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Knowledge of risk factors for oral cancer among adult Iowans

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KNOWLEDGE OF RISK FACTORS FOR ORAL CANCER
AMONG ADULT IOWANS

by
Stella Ogechi Chukwu

A thesis submitted in partial fulfillment
of the requirements for the Master of
Science degree in Dental Public Health
in the Graduate College of
The University of Iowa

May 2013

Thesis Supervisor: Professor Daniel Caplan

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CERTIFICATE OF APPROVAL

MASTER'S THESIS

This is to certify that the Master's thesis of

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has been approved by the Examining Committee
for the thesis requirement for the Master of Science
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To
the Chukwu family and the “Mad Scientist”
thank you for supporting me each step of the way.

“An ounce of prevention is worth a pound of dental cure.”
Dental Public Health Proverb

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LIST OF ABBREVIATIONS

MD	Maryland
NC	North Carolina
NHIS	National Health Interview Survey
NJ	New Jersey
NY	New York
OC	Oral Cancer
US	United States

CHAPTER I

INTRODUCTION

The purpose of this study is to assess adult Iowans' knowledge, opinions, and practices concerning oral cancer prevention and early detection. Specifically the purpose is to determine whether their levels of health literacy, and whether they have had an oral cancer exam, are related to their knowledge of risk factors for oral cancer. Findings from this study will provide baseline information needed to inform future planning and intervention efforts in oral cancer prevention and early detection in Iowa.

Oral cancer (OC), also known as Oropharyngeal Carcinoma, is the 8th most common cancer in the US (1). As of 2009, there were 264,442 people with OC. An estimated 40,250 people will be diagnosed with OC and 7,850 people would have died of this cancer in 2012 (2,3). The median age at the time of OC diagnosis in 2011 was 62 years. Ninety-five percent of OC are diagnosed in people 45 years and older (4). The age adjusted incidence rate in 2011 was 10.8 per 100,000 men and women per year (1).

The overall US 5-year survival rate during 2002-2008 for people diagnosed with OC was 61.5%. For those diagnosed at the localized stage, the 5-year relative survival was 82.4%, for the regional stage 57.3%, and for the distant stage 34.9%. Thirty-five percent of lesions were diagnosed at the localized stage (1). OC comprises 85% of head and neck cancers (5,6), and the majority of OC are squamous cell carcinomas. The primary sites for OC include the lateral borders of the tongue and floor of the mouth (6). Other OC sites include the lip, gingivae, tonsils, minor salivary glands, hard palate, nasopharynx and oropharynx (7). Men are three to five times more likely than women to be affected (2,8,9). There has been a recent increase in OC in those without traditional

risk factors - alcohol and tobacco use (10-12) - that might be attributed to increasing rates of HPV infection (13).

In Iowa, between 2005-2009, OC mortality has been declining slowly. The average number of deaths per year in Iowa is 82 and Iowa's annual death rate is 2.5 per 100,000 (14). In 2007, the age adjusted Iowa statewide OC incidence rate was 9.6 per 100,000 persons per year (15). In Iowa in 2011, oral cavity cancer was among the top ten types of cancer in men (16).

The demographic characteristics of Iowa are changing. Currently there are about three million Iowans, of whom 453,000 are age 65 years and older, and by the year 2030 and 2040 the population of Iowans age 65 years and older is estimated to increase to 667,000 and 856,000 respectively. Those age 65 years and older also are living longer (17). Iowa has similar averages to those of the US with regard to the percentage of people who are 65 years and older, smokers, and alcohol users (18) which are risk factors for OC. The African American and Hispanic populations in Iowa are also expected to increase during the coming years (19). This is important because African American males have lower OC survival rates compared to Caucasian males (1).

A risk factor is a characteristic or behavior that increases one's possibility of disease (20). Risk factors for OC include tobacco and alcohol use, unprotected exposure to sun (which can cause labial carcinoma), lack of dietary fruits and vegetables (21), the use of marijuana (22) and the Human Papilloma Virus-16 (HPV-16), a sexually transmitted virus (21). The American Cancer Society suggests that anyone who is at high risk or over 40 years old should have an OC exam once a year (23).

Another factor that possibly contributes to OC may be low levels of health literacy. The term “health literacy” was first used in a 1998 WHO health promotion glossary (24). Today, health literacy is defined as the “degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (25), while 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” (25). It has been suggested that lower patient health literacy is a barrier to effective medical diagnosis and treatment (26). Given the prevalence of and mortality associated with OC, adequate health literacy needs to be emphasized. Health literacy is recognized as a national problem. In the US only 12 percent of adults are considered proficient in completing tasks essential to navigating the health system and carrying out health instructions (27). The average US adult’s reading skill is at the 8th or 9th grade level, but most health education materials are written at or above the 10th grade reading level (28). As such, the National Institutes of Health has allocated funds for health literacy studies, and health literacy has been included among the Healthy People Initiatives (28,29).

Dentists and other health care providers can be very influential in helping patients quit tobacco and alcohol use by obtaining accurate health histories, providing comprehensive OC exams and explaining the OC exam to patients (30). Providing these exams and screenings can help increase OC risk factor knowledge and awareness as long as the dentists or other health professionals explain what they are doing and why. OC screenings have generally been recommended for high-risk individuals to decrease OC morbidity and mortality (6).

Research Questions and Hypotheses

The two research questions investigated in this study were:

Research Question 1: Is having had an OC exam associated with knowledge of risk factors for OC?

Hypothesis 1: There is a positive association between having had an OC exam and knowledge of risk factors for OC.

This analysis would test the hypothesis generated by the Horowitz study (31), which found that “adults with higher levels of knowledge about risk factors for oral cancers were more likely to have had an oral cancer exam”.

Research Question 2: Is health literacy associated with knowledge of risk factors for OC?

Hypothesis 2: There is a positive association between health literacy and knowledge of risk factors for OC.

