures, and 13 percent said they were not sure or did not recall.

When asked if their oral cancer knowledge is current, seven percent strongly agreed and 74 percent agreed. Only 38 percent of respondents strongly agreed that they were adequately trained to examine patients for oral cancer and only 57 percent strongly agreed that most dentists are qualified to perform oral cancer examinations. When asked if most physicians are adequately trained to perform oral cancer examinations, less than 4 percent strongly agreed, 26 percent agreed, while 45 percent disagreed. Asked if dental hygienists were qualified to perform oral cancer examinations, 27 percent strongly agreed and 49 percent agreed. Lastly, when asked about the qualifications of nurse practitioners to perform oral cancer examinations, 9 percent strongly agreed, 37 percent disagreed and 35 percent disagreed.
With regard to palpating the lymph nodes in patient’s necks, 79 percent of dentists strongly agreed or agreed that they were adequately trained to do so, and 83 percent strongly agreed or agreed that they were comfortable performing this examination. Ninety-seven percent strongly agreed or agreed that oral cancer examinations should be provided annually for adults 40 years and older.

Sixty-five percent strongly disagreed or disagreed that they were adequately trained to provide tobacco cessation counseling to their patients, but 71 percent strongly agreed or agreed that dentists should be trained to provide this counseling. With regard to alcohol cessation counseling, 83 percent disagreed or strongly disagreed that they were adequately trained to provide this education, and 50 percent strongly agreed or agreed that dentists should be trained to provide this education. See Figure 4.7.1 Selected opinions of dentists for a detailed breakout of responses to selected opinion questions.

When asked about their interest in future oral cancer CE courses, 94 percent said they were interested in attending education courses on oral cancer. The four most popular approaches to CE courses were lectures (54 percent), clinical demonstrations (15 percent), study clubs (16 percent) and audiovisual slide or videotape series (15 percent).
Figure 4.7.1 Selected opinions of dentists.

<table>
<thead>
<tr>
<th>Opinion</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>My knowledge about oral cancer is current</td>
<td>7</td>
<td>74</td>
<td>14</td>
<td>0.5</td>
</tr>
<tr>
<td>I am adequately trained to examine patients for oral cancer</td>
<td>38</td>
<td>56</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Dentists are qualified to perform oral cancer examinations</td>
<td>57</td>
<td>42</td>
<td>0.5</td>
<td></td>
</tr>
<tr>
<td>I am adequately trained to palpate lymph nodes in patient’s necks</td>
<td>24</td>
<td>55</td>
<td>17</td>
<td>1</td>
</tr>
<tr>
<td>I am comfortable palpating lymph nodes in necks of patients</td>
<td>30</td>
<td>53</td>
<td>14</td>
<td>2</td>
</tr>
<tr>
<td>I am adequately trained to provide tobacco cessation education</td>
<td>5</td>
<td>27</td>
<td>56</td>
<td>9</td>
</tr>
<tr>
<td>Dentists should be trained to provide tobacco cessation education</td>
<td>16</td>
<td>55</td>
<td>21</td>
<td>3</td>
</tr>
<tr>
<td>I am adequately trained to provide alcohol cessation education</td>
<td>3</td>
<td>12</td>
<td>69</td>
<td>14</td>
</tr>
<tr>
<td>Dentists should be trained to provide alcohol cessation education</td>
<td>11</td>
<td>39</td>
<td>37</td>
<td>5</td>
</tr>
<tr>
<td>Oral cancer exams should be provided annually for adults 40 years and older</td>
<td>68</td>
<td>29</td>
<td>21</td>
<td></td>
</tr>
</tbody>
</table>

Response Percentage
Section 4.8: Adjunctive Procedures

We assessed dentists’ responses to seven questions about the use of adjunctive procedures in detecting and diagnosing oral cancers. Among respondents, the OraCDx Brush Biopsy was the most recognized procedure (92 percent) and the most widely used (45 percent), with approximately half of respondents reporting having used it. Toluidine Blue (TB) and ViziLite Plus with TBlue were the second and third most heard of (87 percent and 83 percent, respectively) and used (21 and 29 percent) adjunctive procedures. Sixty-four percent of respondents reported having heard of the VELscope, but only seven percent reported using this aid. Forty percent of dentists had heard of the Sapphire VELscope, but only two percent said they had used it. Less than 20 percent of respondents had heard of MicroLux DL and Trimira Identafi (18 percent and 7 percent respectively), and both products were used by less than 1 percent of respondents. On average, dentists had heard of four of the seven adjunctive procedures and had used one. See Figure 4.8 Dentists’ awareness and use of adjunctive procedures in detecting and diagnosing oral cancer.
Figure 4.8 Dentists’ awareness and use of adjunctive procedures in detecting and diagnosing oral cancer.
Section 4.9: Comparison of Findings: Current Study vs. Pilot Study

Before conducting the nationwide survey of dentists that is referenced in Section 2.6.1, the researchers pilot tested the NOSCD instrument with 508 general practice dentists in Maryland in 1995 (Canto et al., 2001; Horowitz et al., 2000b). This study provided baseline data for Maryland dentists’ knowledge, practices and opinions relating to oral cancer. As a result of the previous study, several interventions were developed, including hands on training dentists throughout Maryland on how to perform oral cancer screening examinations. Data from the previous study is not available for analysis, but the findings were published (Canto et al., 2001; Horowitz et al., 2000b). Key findings from the current study and the published results from the pilot study are compared.

Response rates for both studies were slightly over 50 percent. Respondents were primarily male (76 percent in the current study vs. 81 percent in the pilot study) and in solo practice (62 percent in the current study vs. 60 percent in the pilot study). One key difference between the respondents is date of graduation from dental school. Forty-nine percent of dentists graduated after 1980 in the pilot survey versus 69 percent in the current study.

Knowledge

Knowledge of Risk Factors. Dentists’ knowledge of real and non-real oral cancer risk factors is similar in the two studies. In both studies, over 90 percent of respondents knew that use of tobacco, a prior oral cancer lesion, and use of alcohol are risk factors for oral cancer. Approximately 70 percent of respondents knew that older age is a risk factor and over 60 percent knew that lip cancer is related to sun exposure. Only a third of
respondents knew that low consumption of fruits and vegetables and the majority of oral
cancers are diagnosed at 60 years of age and older are risk factors. The evidence that
fruit and vegetable consumption is protective against oral cancers was relatively new
information in 1995, so it is understandable that only a third of dentists correctly
identified this as a risk factor in the pilot study (Canto et al., 2001; Horowitz et al.,
2000b). It is disappointing that the awareness of this risk factor has not increased since
the pilot study. With regard to non-real risk factors for oral cancer, over 70 percent of
dentists knew that hot beverages and foods and use of spicy foods is not a risk factor,
while just 50 percent knew that poor oral hygiene as a not a risk factor. Responses were
similar for poorly fitting dentures and family history of cancer. The key difference in
responses between the two surveys was a decrease (approximately ten percent) in dentists
correctly identifying four non-real risk factors (hot beverages and foods, use of spicy
foods, obesity, and poor oral hygiene) between the pilot survey and the current survey.
The real and non-real risk factors and the percentage of dentists correctly identifying each
risk factor are shown for the current study and the pilot study in Figure 4.9.1. [Non-real
risk factors are denoted by “(-)”. ]
Figure 4.9.1 Knowledge of oral cancer risk factors: comparison of current and pilot studies.

### Real and Non-real Risk Factors

- **Use of Tobacco**: 99/99
- **Prior Oral Cancer Lesion**: 97/98
- **Use of Alcohol**: 95/96
- **Hot Beverages and Foods (−)**: 81/76
- **Older Age**: 69/71
- **Use of Spicy Foods (−)**: 69/77
- **Obesity(−)**: 69/79
- **Lip Cancer Related to Sun Exposure**: 62/64
- **Poor Oral Hygiene (−)**: 58/50
- **Poorly Fitting Dentures (−)**: 37/39
- **Low Consumption of Fruits and Vegetables**: 30/33
- **Majority of Oral Cancers Diagnosed at 60 Years of Age and Older**: 29/35
- **Family History of Cancer (+)**: 5/6

**Legend**
- Green: 1996 Study
- Blue: 2009 Study

---

**Percentage of Dentists Correctly Identifying Real and Non-real Risk Factors**

- **Use of Tobacco**: 99/99
- **Prior Oral Cancer Lesion**: 97/98
- **Use of Alcohol**: 95/96
- **Hot Beverages and Foods (−)**: 81/76
- **Older Age**: 69/71
- **Use of Spicy Foods (−)**: 69/77
- **Obesity(−)**: 69/79
- **Lip Cancer Related to Sun Exposure**: 62/64
- **Poor Oral Hygiene (−)**: 58/50
- **Poorly Fitting Dentures (−)**: 37/39
- **Low Consumption of Fruits and Vegetables**: 30/33
- **Majority of Oral Cancers Diagnosed at 60 Years of Age and Older**: 29/35
- **Family History of Cancer (+)**: 5/6

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Knowledge of Diagnostic Procedures. Answers to seven of the ten questions used to assess knowledge of diagnostic procedures were similar for the two studies, differing by only one to two percentage points. There are two notable differences. First, only 31 percent dentists in the pilot study correctly identified the two lesions most likely to be associated with oral cancer, compared to 42 percent of dentists in the current study. Second, in the current study, only 28 percent of dentists correctly responded that oral cancer lesions are most often diagnosed at advanced stages, while 50 percent responded correctly in the pilot study. The oral cancer diagnostic criteria and the percentage of dentists correctly identifying each procedure are shown for both studies in Figure 4.9.2.
Figure 4.9.2 Knowledge of oral cancer diagnostic procedures: comparison of current and pilot studies.