Policy Implications

With Iowa’s “Baby Boomers” nearing retirement, the elderly population (age 65 years or older) is growing and Iowa is expected have the 7th largest elderly population in 2025 (32). Research about adult Iowans’ knowledge of OC risk factors would be beneficial for certain populations that are at higher risk for OC like tobacco users, alcohol users, the elderly and those who have not been vaccinated for HPV-16. This study on adult Iowans’ knowledge and practices concerning OC is needed to provide baseline information upon which to develop educational interventions.

Currently, Iowa has a cancer prevention plan in place. The plan includes programs to decrease tobacco use like the “Farm Progress Show Health and Safety Tent, Tobacco-

Free Schools, and the Community and Worksite Mentoring Project”(33). There are also protective behavior projects in place like “Sun Safety” to educate on the harm of sun and ultraviolet exposure (33). Iowa has passed two major pieces of legislation to reduce tobacco use: the Smoke Free Air Act of 2009 (34), which prohibits smoking in all workplaces; and the cigarette excise tax of 2007, which increased cigarette tax by one dollar per pack of cigarettes (35).

It is important to investigate whether better oral health promotion is needed to reach a diverse audience with various levels of health literacy. Data from this study would be of interest to employers and insurance companies, who may consider providing dental coverage for preventive services. The results of this study could be used in Iowa to convince Medicaid payers to pay for oral cancer examinations, which they currently do not cover (36). The ultimate goal of this study is to obtain baseline data that can be used to develop educational interventions to increase OC literacy and the provision of OC examinations. Through an assessment of what Iowans know and do about OC, a determination can be made as to whether more oral health promotion is needed to increase awareness among Iowans about OC prevention and detection.

CHAPTER II

LITERATURE REVIEW

This section will review the scientific literature related to the study described in this thesis (hereafter referred to as the Iowa study), specifically focusing on whether having an oral cancer (OC) exam is associated with knowledge of risk factors for oral cancer and whether health literacy is associated with knowledge of risk factors for oral cancer. This first section of the literature review will set the foundation for the use of OC exams and its association with knowledge of OC risk factors.

Oral Pharyngeal Cancer

Mehta et al. conducted a retrospective cohort analysis and provided some background information about OC over the last thirty years in the US (37). Changes in demographics, histology, and survival trends also were discussed. The purpose of the Mehta et al. study was to better understand the relationship between HPV and OC and to extrapolate better treatment options, prognosis, and eventually prevention of OC.

The authors found that 60% of head and neck squamous cell carcinoma patients were between the ages of 55 and 65 and typically were males. HPV-associated OC had a better prognosis compared to non-HPV associated OC. HPV positive tumors had a tendency to be localized to the palatine and lingual tonsils (37). Also, “. . . HPV related head and neck squamous cell carcinoma patients are generally five years younger than their traditional non-HPV counterparts with equal occurrence in male and females” (37). With the increased incidence of HPV associated oral cancers (13,38), more attention should be paid by dentists to the visual inspection of the base of the tongue and palatine tonsils during OC examinations (39).

The American Cancer Society has recommended, “on the occasion of a periodic health examination, the cancer related checkup should include examination for cancers” including the oral cavity for early detection in average risk, asymptomatic individuals age 20 years and older (40). Routine dental visits could help with awareness of oral cancer screening exams if the dentist or dental hygienist provides an OC exam and explains what they are doing and why.

The idea of routinely screening every patient was not practical, but selective opportunistic screening was suggested as a better option (41). McGurk et al. suggested molecular screening of saliva and opportunistic screening of individuals at higher risk as a more cost effective strategy than screening all patients. Thus, when determining which patients were at high risk and establishing a standard of care for OC screening and exams, two options and techniques were considered (41). Routine screening was not recommended and was noted ineffective because of low OC frequencies, 7 cases per 100,000 individuals per year in Europe (42). The current recommendations since 2004 from the US Preventive Services Task Force state that “the evidence is insufficient to recommend for or against routinely screening adults for oral cancer” (43).

In 2000, the US Department of Health and Human Services released the 2010 National Health Objectives for oral cancer examinations (29). The 2010 oral cancer objectives differed from the 2000 objectives with more emphasis placed on the importance of oral cancer exams in the 2010 objectives. The 2010 Objective 21.6 stressed a need to increase the number of oral cancers detected at earlier stages, while Objective 21.7 strived to increase the proportion of adults receiving an oral cancer exam in the past 12 months (29).

Dental (Oral Cancer Exam) Utilization Nationally

Health care providers should improve the utilization rates of oral cancer exams especially in higher risk populations, defined in a Macek et al. study as current smokers and edentulous alcohol users who did not see a dentist in the last year (44,45). This increase could help to promote oral cancer awareness and potentially detect oral cancers at earlier stages. Routine OC exams are important in that they allow a patient to obtain counseling from providers on OC risk factors.

Langevin et al. (39) evaluated the relationship between the impact of dental insurance status and regular dental visits for early oral cancer detection. The study involved Boston area dental patients providing a self-administered questionnaire on health behaviors and demographics. The authors hypothesized that “oral and pharyngeal cancer patients without dental insurance visit the dentist less frequently, resulting in fewer encounters allowing for opportunistic screenings, which may lead to diagnostic delays” (39).

Langevin and colleagues suggested opportunistic screening as the more cost-effective alternative to systematic population-based screening programs (46-51). In the Langevin et al. study there was no association between dental insurance status and oral cancer diagnosis stage (overall or by site). Those with dental coverage saw the dentist more regularly than those without coverage, suggesting there was a benefit in having dental insurance with regard to oral cancer screening. The strengths of this study included that the authors highlighted that many dentists may feel competent with the visual component of oral cancer exams, however, “they are less likely to feel adequately trained in tactile skills” (52), with less than half palpating the cervical nodes with regularity and

even fewer palpating the tongue and floor of the mouth on a consistent basis (53). The Langevin et al. study supports the idea that there should be education of providers to ensure that oral cancer exams are performed correctly with respect to palpation (39). Limitations of this study included the level of dental coverage, which could have encompassed underinsured patients among the insured. What takes place during the oral cancer exam is very important and some studies in other states (54-57) did not evaluate the thoroughness or regularity of the examination (39). In studies by Yellowitz et al., many dentists were not very thorough with OC exams in that they did not “know what to look for or where to look when they perform oral cancer examinations – and dentists maintain they do provide such examinations- they may not find or recognize suspicious lesions” due to lack of OC knowledge (58,59).

A Geana et al. study on the knowledge and practices of health care providers suggested there was inconsistent knowledge of risk factors and signs of oral cancer, which translated into inconsistent oral cancer exam practices (45). The objective of the Macek et al. study was to determine by multivariate analyses whether cigarette smoking and alcohol usage were associated with obtaining an oral cancer examination (44). The Macek et al. study stressed the importance of identifying high-risk individuals, specifically those who are or were smokers and alcohol users. This cross-sectional study used the public-access version of the 1998 National Health Interview Survey (NHIS) (60) which included adults 40 years of age and older. Responses to tobacco and alcohol use were combined to produce a variable with three levels (current, former, or never) based on the survey participants’ activities in the past year. Covariates were based on age, sex, race/ethnicity, poverty status, geographic region, presence of a dental visit in the last

year, and dentition status (44). To ensure similar sample sizes between adjusted and unadjusted analyses, those with unknown oral cancer examination history, unknown cigarette smoking status, unknown alcohol use, unknown dentition status, as well as those of “non-Hispanic other” race and those with unknown race/ethnicity were not analyzed (44).

Current smokers, regardless of dentition status, were not more likely to have an oral cancer exam than those who never smoked. Current alcohol users and former alcohol users were more likely to have had a dental visit and receive an examination in the last year than abstainers (44). Results from the Macek et al. study were inconclusive, suggest that high-risk individuals generally did not visit health professionals hence they would not receive an oral cancer exam (44). The second explanation referred to recall bias, it suggested that high-risk individuals who saw a health care professional could have had an exam but did not recall it. Some qualitative studies suggested that oral cancer examinations were not mentioned unless the provider found a suspicious lesion (61). The third rationale was that the individual saw a dentist but did not receive an oral cancer exam. Macek et al. suggested standardized patient records to include high-risk behaviors like tobacco and alcohol status on health history forms, which most dentists incorporated as part of their patient assessment (44). Limitations of this investigation included that the 1998 NHIS did not actually verify that oral cancer exams took place by chart audits or independent observations (44). The “true” prevalence of lifetime oral cancer exams may have been underestimated if people received an exam without their knowledge. The results also could have underestimated the number of those who actually had an oral cancer exam since many people were excluded from the study because they did not meet

established inclusion criteria. Strengths of this study included definitive associations made between risk factors for oral cancer and having an oral cancer exam while controlling for covariates such as socioeconomic status and other demographic variables. The ability to use national data to assess associations between alcohol usage and having an oral cancer exam also was a benefit (44).

Knowledge, Opinions and Practices Regarding OC Prevention

Lack of access to health care providers who could provide an oral cancer exam may include geographic barriers due to the distance to the nearest health provider; lack of dental insurance; lack of knowledge about the importance of OC exams; and cultural factors. With cultural beliefs and social norms, language can also be a barrier. All of these barriers should be considered when evaluating dental care utilization for oral cancer exams.

Barriers

A study by Irwin et al. investigated the quality of OC information on the Internet. The authors hypothesized that “a potential reason for the imbalance in content presentation may be the absence or dearth of basic information or research on various aspects of the disease” (62). Unlike the peer review process for journal publications, which involves a series of steps, information on the Internet does not go through the same process, resulting in variations in the quality of information presented. The original evaluation contained 21 questions; this study modified the evaluation to include 17 questions and used rating and coding systems to evaluate the quality of web health information. The authors designed a search strategy with the help of a Medline Plus search to identify web sites about oral cancer and their quality of OC information. They

searched Google and Yahoo using the keywords oral cancer, mouth cancer, and tongue cancer. The website search avoided and excluded professional and complex terms, then generated a table of the average score for English and Spanish web sites on a scale from 1 to 100 with 100 being the best overall website with respect to quality and content.

The search calculated 5 to 26 percent of website users for oral health were consumers, 11 to 17 percent were providers, and the remaining users were researchers (62). In 2008, 80% of US adults used the Internet to search for general health information and 15 percent used it to find dental health information (62). Many websites did not give references to the literature. Strengths of this Irwin et al. study included the design of a novel way to determine OC content of English and Spanish websites while evaluating for “surface quality” of websites, which was defined as “ a) the information is presented in a manner free from propaganda or disinformation (objectivity), b) the information is a complete, not a partial picture of the subject (completeness) and c) all aspects of the information are given and are not restricted to present a particular viewpoint (pluralism)” (62,63). This assessment tool could be used to determine the usefulness of OC websites, although “no statements about the reliability, validity, or generalizability of results could be made”. Clinicians could use the score to recommend certain websites to patients seeking more OC knowledge. The authors suggested the key to ensure quality in web health information was objectivity, completeness, and pluralism. Information available regarding OC on the Internet could be unreliable as information could change or no longer be available if one revisited the website at a later date. Due to the rapidly changing information presented on the Internet, the Irwin et al. study only presented a “snapshot in time of information” (62). If another researcher were to conduct this same study,

information on websites could be altered as websites change daily. Not many people rated this novel assessment tool and there could have been cultural differences in the way English and Spanish groups present information they felt was important on websites.