Oral Cancer Diagnostic Procedures

- Patient sticks out tongue; posterior dorsum is examined; tongue pulled out, checked on both sides and underside
  - 1996 Study: 87%
  - 2009 Study: 85%

- Squamous cell carcinoma is the most common form of oral cancer
  - 1996 Study: 82%
  - 2009 Study: 83%

- Early oral cancer lesions usually appear as small, painless red areas
  - 1996 Study: 81%
  - 2009 Study: 81%

- The patient is asymptomatic in early stages of oral cancer
  - 1996 Study: 75%
  - 2009 Study: 80%

- When palpated, a lymph node most characteristic of oral cancer is hard, painless, fixed or mobile
  - 1996 Study: 76%
  - 2009 Study: 77%

- Area of the tongue most likely to develop oral cancer - ventral-lateral border
  - 1996 Study: 71%
  - 2009 Study: 72%

- Excluding the lip, the tongue is the most common site of oral cancer
  - 1996 Study: 62%
  - 2009 Study: 59%

- Erythroplakia and Leukoplakia are the two lesions most likely to be associated with oral cancer
  - 1996 Study: 31%
  - 2009 Study: 42%

- Oral cancer lesions are most often diagnosed at advanced stages
  - 1996 Study: 28%
  - 2009 Study: 50%
Practices

Provision of Oral Cancer Examinations. Respondents in the current study reported higher levels of compliance with all four recommended screening procedures than respondents in the pilot study. In the current study, 85 percent of dentists reported providing an oral cancer examination at both the initial and recall visits for patients 40 years of age and older. In the pilot study, only 84 percent of dentists reported providing an oral cancer examination at the initial visit for patients 40 years of age and older, and 78 percent reported doing so on a recall visit. In the current study 88 percent of dentists reported providing oral cancer examinations for 100 percent of their edentulous patients, while 0.0 percent did so in the pilot study. In the pilot study, 6 percent of dentists reported providing examinations for their edentulous patients 80 percent or more of the time. In the current study, 42 percent dentists report routinely palpating lymph nodes in patients’ necks, while only one-third did so in the pilot study. The reported rates of all four examinations have increased since the last study, with the greatest increase in the percentage of dentists reporting that they routinely palpate patient’s lymph nodes. The four screening procedures and the percentage of dentists performing each procedure are shown for both studies in Figure 4.9.3.

Comprehensiveness of Medical History. Respondents in the current study reported similar but slightly higher levels of probing for oral cancer risk factors when taking a patient’s medical history than respondents in the pilot study. In the current study 99 percent of dentists asked about a patient’s history of cancer, while 92 percent reported doing so in the pilot study. In both studies, dentists tended to ask their patients about
tobacco use more than alcohol use. In the current study, 98 percent of dentists asked about present tobacco use, 90 percent asked about previous tobacco use and 78 percent asked about the type and amount of tobacco used. In the pilot study, 91 percent of dentists asked about present tobacco use, 77 percent asked about previous tobacco use and 70 percent asked about the type and amount of tobacco used. With regard to alcohol use, 76 percent of dentists asked about present alcohol use, 67 percent asked about previous alcohol use and only 38 percent asked about the type and amount of alcohol used in the current study. In the pilot study, only 66 percent of dentists asked about present alcohol use, 56 percent asked about previous alcohol use and 36 percent asked about the type and amount of alcohol used. The risk factors and the percentage of dentists assessing each risk factor are shown for both studies in Figure 4.9.4.
Figure 4.9.3 Recommended screening procedures: comparison of current and pilot studies.

<table>
<thead>
<tr>
<th>Recommended Screening Procedures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provide oral cancer exam for edentulous patients</td>
</tr>
<tr>
<td>Provide oral cancer exam at INITIAL visit for age 40 and older</td>
</tr>
<tr>
<td>Provide oral cancer exam at RECALL visit for age 40 and older</td>
</tr>
<tr>
<td>Routinely palpate lymph nodes in neck</td>
</tr>
</tbody>
</table>

Figure 4.9.4 Risk factors assessed when taking a medical history: comparison of current and pilot studies.

<table>
<thead>
<tr>
<th>Medical History: Risk Factors Probed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient's present tobacco use</td>
</tr>
<tr>
<td>Patient's previous tobacco use</td>
</tr>
<tr>
<td>Type and amount of tobacco used</td>
</tr>
<tr>
<td>Patient's present alcohol use</td>
</tr>
<tr>
<td>Family history of cancer</td>
</tr>
<tr>
<td>Patient's past alcohol use</td>
</tr>
<tr>
<td>Type and amount of alcohol used</td>
</tr>
</tbody>
</table>
Opinions

Opinion data from the pilot survey is reported on at a summary level and therefore we are not able to compare data at a detailed level to the current survey data. We were able to compare dentists’ opinions of the adequacy of their training, if they were adequately trained to examine patients for oral cancer and palpate lymph nodes. When asked if their knowledge of oral cancer is current, similar numbers of respondents strongly agreed with this statement (7 percent in current study and 5 percent in pilot study), with the majority of respondents agreeing with the statement (74 percent in current study and 78 percent in pilot study). Asked if they were adequately trained to examine patients for oral cancer, 94 percent of current respondents and 92 percent of pilot study respondents strongly agreed or agreed with the statement. Asked if they were comfortable palpating lymph nodes in patients’ necks, 83 percent of current respondents and 77 percent of pilot study respondents strongly agreed or agreed with the statement.

Additionally, we asked dentists how long it had been since they had taken an oral cancer CE course. The percentage of dentists indicating they had taken a course in the past 12 months doubled between the pilot study and the current study (14 percent to 29 percent). The percentage of respondents that replied they had taken a course in the past two to five years increased from 40 percent to 54 percent, while the number of dentists that took their last CE course more than five years ago decreased by almost half (29 percent to 15 percent). In the previous study, 18 percent of respondents said they had never taken an oral cancer CE course, but less than one percent of respondents in the current study indicated this to be the case.
Chapter 5: Discussion

Section 5.1: Summary of Central Findings

Key findings are organized by knowledge, practices and opinions.

Knowledge

Knowledge of real risk factors. On average, dentists knew six of the eight real risk factors for oral cancer. More than 95 percent of respondents knew that tobacco and alcohol use, as well as a prior oral cancer lesion, are risk factors. Eighty-eight percent of respondents knew that HPV is a risk factor. However, only one third of respondents knew that low consumption of fruits and vegetables and that the majority of oral cancers are diagnosed at 60 years of age and older are risk factors.

Knowledge of non-real risk factors. Dentists were not as knowledgeable about the non-real risk factors or myths associated with oral cancer. On average, dentists identified four of the seven non-real risk factors. While 69 percent or more of dentists were able to correctly identify hot beverages and food, obesity and use of spicy foods as non-real risk factors, less than 53 percent of respondents were able to correctly identify the following factors as non-risks for oral cancer: familial clustering (52 percent), poor oral hygiene (50 percent), poor fitting dentures (39 percent) and a family history of cancer (6 percent).

Knowledge of diagnostic procedures. Dentists correctly identified an average of seven of the ten oral cancer diagnostic procedures. For seven of the ten diagnostic procedures, more than 70 percent of respondents correctly identified the procedure. However, less than 60 percent knew that the tongue is the most common site of oral cancer, only 42
percent knew the two lesions most likely to be associated with oral cancer, and less than 30 percent knew that oral cancer lesions are most often diagnosed at advanced stages.

**Scores on knowledge indices.** Approximately 38 percent of dentists received a high score on the *knowledge of oral cancer risk factors index*. Thirty-nine percent of dentists received a high score on the *knowledge of oral cancer diagnostic procedures index*. Only 17 percent of respondents received a high score on the *combined knowledge index*.