A Slaughter et al. study (64) discussed a Health and Human Services program, “MAP-IT”, as a strategic planning guide to address community health issues. An educational program in Philadelphia used the “MAP-IT” template to help promote better oral health knowledge among African Americans (64). An important goal of this study was to transfer the knowledge gained from the MAP-IT program to other family members.

The focus group that used the “MAP-IT” program, suggested simple phrases and images to raise awareness of preventive dental visits instead of visits to the dentist when only experiencing pain (64). Other findings from the Slaughter et al. study indicated that elders should be more active in asking questions when seeing their dental providers (64). Providers should explain things in as simple terms as possible when communicating educational interventions. Results from other studies had suggested the use of non-technical images with males and females, the use of color, and brief informal texts to make concepts more understandable (65-67). These suggestions would hopefully help everyone, especially elders, to address non-painful oral signs and symptoms that may present as warning signs for OC. The “MAP-IT” program had educational merit and presented motivators that could influence regular dental service utilization among the study population (64). “In summary, racial and ethnic minority older adults had considerable unmet dental care needs and were characterized as being problem-oriented, episodic dental care utilizers” (64). This could have been due to many factors including

lower levels of health literacy and geographic barriers that limited their access to a dentist or not adhering to medical counsel. The Slaughter et al. study suggested that tailored oral health programs brought changes in health knowledge (64). The take-home message for participants was that self-care and regular professional care equals good oral health (64).

A Butani et al. study investigated the literature from years 1980- 2006 using a PUBMED search for sources related to five main categories on cultural oral health information. The five categories included “basic conceptual models on ideas about health and disease, help-seeking for oral conditions, especially the use of folk or traditional health remedies, diet, beliefs and practices about teeth and the oral cavity and oral hygiene practices” (68). An understanding of dental utilization rates was important to analyze patients’ beliefs and values in health practices and prevention.

The authors noted that when several other authors discussed this subject matter, many of them frequently generalized and stereotyped certain ethnic groups without fully understanding the diversity that existed, such as “socio-economic class, income, education, geographic location, religion, language and history of migration into US, or level of acculturation” (68). The ideas in the Butani et al. study support the research premise that individuals who had an OC exam and had higher levels of health literacy were more likely to have OC risk factor knowledge based on their dental exposure (68). Low oral health literacy skills can impede the ability to seek out needed health information and to process, understand and use it to make appropriate decisions to improve oral health (31). The following studies shed light on the lack of OC knowledge and practices among adults.

North Carolina Study

A North Carolina (NC) study conducted by Patton et al. was used to compare OC risk factor knowledge and OC exam experiences with those observed in a 1996 MD study on OC knowledge. One of the objectives for the NC study was to investigate associations on background variables based on three outcomes: knowledge of signs of oral cancer, oral cancer risk factor knowledge, and ever having had an oral cancer examination (69).

The NC study was a telephone survey that consisted of 36 questions. To compare the NC study with the population of adults in NC, sample weights were used. There were five risk factors assessed in this study. The three correct risk factors were tobacco use in any form, regular alcohol drinking, and excessive sun exposure. The two incorrect risk factors were eating hot and spicy foods and frequently biting the lip or cheek.

The response rate was 62%. The categories and results for risk factor knowledge were as follows: 3% in the low (0-1 correct), 41% in the middle (2-3 correct) and 56% in the high category (4-5 correct). Patton suggested “a combination of personal knowledge of oral cancer signs and risk factors, personal awareness of oral health status, and professional oral cancer examinations may influence the early detection, morbidity and mortality of oral cancers” (69). Fourteen percent of adults never heard of OC and 29% never had an OC exam. Patton et al. noted that 23% of those 40 years or older stated they had an OC exam within the last year. “Smokers were 2.3 times less likely and people who were not educated beyond high school were 1.7 times less likely to recall having received an OC examination than non-smokers and those with some college education, respectively” (69). The NC study found higher risk factor knowledge to be significantly associated with “younger age, having more than a high school education, being dentate, feeling personal behaviors over which one has control cause most cancer, being

concerned about cancer, not using smokeless tobacco, and knowing one or more signs of oral cancer” (69).

Maryland Studies

MD is a model state in the efforts it has made over the last 15 years toward improving OC awareness. The 1973-1998 SEER cancer data suggested MD ranked 27th in OC prevalence among all states (70). MD’s mortality rate was ranked the 7th highest for African American men during this period (70). MD conducted several statewide assessments between 1998-2010 (6,30,31) regarding the public’s knowledge, opinions and practices on OC. Horowitz et al. investigated OC knowledge in MD and nationally.

The goal of the Horowitz et al. 1996 MD Adults’ Knowledge of Oral Cancer Prevention and Having Oral Cancer Examinations Study was to determine what MD adults knew and practiced regarding OC. Information was also gathered about OC literacy to help establish the best practices for prevention and early detection of OC (6). In addition, investigators gathered information on why MD adults did or did not receive OC examinations and what they knew about OC (31). The data were collected for a statewide needs assessment to design, implement, and evaluate a state model to increase awareness and treatment of OC in MD. The 2010 MD OC survey of adults used a private survey firm, Opinion America Group (OAG), to recruit participants for a telephone survey (31). This study evaluated the knowledge of OC risk factors, signs and symptoms of OC and factors associated with having had an OC examination among MD adults. This was a descriptive, cross-sectional study of knowledge about risk factors for OC. The results of the 2010 study have not been published yet, however that study (71) provided useful background information and guidance to conduct the present Iowa study. The 1996

and 2010 study used similar NHIS questions. The 1996 study interviewed respondents from land phones only, while the 2010 study surveyed both land and cell phone users. In the 1996 MD study, the association between each of the independent variables and the dichotomous dependent variables were analyzed. The dependent variables were having had an OC examination, knowledge of one sign of OC, and knowledge about risk factors for OC.

With respect to knowledge of one sign of OC, multivariate logistic regression analyses found two variables to be significant, age and level of education (years) while in bivariate analyses one variable was significant, use of smokeless tobacco. The investigators stressed that misinformation on the topic of OC overall was high and knowledge about OC risk factors and signs and symptoms was very low. Limitations and factors that could have contributed to the major difference between national and state data concerning ever having had an OC examination included the “type of interview, response rate, age of population, sex difference, level of education, and more dental visits on a national level” (31). “A major difference between national and state data concerned the lifetime prevalence of ever having had an OC examination” (31). Authors suggested developing continuing education opportunities for dentists to ensure OC exams were performed properly and to help bring more OC awareness to the public. It was also suggested that health care providers should better assess their patients’ behaviors and provide information on OC prevention (31). From the 1996 study and other OC trends gathered in MD, statewide recommendations for better oral health literacy promotion were made. The main conclusions from the 1996 study were that levels of knowledge were low and more educational interventions were needed to target those with lower

levels of knowledge to help improve understanding and the likelihood of requesting an OC exam. The authors stated that more OC interventions should be directed towards higher risk populations, including the less educated, young adults, the elderly and tobacco users.

There were five major themes gathered from a Horowitz et al. 2002 qualitative study on MD adults' perspectives on OC prevention and early detection (6). The themes included 1) awareness of OC and reactions to facts about it, 2) recollections from last visits to the dentist regarding health history taken and performance of an OC examination, 3) what people need to know about OC and OC screening, 4) whether information would motivate people to seek an OC examination and 5) ways healthcare providers should communicate with the public (6). Three focus groups at two different locations were interviewed for this qualitative descriptive study. The participants were randomly chosen from a telephone list and a trained facilitator led the focus groups.

The Horowitz et al. 2002 study found that the majority of participants were “not well informed” about OC and had “never heard” of an OC examination (6). “Participants thought it was strange and disturbing that OC rarely was publicized” and they felt efforts to increase awareness were needed (6). Most participants felt most comfortable seeking physicians for OC related issues because of the (negative) stigma society had associated with dentists (6). Findings from this study also included that dentists did not inform patients when they had performed an OC examination (6). This could have meant that some patients were screened but were not aware of the examination, which could have provided an excellent educational opportunity to discuss OC risk factors and the importance of OC exams (6). At the time of this Horowitz study there were some dentists

who were “reluctant to advise tobacco users to stop their use, because they think such counseling is intrusive and because people in general tend to know already that tobacco use is bad for one’s health” (6). With thorough, accurate health histories, comprehensive OC exams and an explanation of procedures with patients, dentists can be very influential in helping patients quit tobacco use, a very useful and needed action to help in lowering rates of OC (6).

Oral Cancer Awareness

In the past three decades little improvement has been made with respect to survival rates of OC. Alfano et al. suggested better efforts are still needed for earlier diagnosis (30). The next section will summarize the Alfano et al. review article. This article was done as part of a needs assessment to determine appropriate interventions that could help with better OC outcomes (30). The authors highlighted what was done in the MD, NJ and NY areas to bring more OC awareness to their communities. Alfano et al. defined the problem of OC morbidity and mortality and tried to initiate change through focus groups, pamphlets, legislation, professional endorsement, and media programs (30). The Oral Cancer Consortium (OCC) is a coalition formed to increase OC awareness. The OCC gained media attention after they fueled a sense of urgency among the public that OC exams for those at high risk were important. The OCC stressed the importance of OC exams during routine dental visits to help prevent this life-threatening cancer. The consortium’s approach to increasing awareness was to offer continuing education courses and stimulate the public through media techniques that have proven effective (30). Efforts of the OCC were formally evaluated for better OC diagnostic practices in areas with existing and active educational programs. The OCC found the most effective tool

was the use of live television broadcasts to help consumers understand the importance of seeing their dentist for OC screening (30). With approximately 20 minutes of airtime, several interviews with dental representatives from several dental schools in the NY area helped to discuss the causes of OC, how deadly the disease could be, and what comprises an OC examination (30).

Alfano et al. reported that according to a 1996 MD study (30), in 1996, 20% of MD adults received an OC exam not performed by their dentist, but by their physician. Unfortunately, by the time these adults received an exam, most of the OC diagnosed were at a later stage (30). The results of the first phase of the MD study stated that “in general the adults in MD were not knowledgeable about OC prevention and early detection” (30). The majority of participants responded that the examiners did not palpate during their OC examination, which is an important part of the examination (30,65,72-74). A majority of edentulous patients did not receive OC examinations and providers could not identify the most common sites of OC (30,65,72-74). Alfano et al. reported there was an increase in OC diagnostic practices in the MD and NY region. The clinical implications of increased OC awareness for the dental professional and public were significant; effective efforts were needed to encourage OC exams as a routine part of every oral exam. The rationale was that this effort could also help to motivate patients to visit the dentist annually (30). Based on the results from numerous Horowitz et al. studies (6,30,31) the MD Department of Health and Mental Hygiene provided funding to conduct studies across the state on educational interventions on many levels (30). In NY, legislation was passed that a NY dentist had to take a course on OC exams (11). From the Alfano et al. study, efforts were made to create a MD OC Awareness Week, September 16-22, 2001, similar to the media

activities created in NY (30). These public health awareness initiatives continue and tend to culminate during the month of April on a national level.

Health Literacy

The association between health literacy and knowledge of OC risk factors was assessed in the Iowa study. This section will discuss the importance of health literacy on health outcomes and will specifically discuss general and oral health literacy.

General Health Literacy

The Institute of Medicine (IOM) defines health literacy as the “capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (30,75-77). An estimated 90 million US adults could have had unnecessary increased healthcare utilization due to low health literacy levels (77). Forty-three percent of adults function at a basic or below basic level of health literacy (27).