**Scores on knowledge indices and opinions.** Dentists who strongly agreed or agreed that their oral cancer knowledge is current were more likely to receive a high score on the *knowledge of oral cancer diagnostic procedures index* and the *combined knowledge index*. Dentists who strongly disagreed or disagreed that their knowledge oral cancer knowledge is current were more likely to receive a low score on both of these indices. Our analysis did not find an association between dentists’ opinions of the currency of their oral cancer knowledge and the *knowledge of oral cancer risk factors index*.

**Practices**

**Comprehensiveness of medical history.** On average dentists screened for seven of the ten oral cancer risk factors. More than 90 percent of dentists assess a patient’s use of tobacco products and their history of cancer. Fewer dentists assess alcohol use than tobacco use. Seventy-six percent assess present alcohol use, while only 38 percent assess the type and amount of alcohol used. Only 55 percent of dentists assess a patient’s risk for HPV and less than 21 percent assess if the patient received the HPV vaccine.

**Provision of examinations.** On average, dentists performed three of the four screening examinations. Eighty-five percent of dentists reported providing examinations for 100
percent of their patients 40 years of age and older on both initial and recall visits. Eighty-eight percent provide oral cancer examinations to their edentulous patients, while only 42 percent report that they routinely palpate their patient’s necks.

**Adjunctive Procedures.** On average, dentists had heard of four of the seven adjunctive procedures used to help detect and diagnose oral cancer lesions and on average had used one. Among respondents, the OraCDx Brush Biopsy was the most recognized (92 percent) and widely used (45 percent) procedure. Toluidine Blue (TB) and ViziLite Plus with TBlue were the second and third most recognized (87 percent and 83 percent, respectively) and used (21 and 29 percent respectively) adjunctive procedures.

**Scores on screening practices indices.** Forty-two percent of dentists received a high score on the *comprehensiveness of medical history index*. Approximately 38 percent of dentists received a high score on the *provision of oral cancer examinations index*. Only 19 percent of respondents received a high score on the *combined screening practices index*.
Opinions

When asked to rate their undergraduate training in oral cancer, 35 percent rated their education as “very good”, 48 percent rated it as “good” and 13 percent rated their training as poor. Asked if their oral cancer knowledge is current, seven percent of dentists strongly agreed and 74 percent agreed with the statement. However, only 38 percent of dentists strongly agreed that they were adequately trained to examine patients for oral cancer, while 57 percent strongly agreed that most dentists were trained to perform oral cancer examinations. Asked if physicians were adequately trained to perform oral cancer examinations, less than 4 percent of dentists strongly agreed, while 27 percent strongly agreed that dental hygienists were adequately trained to perform these examinations. With regard to palpating lymph nodes in patient’s necks, 79 percent of dentists strongly agreed or agreed that they were adequately trained to do so, and 83 percent strongly agreed or agreed that they were comfortable performing this examination.

When asked about tobacco cessation counseling, 65 percent strongly disagreed or disagreed that they were adequately trained to provide this counseling to their patients. However, 71 percent strongly agreed or agreed that dentists should be trained to provide tobacco cessation counseling. Eighty-three percent strongly disagreed or disagreed that they were adequately trained to provide alcohol cessation counseling to their patients, while 50 percent strongly agreed or agreed that they should be trained to provide alcohol cessation counseling. Asked about their interest in future oral cancer CE courses, 94 percent of respondents said they were interested in attending such courses. The four most
popular approaches to CE courses were lectures, clinical demonstrations, study clubs, and audiovisual slide or videotape series.
Section 5.2: Implications of Findings

To better understand oral cancer prevention and early detection in Maryland, we surveyed dentists to assess their efforts to determine a patient’s risk for oral cancer, detect and diagnose oral cancers, and counsel patients to reduce their risk for oral cancer. Our study found both deficiencies and inconsistencies in dentists’ knowledge and practices.

For dentists to provide optimal care for their patients, they must have accurate knowledge of oral cancer signs, symptoms and risk factors and examination skills. Tobacco and alcohol use account for over 75 percent of all oral cancers. Thus, it is encouraging to see that 99 percent of respondents know that tobacco is a risk factor for oral cancer and that 98 percent assess a patient’s present use of tobacco. It is also encouraging that 96 percent of respondents know that alcohol is a risk factor. However, it is of concern that only 76 percent of dentists reported assessing this risk factor when taking a medical history. Many people who use tobacco products also use alcohol and vice versa, and the synergistic effect of these two products increase the risk for oral cancer by as much as 15-fold. Patients must be screened for both tobacco and alcohol to assess their risk for oral cancer.

It is estimated that 25 percent of all oral cancers are linked to HPV. Eighty-eight percent of respondents identified HPV as a risk factor for oral cancer, but only 55 percent reported assessing a patient’s risk for HPV. The number of HPV-related cancers is increasing in Maryland and the U.S. Thus, it is critical that dentists screen for this risk factor and counsel patients to reduce their risk.

The scientific evidence surrounding the protective effect of fruit and vegetable consumption against oral cancer has increased in the past twenty years. Thus it is
concerning that only one third of respondents correctly identified low consumption of fruits and vegetables as a risk factor for oral cancer. It is also troubling that dentists believe several factors such as poor oral hygiene and poor-fitting dentures increase the risk for oral cancer, when in fact there is no scientific evidence to support these beliefs.

Dentists must also have knowledge of how to detect and diagnose oral cancers. Eighty-five percent of dentists correctly identified the procedure for examining the tongue for oral cancer. More than 80 percent knew the most common form of oral cancer and the appearance of early lesions. However, less than 75 percent knew the area of the tongue most likely to develop oral cancer lesions and only 42 percent knew the two lesions most commonly associated with oral cancer. If dentists do not know what to look for and where to look in the oral cavity, it is likely that some cancers will not be detected at early stages.

Practices, such as providing oral cancer examinations and taking a complete medical history, are critical aspects of oral cancer prevention and early detection efforts. A comprehensive examination is the primary method used to detect and diagnose oral cancer. Eighty-five percent of dentists report providing oral cancer examinations to 100 percent of their patients 40 years of age and older at initial and recall visits. Palpation is a critical component of the oral cancer examination. Seventy-nine percent of respondents strongly agreed or agreed that they were adequately trained to palpate the lymph nodes in patients’ necks, and 83 percent strongly agreed or agreed that they were comfortable performing this examination. However, only 42 percent reported routinely palpating the lymph nodes in patient’s necks. Thus, the number of dentists actually conduct
comprehensive screening examinations is less than the 85 percent of dentists that report
doing so, and as a result, some cancers may go undetected or be detected at late stages.

A complete medical history helps a dentist (and other healthcare professionals)
assess a patient’s risk for oral cancer, and provides the opportunity to counsel the patient
to reduce their risk for oral cancer. Among our respondents, 98 percent assess present
tobacco use, 76 percent assess present alcohol use, and 50 percent ask about a patient’s
history of HPV. Seventy-five percent of oral cancers are related to tobacco and alcohol
use and 25-30 percent of oral cancers are HPV-related, so it is imperative that dentists are
trained to counsel their patients about these modifiable risks. In our study, 65 percent of
dentists strongly disagreed or disagreed that they were adequately trained to provide
tobacco cessation counseling to their patients and 83 percent strongly disagreed or
disagreed that they were adequately trained to provide alcohol cessation counseling. This
deficiency in counseling skills is a missed opportunity to build upon the relationship
between the dentist and patient and help the patient reduce their risk for oral cancer.

To conduct comprehensive oral cancer screening examinations and provide
patients with appropriate information about oral cancer risk factors, dentists’ knowledge
must be accurate and current. Our survey indicates that there are deficiencies in dentists’
knowledge and screening practices and inconsistencies between what they know and
what they report doing. To address these deficiencies, CE courses are needed to help
dentists increase their knowledge of oral cancer risk factors and diagnostic procedures,
improve their skill at providing comprehensive screening examinations, and help them
provide tobacco and alcohol cessation education for their patients. Ninety-four percent of
dentists said they were interested in attending CE education courses.
Our study also indicates that students in dental school require additional training. We might expect more recent dental school graduates to have greater knowledge of oral cancer prevention and early detection than dentists that graduated previously because of recent efforts by some dental schools to treat oral cancer similar to other dental school subjects. Thus, we might expect dentists graduated between 1980 and 1989 to have lower scores on the knowledge indices, than more recent graduates. However, our survey results indicate that while recent graduates (2000 to 2009) were more likely to have higher levels of knowledge of oral cancer risk factors, they were less likely to have higher levels knowledge of diagnostic procedures or higher levels of compliance with recommended screening practices. It is possible that the dentists that graduated between 1980 and 1989 benefited from oral cancer training that was held throughout Maryland as a result of the previous study. The best way to address these deficiencies in knowledge and practices is to provide more comprehensive oral cancer training in dental school. For example, dental school programs require students to perform a specified number of procedures such as fillings, but many programs do not require students to evaluate oral cancer signs and symptoms, nor do they teach students oral cancer examination procedures that include palpation. Thus, all dental school programs should require students to perform a specified number of oral cancer examinations in order to graduate from the program. Placing greater emphasis on oral cancer prevention and early detection in school, and requiring students to demonstrate competency in providing oral cancer examinations, will predispose students to providing these examinations effectively and routinely when they leave school. In addition, requiring dentists to demonstrate
competency in performing oral cancer examinations for licensing and re-licensure would continue to reinforce the importance of this practice.
Section 5.3: Limitations

This study has several limitations. First, response bias may be a factor in that respondents may not be representative of the source population for two reasons. Our randomized sample used un-weighted data and therefore may not reflect the underlying distribution of dentists in the state, especially dentists in community health centers, “other” types of practices and minority populations. Oversampling could have increased the power to detect differences by type of practice and race/ethnicity. Further, respondents might have greater knowledge or think they have greater knowledge of oral cancer diagnostic and screening practices than non-respondents, making them more inclined to respond to the survey. Thus, our results may reflect a situation in which the knowledge of oral cancer is higher in the study population than in the source population. Due to problems with the second mailing we did not call non-respondents to determine if their background characteristics were similar to respondents, which was part of our original plan. Second, our results rely on self-report data, which means that respondents could over-report their screening practices (number of exams provided to patients and the number of risk factors assessed when taking a medical history). Third, the second survey mailing contained an incomplete version of the survey. Thus, we did not include their responses in our analysis. This reduced the effective response rate from 53.6 percent to 40.1 percent.
Section 5.4: Directions for Future Research and Intervention

To reduce the morbidity and mortality associated with oral cancer, dentists must have accurate knowledge and proficient skills to detect and diagnose oral cancers at early stages. The results of our study indicate that there are gaps in dentists’ knowledge of oral cancer diagnostic procedures and risk factors, as well as gaps in practices related to providing oral cancer screening exams, assessing risk factors, and counseling patients to reduce their risk. To address these deficiencies, actions are needed in education, policy and research.

Education

Continuing education (CE) programs. In our survey, most dentists expressed an interest in furthering their education regarding oral cancer. CE programs based on the latest scientific research and clinical best practices, delivered in preferred formats such as online courses, lectures and clinical demonstrations, can help dentists provide accurate information and evidence-based care to their patients. The CE programs should emphasize screening for risk factors; performing oral cancer examinations; and counseling to modify behaviors associated with increased risk for oral cancer. The Maryland State Dental Association (MSDA) should take the lead in developing the CE courses for dentists within Maryland, and work closely with the University of Maryland Dental School at University of Maryland, Baltimore. Working together, they can ensure that the content, messaging, and format of the CE courses meet both organizations’ requirements and minimize duplication of efforts. Additionally, a unified message of
support for the program from both organizations can help raise awareness and support for the CE programs.

**Dental school curricula.** There is an urgent need for comprehensive oral cancer training for all dental students to ensure a dental workforce that is competent and predisposed to providing routine oral cancer examinations (Horowitz et al., 1996). A majority of dental schools do not require students to evaluate oral cancer signs and symptoms and do not train their students in oral examination procedures that include palpation (Horowitz et al., 1996). Many dental schools still have requirements that students perform a specified number of different types of restorations and procedures. But to our knowledge, none has requirements for performing oral cancer examinations. While there are curricular guidelines for teaching undergraduate and graduate dental students how to provide an oral cancer examination (American Association of Dental Schools, 1987; 1991; 1992a; 1992b), there is no process to enforce these guidelines. Without enforcement of these guidelines, inconsistencies in the knowledge, skills and practices relating to oral cancer prevention and early detection among new dental graduates are likely to continue for the foreseeable future. We agree with previous suggestions (Horowitz et al., 1996) that regulatory guidelines for educational curricula are needed to improve the competencies of dental school graduates with regard to oral cancer prevention and early detection. The American Board of Dental Examiners is the logical organization to spearhead this effort as they are the organization that assesses dental and dental hygiene schools in US and Canada and provides accreditation.
The curricula should also emphasize preventive measures to reduce the risk for oral cancer. Too often the focus is on treatment instead of prevention in our dental and medical schools. For dentists to approach oral cancer from the preventive perspective, they must routinely assess a patient’s risk for oral cancer and be comfortable and confident in providing tobacco and alcohol cessation counseling. With more than 80 percent of all oral cancers associated with tobacco and alcohol use, it is imperative that dentists screen for these risk factors and provide counseling to help their patients discontinue tobacco and limit alcohol use. With the increase in the number of oral cancers associated with HPV, dentists must also assess a patient’s risk for HPV. They need to discuss how HPV is transmitted (through oral, vaginal and anal sex) and how to decrease risk (not engaging in oral sex and getting the HPV vaccine if appropriate).

*Training other healthcare providers.* While dentists play a critical role in the prevention and early detection of oral cancer, healthcare providers such as dental hygienists, physicians and nurse practitioners should also be trained to perform oral cancer examinations on a routine basis (Horowitz et al., 1996). The rationale for training these providers is that some populations at high risk for oral cancer tend to use dental services less frequently than medical services. These high-risk populations include the edentulous elderly; individuals aged 65 years and older; minorities; and, individuals with low incomes, lacking private health insurance, and with less than a high school education (National Center for Health Statistics, 2009a; 2009b). For example, in 2007, more than 80 percent of individuals 65 years and older visited a physician annually, where as only 58 percent visited a dentist (National Center for Health Statistics, 2009a; 2009b). In
addition, they visited their physician more frequently than they visited their dentist (Cherry et al., 2008). Training these healthcare providers to perform oral cancer examinations as part of a comprehensive screening exam would provide many high-risk individuals with an oral cancer examination that they might otherwise not receive (Horowitz et al., 1996).

**Policies**

**Licensing and re-licensure.** State, regional, and national licensing dental board examinations all contain some questions related to oral cancer. However, no state dental board requires applicants to perform an oral cancer screening examination to obtain a license to practice (Horowitz et al., 1996). The best way to ensure that healthcare professionals have specific competencies, such as performing an oral cancer examination, is to require that they demonstrate the competency during dental school, for licensure and re-licensure. New York State was the first state to take steps in this direction. In 2001, it mandated that all dentists take two hours of coursework and training on a one-time basis on how to recognize, diagnose and treat the effects of tobacco on oral health (Gajendra et al., 2006). Maryland can follow in New York’s footsteps and mandate a one-time training for all dentists, or it can take the lead and require that all dentists demonstrate proficiency with oral cancer examinations for licensing and re-licensure. To accomplish this, stakeholders from professional, state and national organizations would need to work together to plan, develop and implement oral cancer licensure and re-licensure requirements. While this would require considerable effort in the short term, in the long term it could lead to dentists having greater knowledge, skills and practices related to oral
cancer prevention and early detection. With greater knowledge and skills, dentists may be better able to detect cancers at earlier stages and counsel their patients reduce their risk, helping Maryland reduce its high oral cancer mortality rate.

Research

CE courses. Ninety-four percent of respondents said they were interested in oral cancer CE courses. Future research could review current CE materials to determine appropriateness, strengths and possible deficiencies. This information could be used to inform the development of new CE courses.

Follow-up studies. This study is a follow-up to a baseline study conducted in Maryland in 1995 that surveyed dentists about their oral cancer knowledge, practices and opinions. The initial study was part of a larger study that included dental hygienists, physicians, nurse practitioners and adults in Maryland. Follow-up studies should be conducted with these populations to determine their current knowledge, practices and opinions relating to oral cancer. This information can be used to develop future interventions to increase oral cancer prevention and early detection. Researchers at the University of Maryland School of Public Health have the expertise to lead this research effort and should pursue funding for this work.
Section 5.5: Conclusions

To reduce the morbidity and mortality associated with oral cancer, dentists must have accurate knowledge and proficient skills to detect and diagnose oral cancers at early stages. Additionally, they must perform routine oral cancer screening examinations and counsel patients to modify behaviors that increase the risk for oral cancer. Our findings indicate that deficiencies exist in dentists’ knowledge and practices relating to oral cancer prevention and early detection. There are also inconsistencies between dentists’ knowledge and screening practices.