A study by Chew et al. examined whether a single question could help identify individuals with inadequate health literacy by conducting an observational study with hospital veterans (78). Based on Chew’s studies, limited health literacy was similar to a reading level of at or below the 6th grade reading level. Chew describes this individual as one who may misread medication bottles and appointment slips (78). An individual with marginal health literacy level would typically read at the 7th-8th grade reading level and may misread educational brochures and informed-consent documents (78). One with adequate health literacy read at the 9th grade or higher reading level and was generally able to complete most tasks in the health care setting (78).

Results suggested that the best question to assess inadequate health literacy was “How confident are you filling out medical forms by yourself?”(78). The two most frequently used health literacy assessments, S-TOFHLA and REALM, were used to classify patients as inadequate, marginal, or adequate (78) with respect to health literacy. The three health literacy screening questions were: “How often do you have someone (like a family member, friend, hospital/clinic worker or caregiver) help you read hospital materials?” “How often do you have problems learning about your medical condition because of difficulty understanding written information?” and “How confident are you filling out forms by yourself?”(79). A random sample of males at a VA clinic were asked a single question, “How often do you have someone help you read hospital materials?” and this question was predictive of inadequate health literacy (79). Another study done at a university clinic used the question “How confident are you filling out forms by yourself?” and found it to be predictive of identifying patients with limited health literacy (80). In the Chew et al. study, out of a random sample of 4,384 patients, 1,796 (41%) completed an interview at four VA medical centers based on three health literacy-screening questions and two validated health literacy measures (78). The authors highlighted, “poor health literacy has been associated with poor health outcomes such as poorer health knowledge, poorer medication adherence, poorer control of chronic illness, and higher hospitalization rates”(78,81). One strength of this study included the ability to compare two frequently used health literacy assessments against screening questions.

A review article by Parker provided background to the health literacy challenge and how it affected patient-provider communication. This article summarized the challenges of poor health literacy skills and discussed the implications in a patient’s

overall health experience (28). Inadequate health literacy was most common in the elderly population with the elderly having the greatest need of health literacy skills due to a higher prevalence of chronic diseases, thus making it imperative for healthcare providers to understand the implications of inadequate health literacy (28). Patients with limited health literacy tended to have lower SES and health knowledge. Higher risk patients, and those with “extensive and complicated health care problems” tended to be the individuals with more health literacy challenges (28).

Parker stated that healthcare providers should not take a patients’ ability to read and understand for granted as the majority of patients seemed to have difficulty with self-care instructions and communication with health care providers, perhaps due to limited health background (28). Parker suggested for higher risk individuals, poorer knowledge may be associated with increased medication errors and non-adherence (28). The authors also stated that social stigmas regarding lower levels of literacy are present in all aspects of life, even in the health care setting; stigmas cause people with trouble reading to feel ashamed, embarrassed and hide their trouble from health care providers (28).

The Agency for Healthcare Research and Quality (AHRQ) conducted an evidence based review on health literacy, which stated, “low reading skills and poor health were clearly related” (82). Approximately 50% of adults were unable to understand printed medical material (83). The impact of inadequate health literacy was major, as “80% of people had limited ability to fill out medical forms” (84). This inability could have caused shame and made one not likely to ask for assistance, not know what to do for follow up prevention, or leave the medical office with questions unanswered (85). Poor

health literacy problems can also affect timely keeping of appointments and failed dental appointments (86).

A Drainoni et al. study supported the importance of adequate health literacy of patients with chronic illnesses (87). The goal of the study was to investigate the health literacy levels of HIV positive people with concurrent conditions (e.g., substance abuse, incarceration, mental illness, living in an urban area) who also are at risk for receiving inferior health care. This study recruited 231 HIV positive adults from three outreach programs with similar program missions: to improve the health literacy of their participants (87). Participants completed an English or Spanish interview and had to have one of the mentioned concurrent conditions. The validated survey instrument used questions from the Addition Severity Index (88,89), health related indicators, and TOFHLA, a health literacy assessment (87).

Seventy-two percent of participants scored at the adequate health literacy level. “Lower health literacy group were less likely to discuss lab test results and treatment plans with health care providers.” African Americans and those whose primary language was not English were more than twice as likely as Whites to have lower levels of health literacy (87). Four demographic factors (race/ethnicity, education, sexual orientation, and primary language spoken) and the risk factor “having a mental health disorder” were significantly associated with health literacy levels. Those without a high school education were 15 times as likely as those with some secondary education to have lower health literacy (87). The authors stated “further investigation into the relationship between health literacy and the engagement and retention of people living with HIV” are needed (87). The limitations of the Drainoni et al. study included the measurement of health

literacy, since TOFHLA relies solely on reading comprehension and numeracy, while medical directions are usually given by verbal communication and recall (87).

Oral Health Literacy

The National Institute of Dental and Craniofacial Research and the Health and Human Services Working Group on Functional Health Literacy define oral health literacy 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” (90). The concept of limited oral health literacy has been associated with poor oral health knowledge, fewer dental visits, increased dental caries severity, and poor oral health quality of life (26,91-94). Oral health literacy includes the knowledge of OC risk factors, which is evaluated in the Iowa study.

Currently, there are several instruments to measure adult oral health literacy in a research setting, including the Rapid Estimate of Adult Literacy in Dentistry-30 (REALD-30) and the Test of Functional Health Literacy in Dentistry (TOFHLiD) (94). REALD-30 is a 30 word-recognition test to assess oral health literacy that includes a list of dental conditions as well as prevention and treatment terms that subjects read aloud. This instrument is based on the idea that those who have difficulty pronouncing medical and dental words also could have trouble comprehending the words, leading to poorer health outcomes compared to those who can pronounce these words (81). The TOFHLiD contains two sections, including one on reading comprehension and the other on numeracy, to measure functional oral health literacy (94). Gong et al. suggest that TOFHLiD demonstrates the “moderate ability to discriminate between dental and medical health literacy” and that more research on TOFHLiD is needed (81).

Having optimal oral health literacy means being able to understand, interpret and communicate basic oral health information orally and in written form (95). The purpose of the Jones et al. study (26) was to determine the oral health literacy of patients and examine factors that might be associated with their oral health literacy levels. Adult patients in two private dental offices were given the short version of the REALD-30 test.

Those who experienced literacy difficulty were more likely to be men, minorities, the elderly and the less educated (26). The authors suggested there was a disconnect between the ideal reading level needed for dental health educational materials and the ability of the readers to use them. They also stated there was a gap in the oral health literacy literature, with very little research conducted. Lower oral health literacy levels may be a barrier to the use of resources and consequently lead to poor dental outcomes. According to the investigators, during the time of the Jones et al. study there were no medical or dental tests available that gave an overall measure of a person's reading fluency, vocabulary, ability with numbers, oral and written communication skills or his or her capacity to use these skills for health related care (23,96). The study was useful in identifying factors that led to the lack of important health knowledge, unhealthy personal behaviors and poor compliance with medical and dental visits (26). For patients with low oral health literacy, this study suggested that recommending preventive dental services may not be the best way to target this population that was less compliant and unwilling to follow recommended practices. It may be more effective to counsel this group on risk factors to increase their knowledge (97).

Low health literacy costs the nation an average of \$106 to \$238 billion each year (98). Only one in ten US adults is proficient in understanding health related written

material, which highlights the discrepancy of health care needs among the majority of US adults (27). This affects how patients communicate with their providers, how they ask questions (if at all) and what they would admit to understanding (86). The demographics of the US are continuously changing to a “more diverse, older and less educated population” which relies on more self-care related services (86). Thus health literacy issues need to be reassessed to meet the needs of the people with low health literacy levels (86). In 2012, a review article was published (99) by Horowitz and Kleinman that discussed what California has done in clinical settings to improve the oral health of their residents. The authors stressed patient-centered health, defined as “providing care that is respectful of and responsive to individual patient preference, needs, and values ensuring that patient values guide all clinical decisions”(100).

To help provide patient-centered health, the article included recommendations to foster clinical health literacy-based practices for the private and public sector (86). The authors suggested that it is essential that communication skills are effective because the dental team and the environment play an important role in a patient’s health literacy. Effective communication involves “speaking and presenting information in a clear and appropriate format and active listening” (99). By assessing a clinical practice, one can review materials and practices that permit better collaboration with patients regarding health decision-making. The authors suggested using the Agency for Healthcare Research and Quality’s assessment, “Health Literacy: A Universal Precautions Toolkit” (101). This resource does not focus on the dental environment but is thought to be a good method to assess the health literacy of patients in a health care environment (102). The validated health literacy screening questions applicable for a clinical setting from Chew et al. also

were highlighted (79). Authors discussed several oral health literacy tools including the REALD-30, REALD-90 and the TOFHLiD. Though these instruments do not actually measure health literacy, they could provide reading skill approximation relative to health content (99). Other helpful suggestions included asking patients how they like to learn, and suggesting that patients “write down and bring to the appointment any questions they might have about their oral health” (99).

Summary

The literature supports the need for better OC prevention interventions, especially with regard to OC risk factor education. The previously mentioned studies suggest that the Iowa study could be beneficial to help OC prevention awareness. The literature suggests that HPV vaccination and health promotion could address sexual health, and that tobacco cessation programs could help prevent OC (37). Periodic OC exams for those 40 years and older and high-risk individuals (2) represent one of the few ways of detecting this cancer (41). An increased knowledge of oral cancer risk factors would prompt more individuals to ask for an OC exam if one were not provided during the dental visit (44).

It is hoped that useful OC prevention programs and strategies effective in reaching high-risk populations could be designed. OC efforts in states like MD, NY, and NJ have brought media attention to OC awareness (30). Many people face challenges with health literacy; one important message was that one should not use the level of education attained as an indicator of health literacy (28). Better understanding of health literacy is needed to reduce ethnic disparities in healthcare access to better develop effective patient education between the patient and provider (85). To improve oral health literacy, the process begins with providers effectively improving their communication

with patients (99). The support and development of recommendations from organizations like the American Dental Association's National Oral Health Literacy Advisory Committee provide guidance to improve oral health literacy (103).

In conclusion, there are several published studies related to OC awareness and prevention, including several specifically relating to oral cancer risk factor knowledge and its association with one having had an OC exam and health literacy levels. The next chapter will discuss the methodology used in the Iowa telephone survey on adults' knowledge of oral cancer risk factors.

CHAPTER III

METHODS

To determine what the public knew about OC, it was decided to utilize Chew's health literacy questions in addition to Horowitz's 2010 questionnaire on MD adults' knowledge of OC. This study used a 31 item survey previously used with MD adults in 2010 to determine their knowledge and understanding of oral cancer prevention (59,71,104). The addition of the Chew's questions to the Horowitz questionnaire provided the potential for a more coherent understanding of how dental utilization, OC exams and health literacy could be related to knowledge about OC risk factors.

Research Question 1: Is having had an OC exam associated with knowledge of risk factors for OC?

Hypothesis 1: There is a positive association between having an OC exam and knowledge of risk factors for OC.

This project tests the hypothesis generated by the Horowitz study (2001), which found that "adults with higher levels of knowledge about risk factors for oral cancers were more likely to have had an oral cancer exam."

Research Question 2: Is health literacy associated with knowledge of risk factors for OC?

Hypothesis 2: There is a positive association between health literacy and knowledge of risk factors for OC.