Accurate and current knowledge and skills are the foundation of optimal patient care, and are essential for improving oral cancer prevention and early detection efforts in Maryland. Existing oral cancer CE course materials should be evaluated to identify strengths and deficiencies, and a comprehensive program should be designed. The CE programs should emphasize screening for risk factors; performing oral cancer examinations; and counseling to modify behaviors associated with increased risk for oral cancer. The Maryland State Dental Association should take the lead in developing the CE courses for dentists within Maryland, and work closely with the University of Maryland Dental School at University of Maryland, Baltimore. To ensure that dental professionals have oral cancer screening competencies, the Maryland state dental board should require applicants to perform oral cancer screening examinations for licensure and re-licensure. Maryland would be the first state to mandate such competencies. This greater emphasis on oral cancer knowledge and skills, may lead to detection of cancers at earlier stages. Lastly, dental school curricula should be modified to place greater emphasis on oral cancer prevention and early detection. Schools should require students
to perform oral cancer examinations as part of the curricula, emphasize risk assessment
and counseling to reduce risk.
Chapter 6: Appendices

Appendix A: IRB Application

UNIVERSITY OF MARYLAND, COLLEGE PARK
Institutional Review Board
Initial Application for Research Involving Human Subjects

Name of Principal Investigator (PI) or Project Faculty Advisor: Alice M. Horowitz, PhD
(NOT a student or fellow)
Tel. No 301.405.9797

Name of Co-Investigator (Co-PI)
Tel. No

E-Mail Address of PI: ahorowit@umd.edu
E-Mail Address of Co-PI

Name and address of contact to receive approval documents
Alice M. Horowitz, PhD
3310 SPH Bldg.

Name of Student Investigator: Catherine Maybury
Tel. No. 703.424.8499
E-Mail Address of Student Investigator: camaybury@yahoo.com

Check here if this is a student master’s thesis X or a dissertation research project

Department or Unit Administering the Project: School of Public Health, Office of the Dean

Project Title: Survey of Maryland Dentists’ Knowledge, Opinions and Practices related to Oral Cancer

Funding Agency: Friedman Family Dental Research Project
ORAA Proposal ID Number:

Names of any additional Federal agencies providing funds or other support for this research project:

Target Population: The study population will include (Check all that apply):
pregnant women neonates individuals with mental disabilities
minors/children prisoners individuals with physical disabilities
human fetuses students

Exempt or Nonexempt (Optional): You may recommend your research for exemption or nonexemption by checking the appropriate box below. For exempt recommendation, list the numbers for the exempt category(s) that apply. Refer to pages 6-7 of this document.

X Exempt----List Exemption Category(s) 2
Or  □ Non-Exempt

If exempt, briefly describe the reason(s) for exemption.

This research will use a survey to collect data. Information will be recorded in a manner such that study subjects can not be identified and results will be reported in aggregate form.

Date Signature of Principal Investigator or Faculty Advisor

Date Signature of Co-Principal Investigator
Abstract:

The purpose of this study is to survey general practice dentists within the state of Maryland to assess their knowledge, opinions and practices concerning oral cancer. The survey instrument is based on the National Oral Cancer Survey of Dentists (NOSCD) created by Dr. Alice Horowitz and colleagues in 1995. The NOSCD has been updated to include questions about HPV as a risk factor for oral cancer and the use of adjunctive procedures in diagnosing oral cancer.

Strategies to protect study subjects include: protecting subject identity by assigning a randomly generated number to each subject and using the number to track whether subjects respond; no reporting on individual responses (individual responses will only be grouped with information from other respondents for the purpose of reporting); returned surveys will be stored in a locked file cabinet in a locked room at the University; and, survey responses will be entered into a password protected database housed at the University. Only researchers involved with the project will have access to the information stored in the file cabinets and database. Following the completion of the project, all identifying paper information will be shredded and disposed and all electronic data will be deleted.

Subject Selection:

a. The subjects will be general practice dentists currently practicing in Maryland. Subjects will be randomly selected from a list of practicing dentists. This list will be obtained from the Maryland State Dental Association. A copy of the survey, recruitment letters and post-card are attached (Attachments A, B, C and D).

NOTE: The attached survey instrument will be reformatted so it can be folded and mailed directly instead of placed in an envelope.
b. The selection criteria are that the dentists be general dentists currently practicing in Maryland. Dental specialists, such as oral surgeons, orthodontists and pedodontists, will be excluded from the study.

c. The objective of this study is to assess the knowledge, opinions and practices about oral cancer of dentists in Maryland. Therefore, subjects must be general dentists currently practicing in Maryland.

d. 1,169 subjects will be recruited. (See 3 below.)

3. Procedures:

Sample population:
Parameters used to determine the number of study subjects:
N= Total population of general practice dentists in Maryland; N= 2500
Error rate = 3%
P = .05
Confidence Interval = 95%
Expected response rate = 40%

The survey will be distributed to 1,169 randomly selected subjects. With a 40% response rate, 468 subjects will complete the survey. Non-responses (including refusal) are expected. Therefore we will sample 60% more than the needed sample size. After the data collection, we can assess the sample bias by comparing certain characteristics (some known demographics) of those who responded and those who did not respond.

Survey data will be double entered into a spreadsheet. Analytic methods will vary depending on types of outcomes. Linear regression may be used to determine predictors of dentist’s knowledge, opinions and practices. That is, it will allow estimates in any differences by year of graduation, age, gender, etc.

Procedures:
- Subjects will receive the survey instrument, a cover letter explaining the purpose of the survey, and the request to return the survey within two weeks. Subjects complete the survey once. The survey is designed to take about 15 minutes to complete. (Attachments A and B)

- Three weeks after the initial mailing, a second complete mailing will be sent to non-respondents, asking them to complete the survey and return it within two weeks. (Attachments A and C)

- Three weeks after the second mailing, postcard reminders will be sent
to all non-respondents, asking them to complete the survey and return it within two weeks. (Attachment D)

- Three weeks after the postcard mailing, ten percent of the non-respondents will be randomly selected from the total list of non-respondents. They will be called and asked if they will participate in a brief phone survey. This procedure will help us to compare the background characteristics of the non-respondents to the respondents. (Attachment E).

4. **Risks and Benefits:**

There are no known risks associated with participating in this research project. No sensitive information is being collected. All answers will be kept confidential and confidentially is being assured as described in Section 5 below. All investigators have had IRB training and are trained in the protection of human subjects. There is no monetary or other compensation is being offered for participation.

There are no known immediate benefits associated with participating in this research project. Although this research is not designed to benefit individual dentists, the results will help us: learn more about general practice dentists’ knowledge of oral cancer risks and diagnostic procedures for oral cancer; describe relationships between dentists’ background characteristics and their knowledge about oral cancer; describe associations between dentists’ levels of oral cancer knowledge and their opinions about how current their oral cancer knowledge is; and, describe dentists’ interest in future continuing education (CE) and their preferred approaches to CE. This information will be used in developing interventions that include future training and CE courses for dentists.
5. **Confidentiality:**

Confidentiality will be protected in the following ways:

a. Each subject on the list of dentists obtained from the Maryland State Dental Association will be assigned a randomly generated number. The generated number will be used to track whether a subject responds or does not respond to the survey. No names will be recorded. This procedure protects the identity of individual dentists.

b. All information that is provided by individual subjects will only be grouped with information from other dentists for the purpose of reporting and presenting. This protects the identity of individuals.

c. Survey responses (paper format) will be stored in a locked file cabinet in a locked room at the University. Only those researchers involved with the project will have access to this information.

d. To analyze the data, survey responses will be entered into a database housed at the university. The database will be password protected and only those researchers involved with the project will have access to the information stored in the database.

e. Following the completion of the project, all identifying paper information will be shredded and disposed. All electronic data will be deleted.

6. **Information and Consent Forms:**

The initial request, asking subjects to participate in this study, is a cover letter (Attachment B) that states that this study is a survey of dentists’ knowledge, opinions, and practices regarding oral cancers, as well as personal information about their practice setting and year of graduation. The cover letter states the significance of oral cancer in Maryland. The letter informs the subject that this study is a follow-up to an earlier study, and that the results will be presented in aggregate form only and their name will not be associated with their answers in any reports. The cover letter tries to establish credibility with the subjects by mentioning that this study is a collaboration between the Maryland State Dental Association and the School of Public Health, University of Maryland, College Park.

There is no deceptive information in the initial cover letter or in the other correspondence that will be sent to study subjects (Attachments C and D). The real purpose of the study is disclosed to study subjects

This study will use implied consent. If a subject completes the anonymous survey and returns it to the study team, their consent to participate in the study is inferred by their act of returning the survey.

7. **Conflict of Interest:**
No conflict of interest.

8. **HIPAA Compliance:**
   Not Applicable.

9. **Research Outside of the United States:**
   Not Applicable.

10. **Research Involving Prisoners:**
    Not Applicable.
Appendix B: Project Plan
<table>
<thead>
<tr>
<th>Task/Deliverable</th>
<th>Target Completion Date</th>
<th>Actual Completion Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Review Literature</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Initial Review of Literature</td>
<td>09/30/2009</td>
<td>09/30/09</td>
</tr>
<tr>
<td>Complete Review of Literature</td>
<td>08/01/2010</td>
<td>08/01/2010</td>
</tr>
<tr>
<td>IRB Approval</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Submit IRB application</td>
<td>08/27/2009</td>
<td>08/26/2009</td>
</tr>
<tr>
<td>Receive IRB approval/feedback</td>
<td>09/24/2009</td>
<td>09/03/2009</td>
</tr>
<tr>
<td>Sample Population</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Determine sample size</td>
<td>08/24/2009</td>
<td>08/24/2009</td>
</tr>
<tr>
<td>Obtain data file (list of dentists) from MSDA</td>
<td>09/25/2009</td>
<td>11/13/2009</td>
</tr>
<tr>
<td>Finalize data file (review for accuracy, duplicates, etc.)</td>
<td>09/30/2009</td>
<td>12/09/2009</td>
</tr>
<tr>
<td>Documents</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Create recruitment letter #1 (cover letter)</td>
<td>08/24/2009</td>
<td>08/24/2009</td>
</tr>
<tr>
<td>Create recruitment letter #2 (cover letter)</td>
<td>08/24/2009</td>
<td>08/24/2009</td>
</tr>
<tr>
<td>Create recruitment letter #3 (post card)</td>
<td>08/24/2009</td>
<td>08/24/2009</td>
</tr>
<tr>
<td>Create survey for phone follow-up of non-respondents</td>
<td>08/24/2009</td>
<td>08/24/2009</td>
</tr>
<tr>
<td>Obtain permission of MSDA to use their name in the recruitment letters</td>
<td>09/14/2009</td>
<td>09/14/2009</td>
</tr>
<tr>
<td>Cover letter - approved by MSDA</td>
<td>09/30/2009</td>
<td>11/17/2009</td>
</tr>
<tr>
<td>Create final version of recruitment letter #1</td>
<td>09/30/2009</td>
<td>11/24/2009</td>
</tr>
<tr>
<td>Create final version of recruitment letter #2</td>
<td>09/30/2009</td>
<td>01/04/2010</td>
</tr>
<tr>
<td>Create final version of recruitment letter #3</td>
<td>09/30/2009</td>
<td>02/04/2010</td>
</tr>
<tr>
<td>Task/Deliverable</td>
<td>Target Completion Date</td>
<td>Actual Completion Date</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------------</td>
<td>------------------------</td>
<td>------------------------</td>
</tr>
<tr>
<td><strong>Create Survey</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Create new (additional) survey questions (HPV and Adjunctive Procedures)</td>
<td>08/24/2009</td>
<td>08/24/2009</td>
</tr>
<tr>
<td>Validate new survey questions (using panel of experts)</td>
<td>09/30/2009</td>
<td>11/05/2009</td>
</tr>
<tr>
<td>Create final survey form (layout/formatting)</td>
<td>10/15/2009</td>
<td>12/01/2009</td>
</tr>
<tr>
<td><strong>Mail Survey</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1st mailing</td>
<td>10/21/2009</td>
<td>12/16/2009</td>
</tr>
<tr>
<td>2nd mailing</td>
<td>11/06/2009</td>
<td>01/11/2010</td>
</tr>
<tr>
<td>3rd mailing</td>
<td>11/23/2009</td>
<td>02/16/2010</td>
</tr>
<tr>
<td><strong>Collect Survey Responses</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Create procedures for collecting response data</td>
<td>10/23/2009</td>
<td>12/01/2009</td>
</tr>
<tr>
<td>Collect returned surveys and mark as returned</td>
<td>10/23 – 12/11/2009</td>
<td>12/18/2009 - 03/31/2010</td>
</tr>
<tr>
<td>Install SPSS Software</td>
<td></td>
<td>01/18/2010</td>
</tr>
<tr>
<td>Create template for recording response data (individual surveys)</td>
<td>10/23/2009</td>
<td>01/31/2010</td>
</tr>
<tr>
<td>Enter data (individual survey responses)</td>
<td>10/23 – 12/18/2009</td>
<td>03/15/2010 - 04/04/2010</td>
</tr>
<tr>
<td>Re-check accuracy of survey responses (10%)</td>
<td>12/18/2009</td>
<td>04/04/2010</td>
</tr>
<tr>
<td>Phone follow-up (with randomly selected non-respondents - 10%)</td>
<td>12/09 – 12/18/2009</td>
<td></td>
</tr>
<tr>
<td>Task/Deliverable</td>
<td>Target Completion Date</td>
<td>Actual Completion Date</td>
</tr>
<tr>
<td>-----------------------------------------------</td>
<td>------------------------</td>
<td>------------------------</td>
</tr>
<tr>
<td><strong>Printing</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Determine printing and handling costs</td>
<td>09/11/2009</td>
<td>11/05/2009</td>
</tr>
<tr>
<td><strong>Analysis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Create analysis plan</td>
<td></td>
<td>08/15/2010</td>
</tr>
<tr>
<td>Perform Analysis</td>
<td></td>
<td>10/30/2010</td>
</tr>
<tr>
<td><strong>Other Project Tasks</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Status letter to Dr. Friedman</td>
<td>09/30/2009</td>
<td>09/28/2009</td>
</tr>
</tbody>
</table>
Appendix C: Survey Instrument
2009 Maryland Survey of Dentists: Oral Cancer

Thank you for taking the time to complete this short survey. Your confidential answers will be used to develop continuing education and other interventions to improve oral cancer prevention and education.

If you are not in clinical practice, please return this postage-paid survey. This will help account for all surveys mailed and prevent unnecessary follow-up requests.

Please read each question and provide your most appropriate response.

Tell us about the practice where you work.

1. Please provide your best estimate of the percentage of patients age group for whom you provide an oral cancer examination at their INITIAL (emergency or scheduled) and RECALL appointments? If you do not provide oral cancer exams write “0.”

<table>
<thead>
<tr>
<th>Age</th>
<th>Initial</th>
<th>Recall</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-39</td>
<td>___Percent</td>
<td>___Percent</td>
</tr>
<tr>
<td>40+</td>
<td>___Percent</td>
<td>___Percent</td>
</tr>
</tbody>
</table>

2. If you do not provide oral cancer examinations for your patients in either age group, what is the single most important reason for not doing so? (CHECK ONLY ONE PER AGE GROUP)

   - 1. Not reimbursed by third party payers
   - 2. Not necessary/not needed
   - 3. Unsubstantiated by research
   - 4. Takes too much time
   - 5. Not adequately trained in exam technique
   - 6. Not cost-effective
   - 7. Patients unwilling to pay for procedure
   - 8. Other (Specify)_________

3. Please provide your best estimate of the percentage of your edentulous patients for whom you provide an oral cancer examination.

   ___Write in percent; if none write “0”.  (19-21)

4. Please provide your best estimate of the percentage of your adult patients (18 years and older) for whom you routinely feel their necks to palpate their lymph nodes.

   ___Write in percent; if none write “0.”  (22-24)

5. In the past 12 months, about how many patients did you biopsy for suspicious oral lesions?

   ___Write in number; if none write “0.”  (25-27)

6. In the past 12 months, about how many patients did you refer for diagnosis of suspicious oral lesions?

   ___Write in number; if none write “0.”  (28-30)

7. To whom do you refer patients with a suspicious lesion in their mouth? (CHECK ONLY ONE) (31)

   - 1. Oral surgeon
   - 2. Oral and maxillofacial surgeon
   - 3. Dermatologist
   - 4. Ear, nose and throat specialist
   - 5. Other, please specify _______________

8. Please provide your best estimate of the percentage of your adult (18+ years of age) patients who have some type of dental insurance including Medicaid and Medicare.

   ___Write in percent; if none write “0.”  (32-34)
**Signs, Symptoms and Risk Factors**

9. Excluding the lip, which of the following is the **most** common site of oral cancer? (CHECK ONLY ONE)  
   - 1. Soft palate  
   - 2. Tongue  
   - 3. Gingiva  
   - 4. Buccal mucosa  
   - 5. Floor of mouth  
   - 6. Tonsil  
   - 7. Don’t know/Not sure

10. The **most** common form of oral cancer is: (CHECK ONLY ONE)  
   - 1. Lymphoma  
   - 2. Squamous cell carcinoma  
   - 3. Basal cell carcinoma  
   - 4. Adenocarcinoma  
   - 5. Kaposi’s sarcoma  
   - 6. Don’t know/Not sure

11. Which **ONE** of the following factors is **LEAST** likely to be associated with oral cancer: (CHECK ONLY ONE)  
   - 1. Increasing age  
   - 2. Familial clustering  
   - 3. Alcohol consumption  
   - 4. Tobacco use  
   - 5. Don’t know/Not sure

12. The symptom most commonly expressed by a patient with an **EARLY** oral cancer is: (CHECK ONLY ONE)  
   - 1. Pain  
   - 2. Ulceration  
   - 3. Swelling  
   - 4. None; patient is asymptomatic  
   - 5. Don’t know/Not sure

13. The majority of oral cancers are diagnosed in people who are: (CHECK ONLY ONE)  
   - 1. Less than 18 years of age  
   - 2. 18 - 39 years of age  
   - 3. 40 - 59 years of age  
   - 4. 60 + years of age or older  
   - 5. Don’t know/Not sure

14. A lymph node most characteristic of oral cancer metastasis, **when palpated**, is: (CHECK ONLY ONE)  
   - 1. Hard, painful, mobile  
   - 2. Hard, painless, mobile or fixed  
   - 3. Soft, painful, mobile  
   - 4. Soft, painless, fixed or mobile  
   - 5. Don’t know/Not sure

15. Which areas of the tongue are **most likely** to develop oral cancer? (CHECK TWO)  
   - 1. All of the tongue  
   - 2. Dorsal surface  
   - 3. Ventral - lateral border  
   - 4. Anterior - lateral border  
   - 5. Base of tongue  
   - 6. None of the above  
   - 7. Don’t know/Not sure

16. Oral cancer lesions are **most often** diagnosed in which stage: (CHECK ONLY ONE)  
   - 1. Premalignant  
   - 2. Early/local  
   - 3. Regional/distant  
   - 4. Don’t know/Not sure

17. Lip cancers: (CHECK ONLY ONE)  
   - 1. Are related to sun exposure  
   - 2. Are increasing each year  
   - 3. Have a worse prognosis than most oral cancers  
   - 4. Affect the upper lip more frequently than the lower lip  
   - 5. Have not been related to any form of tobacco use  
   - 6. Don’t know/Not sure

18. Early oral cancer lesions **usually** appear as: (CHECK ONLY ONE)  
   - 1. Small painless red area  
   - 2. Small painful red area  
   - 3. Small painful white area  
   - 4. Small bleeding area  
   - 5. Don’t know/Not sure
19. When examining the tongue for oral cancer, the clinician should: (CHECK ONLY ONE)

☐ 1. Have patient stick out tongue as far as possible for inspection
☐ 2. Examine posterior dorsum of the tongue with a tongue blade or mirror
☐ 3. Pull the patient’s tongue and inspect both sides of it
☐ 4. Inspect the underside of the tongue by having the patient raise tongue
☐ 5. All of the above
☐ 6. Don’t know/Not sure (46)

20. Of the following conditions, which TWO are most likely to be associated with oral cancer? (RANK IN ORDER OF IMPORTANCE) (47-48)

☐ 1. Leukoplakia
☐ 2. Erythroplakia
☐ 3. Pemphigus vulgaris
☐ 4. Migratory glossitis
☐ 5. Denture stomatitis
☐ 6. Don’t know/Not sure

First _____
Second _____
Write in number

Tell us about the health histories you intake.

21. When taking a medical history, which of the following do you assess? (CIRCLE ONE RESPONSE ON EACH LINE)

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Don't Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Patient’s past alcohol use</td>
<td>1</td>
<td>2</td>
<td>(49)</td>
</tr>
<tr>
<td>b. Patient’s present alcohol use</td>
<td>1</td>
<td>2</td>
<td>(50)</td>
</tr>
<tr>
<td>c. Type &amp; amount of alcohol used</td>
<td>1</td>
<td>2</td>
<td>(51)</td>
</tr>
<tr>
<td>d. Patient’s previous tobacco use</td>
<td>1</td>
<td>2</td>
<td>(52)</td>
</tr>
<tr>
<td>e. Patient’s present tobacco use</td>
<td>1</td>
<td>2</td>
<td>(53)</td>
</tr>
<tr>
<td>f. Type &amp; amount of tobacco</td>
<td>1</td>
<td>2</td>
<td>(54)</td>
</tr>
<tr>
<td>g. Patient’s history of cancer</td>
<td>1</td>
<td>2</td>
<td>(55)</td>
</tr>
<tr>
<td>h. Patient’s history of HPV</td>
<td>1</td>
<td>2</td>
<td>(56)</td>
</tr>
<tr>
<td>i. HPV vaccine recipient</td>
<td>1</td>
<td>2</td>
<td>(57)</td>
</tr>
<tr>
<td>j. Family history of cancer</td>
<td>1</td>
<td>2</td>
<td>(58)</td>
</tr>
</tbody>
</table>

22. In the United States, which of the following factors places an individual at high risk for oral cancers? (CIRCLE ONE RESPONSE ON EACH LINE)

<table>
<thead>
<tr>
<th>Factor</th>
<th>Yes</th>
<th>No</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Older age</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>b. Use of alcohol</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>c. Use of tobacco products</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>d. Family history of cancer</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>e. Low consumption of fruits and vegetables</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>f. Prior oral cancer lesion</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>g. Poor fitting dentures</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>h. Poor oral hygiene</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>i. Use of spicy foods</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>j. Human papillomavirus</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>k. Hot beverages &amp; foods</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>l. Obesity</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
Tell us your opinions.

23. Please indicate the extent to which you agree or disagree with each of the following statements: (CIRCLE ONE RESPONSE ON EACH LINE)

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
<th>Don’t Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>a.</td>
<td>My knowledge about oral cancer is current.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
<td>SD</td>
</tr>
<tr>
<td>b.</td>
<td>Oral cancer examinations for those 40 years of age and older should be provided annually.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
<td>SD</td>
</tr>
<tr>
<td>c.</td>
<td>Oral cancer examinations for adults 18-39 years of age should be provided annually.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
<td>SD</td>
</tr>
<tr>
<td>d.</td>
<td>I am comfortable referring patients with suspicious oral lesions to specialists.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
<td>SD</td>
</tr>
<tr>
<td>e.</td>
<td>Oral cancer exams can be discontinued after 3 negative exams.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
<td>SD</td>
</tr>
<tr>
<td>f.</td>
<td>My patients are sufficiently knowledgeable about oral cancer risk factors.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
<td>SD</td>
</tr>
<tr>
<td>g.</td>
<td>My patients are sufficiently knowledgeable about oral cancer signs and symptoms.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
<td>SD</td>
</tr>
<tr>
<td>h.</td>
<td>Oral cancer examinations should be a separate reimbursable procedure.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
<td>SD</td>
</tr>
<tr>
<td>i.</td>
<td>I am comfortable palpating lymph nodes in necks of patients.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
<td>SD</td>
</tr>
<tr>
<td>j.</td>
<td>The use of smokeless tobacco places a person at greater risk for oral cancer than those who smoke cigarettes.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
<td>SD</td>
</tr>
<tr>
<td>k.</td>
<td>Dentists are qualified to perform oral cancer examinations.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
<td>SD</td>
</tr>
<tr>
<td>l.</td>
<td>Dental hygienists are qualified to perform oral cancer examinations.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
<td>SD</td>
</tr>
<tr>
<td>m.</td>
<td>Physicians are qualified to perform oral cancer examinations.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
<td>SD</td>
</tr>
<tr>
<td>n.</td>
<td>Nurse practitioners are qualified to perform oral cancer examinations.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
<td>SD</td>
</tr>
<tr>
<td>o.</td>
<td>Early detection improves 5-year survival rates from oral cancers.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
<td>SD</td>
</tr>
<tr>
<td>p.</td>
<td>Lesions associated with smokeless tobacco generally resolve when use is discontinued.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
<td>SD</td>
</tr>
</tbody>
</table>
24. Please indicate the extent to which you personally agree or disagree with each of the following statements:
(CIRCLE ONE RESPONSE ON EACH LINE)

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
<th>Don't Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. I am adequately trained to provide tobacco cessation education.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
<td>SD</td>
<td>DK</td>
</tr>
<tr>
<td>b. I am adequately trained to provide alcohol cessation education.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
<td>SD</td>
<td>DK</td>
</tr>
<tr>
<td>c. Dentists should be trained to provide tobacco cessation education.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
<td>SD</td>
<td>DK</td>
</tr>
<tr>
<td>d. Dentists should be trained to provide alcohol cessation education.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
<td>SD</td>
<td>DK</td>
</tr>
<tr>
<td>e. I am adequately trained to examine patients for oral cancer.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
<td>SD</td>
<td>DK</td>
</tr>
<tr>
<td>f. Most dentists are adequately trained to perform oral cancer examinations.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
<td>SD</td>
<td>DK</td>
</tr>
<tr>
<td>g. Most physicians are adequately trained to perform oral cancer examinations.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
<td>SD</td>
<td>DK</td>
</tr>
<tr>
<td>h. I am adequately trained to palpate lymph nodes in patient’s necks.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
<td>SD</td>
<td>DK</td>
</tr>
</tbody>
</table>

Adjacent Procedures

25. Have you ever heard of the following aids for the diagnosis of oral cancer? Have you used any of the following aids for the diagnosis of oral cancer in the past twelve months? (CIRCLE TWO RESPONSES ON EACH LINE)

<table>
<thead>
<tr>
<th>Have you ever heard of these aids?</th>
<th>Have you ever used these aids?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>No</td>
</tr>
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</tr>
<tr>
<td>a. Toluidine Blue (TB)</td>
<td>1</td>
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<tr>
<td>b. ViziLite Plus with TBlue</td>
<td>1</td>
</tr>
<tr>
<td>c. MicroLux DL</td>
<td>1</td>
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<tr>
<td>d. VELscope</td>
<td>1</td>
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<tr>
<td>e. OralCDx brush biopsy</td>
<td>1</td>
</tr>
<tr>
<td>f. Sapphire VELscope</td>
<td>1</td>
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<td>h. Trimira Identafi</td>
<td>1</td>
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</tbody>
</table>
### Continuing Dental Education

26. Have you ever attended a continuing education course on oral cancer? (CHECK ONLY ONE)  
- □ 1. YES  
- □ 2. NO [SKIP TO QUESTION 28]  

27. When was the last time you attended a continuing education course on oral cancer? (CHECK ONLY ONE)  
- □ 1. Within the past year  
- □ 2. During the past 2 - 5 years  
- □ 3. More than 5 years ago  
- □ 4. Never  
- □ 5. Have yet to attend; graduated dental school within the last year  
- □ 6. Don't know/Not sure

28. Are you interested in attending continuing education courses on oral cancer in the future? (CHECK ONLY ONE)  
- □ 1. Yes  
- □ 2. No [SKIP TO QUESTION 30]  
- □ 3. Not sure/Undecided

29. What types of educational approaches do you prefer? (RANK TWO APPROACHES IN ORDER OF PRIORITY)  
- □ 1. Handout/booklet with self-test  
- □ 2. Continuing education journals  
- □ 3. Audiovisual slide or videotape series  
- □ 4. Satellite telecommunications program viewed at medical centers or taped for future viewing  
- □ 5. Lectures  
- □ 6. Clinical demonstration course  
- □ 7. Study clubs  
- □ 8. Computer-based programs  
- □ 9. Conference call with expert in the field  
- □ 10. Online  
- □ 11. Other, please specify ____________

### Tell us something about you.

30. What is your primary occupation? (CHECK ONLY ONE)  
- □ 1. Private practice dentist  
- □ 2. Dental school faculty/staff member  
- □ 3. Uniformed services/Federal employee  
- □ 4. State or local government employee  
- □ 5. Hospital staff dentist  
- □ 6. Graduate student/intern/resident  
- □ 7. Health/dental organization staff member  
- □ 8. Not in practice/looking for openings/waiting for licensure  
- □ 9. Other, please specify ____________

31. Which of the following best describes your practice setting? (CHECK ONLY ONE)  
- □ 1. Solo practice  
- □ 2. Group private practice  
- □ 3. Community health center  
- □ 4. Hospital  
- □ 5. Other, please specify ____________

32. What is your age? (CHECK ONLY ONE)  
- □ 1. 20 - 29 years  
- □ 2. 30 - 39 years  
- □ 3. 40 - 49 years  
- □ 4. 50 - 59 years  
- □ 5. 60 - 69 Years  
- □ 6. 70 - 79 Years  
- □ 7. 80 years and older  

33. What is your gender?  
- □ 1. Male  
- □ 2. Female

34. In your opinion, did your dental school treat oral cancer exams similar to other procedures in terms of clinical requirements and the receipt of credit? (CHECK ONLY ONE)  
- □ 1. YES  
- □ 2. NO  
- □ 3. Not sure/Don’t recall
35. How would you rate your undergraduate training regarding oral cancer examinations? (CHECK ONLY ONE) (119)

☐ 1. Very good
☐ 2. Good
☐ 3. Poor
☐ 4. Very Poor
☐ 5. Not sure

36. Year of graduation from dental school: 19___ (120-121)

37. In what country were you born? ___________________________ (122-131)

38. In what country did you receive your primary dental training? ___________________________ (132-141)

39. What is your race/ethnicity? (CHECK ONLY ONE) (142)

☐ 1. White
☐ 2. Black
☐ 3. Hispanic
☐ 4. Asian/Pacific Islander
☐ 5. American Indian/Native Alaskan
☐ 6. Other, please specify ________________

Thank you for your assistance with this project. Please return this questionnaire by refolding and placing tape as indicated. Drop in the mail. Postage is paid.
December 16, 2009

Dr. John Smith
1234 Main Street
Any City, MD XXXXX-XXXX

Dear Doctor Smith,

In 2009, an estimated 35,720 adults in the United States will be diagnosed with oral cancer and over 8,000 deaths from the disease will occur. Maryland has significantly decreased its mortality rate for oral cancer in the last decade. For the 2001-2005 reporting period, Maryland ranks 25th among all states compared to 8th as reported for 1997-2001, and now has a slightly lower mortality rate than the U.S. average. However, the annual age-adjusted incidence rate for oral cancers remains significantly higher in Maryland than the national average.

While the state has made progress in its oral cancer prevention initiatives, there is still more work to be done in providing oral cancer education and oral cancer screenings. To develop future interventions, the Maryland State Dental Association and the Herschel S. Horowitz Center for Health Literacy at the University of Maryland, School of Public Health are collaborating on a study of dentists’ practices and opinions about oral cancer. This study is a follow-up to an earlier study conducted in 1995.

You can help by completing the enclosed questionnaire, *Maryland Survey of Dentists: Oral Cancer*. Our pretest showed that the survey could be completed in 15 minutes. **Your assistance is vital to the success of this project.** Help us avoid the expense of follow-up costs by completing this survey today.

Please be aware that your name will not be associated with your answers in any reports. The results from this project will be presented in aggregate form only. Identification numbers linked to your name are used for follow-up purposes so we can send second and third mailings when necessary. No identifying information will be released.

If you have any questions, please call Dr. Alice Horowitz at (301) 405-9797. Thank you in advance for your assistance with this study.

Sincerely,

William F. Martin III, DDS
President, Maryland State Dental Association
January 11, 2010

Dr. John Smith  
1234 Main Street  
Any City, MD XXXXX-XXXX

Dear Doctor Smith,

We hope that you had a wonderful holiday season! Three weeks ago, the Maryland State Dental Association mailed a copy of the *Maryland Survey of Dentists: Oral Cancer* questionnaire to you. Unfortunately, we have not yet received your reply.

If you have already returned your completed questionnaire, please accept our thanks. If not, would you please take a few moments to fill out the enclosed questionnaire as completely as you can? Our pretest showed that the survey could be completed in 15 minutes.

**Your assistance is vital to the success of this project.** Help us to avoid the expense of follow-up costs by completing this short form today.

Please be aware that your name will not be associated with your answers in any reports. The results from this project will be presented in aggregate form only. Identification numbers linked to your name are used for follow-up purposes so we can send a third mailing when necessary. No identifying information will be released.

If you have any questions, please call Dr. Alice Horowitz at (301) 405-9797. Thank you in advance for your assistance with this study.

Best wishes for a healthy, happy and productive 2010.

Sincerely,

William F. Martin III, DDS  
President, Maryland State Dental Association
February 01, 2010

Dr. John Smith
1234 Main Street
Any City, MD XXXXX-XXXX

Dear Doctor Smith,

Several weeks ago, the Maryland State Dental Association mailed a copy of the *Maryland Survey of Dentists: Oral Cancer* questionnaire to you and a subsequent copy. Unfortunately, we have not yet received your reply.

If you have already returned your completed questionnaire, please accept our thanks. If not, would you please take a few moments to fill out the enclosed questionnaire as completely as you can? Our pretest showed that the survey could be completed in 15 minutes.

**Your assistance is vital to the success of this project.** Help us to avoid the expense of follow-up costs by completing this short form today.

Please be aware that your name will not be associated with your responses in any reports. The results from this project will be presented in aggregate form only. Identification numbers linked to your name are used for follow-up purposes so we can account for a response rate. No indentifying information will be released.

If you have any questions, please call Dr. Alice Horowitz at (301) 405-9797. Thank you in advance for your assistance with this study.

Best wishes for a healthy, happy and productive 2010.

Sincerely,

William F. Martin III, DDS
President, Maryland State Dental Association
References


64. Murdock JM and Gluckman JL. (2001). African-American and white head and neck carcinoma patients in a university medical center setting: are treatments provided and are outcomes similar or disparate? *Cancer; Vol. 91(S1), 279–283.*