To answer these questions, an Iowa statewide, computer assisted random-digit dial telephone survey was conducted using trained interviewers from Opinion America Group (OAG), a private survey consulting firm in New Jersey. The survey format

employed a computer-assisted telephone interview that prompted interviewees with survey questions. The same survey instrument and consulting firm had been used in MD in 2010 to gather information about OC literacy among MD adults. The methods for this study were similar to those used by OAG for the unpublished 2010 survey (71,104) by Horowitz on MD adults' knowledge about OC which is based on questions contained in previous National Health Interview Surveys (NHIS) (105). Unlike the MD study, the Iowa survey did not oversample any particular subgroups.

A sample of 10,100 phone numbers was purchased from OAG, with telephone numbers provided from separate cell and land phone sampling frames. This stratification was done because according to NHIS, 34% of adults in the US live in households with only cell phones (106), and trends for the period from 2003-2012 suggest an increase in the number of people using only cell phones. Iowa residents over the age of 18 were randomly selected using these sampling frames. We targeted approximately 30% of the total sample to be from cell phone exchanges.

Permission to use the survey for the Iowa study was obtained from Dr. Horowitz (71). The survey contained 36 questions, including 31 from the 2010 Horowitz study, three Chew health literacy screening questions and two designed by the study investigators (Appendix A). The survey lasted about ten minutes per respondent. Data collection took place from January – February 2012. Respondents did not receive compensation for participation.

The main exposure variable for Research Question 1 (i.e., whether participants had ever had an OC examination) was determined by survey question 4:

Q4. Have you ever had a test or exam in which the doctor or dentist pulls on your tongue, sometimes with gauze wrapped around it, and feels under the tongue and inside the cheeks?

1. Yes, I'm sure
2. Yes, I think so
3. No
4. Don't know, not sure
5. Refused

If the participant answered 1 or 2 they were considered to have had an OC exam; otherwise they were considered not to have had an OC exam.

The main exposure variable for Research Question 2 was health literacy. It was assessed with a series of three questions: #28) How often do you have someone help you read health materials? #29) How confident are you filling out medical forms by yourself? and #30) How often do you have problems learning about your health condition because of difficulty understanding written information? After evaluating the distributions from the three health literacy questions, it was decided that one question, "How confident are you filling out medical forms by yourself?" would be used as a single proxy variable for health literacy in both bivariate analyses and multivariable regression analyses. In a Chew et al. study (78), the same question, "How confident are you filling out medical forms by yourself?" was determined most effective in identifying individuals with inadequate health literacy. The three questions and their associated response choices are shown below.

Chew Health Literacy Questions

Q28. How often do you have someone help you read health materials?

1. Always
2. Very Often
3. Sometimes
4. Rarely
5. Never

Q29. How confident are you filling out medical forms by yourself?

1. Extremely
2. Very
3. Moderately
4. Slightly
5. Not at all

Q30. How often do you have problems learning about your health condition because of difficulty understanding written information?

1. Always
2. Very Often
3. Sometimes
4. Rarely
5. Never

The outcome variable for both research questions was knowledge of OC risk factors and was based on responses for the twelve potential risk factor items, question 13 a-l (Appendix A). If the participant answered “yes” to “increases chances of getting oral cancer” to items a, b, d, e, f, g, h, and l, those responses were considered correct (Table 1). If the participant answered “no” or “does not increase chances” to items c, i, and j those responses were considered correct. Due to inconclusive scientific evidence, a response of “don’t know” to question 13h (smoking marijuana as a risk factor for OC) was also considered a correct response (22). Poor oral hygiene, question 13k, was not considered a risk factor and a response of “don’t know” was also considered correct (107). For each question, a score of either 0 = incorrect or 1 = correct was obtained, thus there were 12 potential points for OC risk factor knowledge. A total score of eight or higher correct responses out of the 12 risk factor questions was considered high OC risk

factor knowledge. This cut point was the median number correct based on the results, and was chosen during data analysis to create roughly equally sized groups with high and low OC risk factor knowledge.

Table 1. Oral Cancer Risk Factors

Correct	Incorrect
<ul style="list-style-type: none"> ■ a. Too much sun exposure ■ b. Alcohol ■ d. Cigar ■ e. Chewing tobacco ■ f. Smoking beedies ■ g. Having a virus ■ h. Marijuana * ■ l. Oral sex 	<ul style="list-style-type: none"> ■ c. Excessive coffee drinking ■ i. Eating hot or spicy food ■ j. Biting on your lip or cheek ■ k. Poor oral hygiene **

Note: * 2 correct responses-Increase chance or do not know

**2 correct responses-Does not increase chance or do not know

Sample Size Calculations

The sample size was based on frequency distributions from the 1998 MD Study. To achieve a 90% power with a Type I error level of 0.05, using chi-square tests to detect the differences as described in the null hypothesis for Research Question 1, at least 462 participants (n=231 per group) were needed.

Data Analysis

SAS Version 9.3 was used for all data analyses. First, univariate frequency distributions were generated and evaluated, and values of certain variables were grouped together conceptually for the purposes of bivariate analyses. For the bivariate analyses, chi-square tests were used to test the statistical significance of an association between binary variables and the binary outcome variable. The Cochran Mantel-Haenszel chi-square test was used to analyze the ordinal variable responses versus the binary outcome variable. Additionally, the Fisher's exact test was used to examine the association of the outcome variable with categorical independent variables when the sample size was relatively small (i.e. if the expected frequency in any cell was less than five).

To address the two research questions, simple logistic regression analysis was conducted, followed by multiple logistic regression analysis. For each simple logistic regression model, only the main exposure variable was entered. For the multiple logistic regression models, the main exposure variable was forced into the model, and single covariates were added one at a time to that model in a forward stepwise fashion. The forward stepwise logistic regression models then were verified using backward elimination.

Potential covariates were selected based on several factors, including p-value <0.10 in the bivariate analysis; cell size; and conceptual relationship to the outcome variable. A limit of 24 covariates was decided upon since the rule of thumb for logistic regression is that the smaller sample size of n=241 in the low OC knowledge group should have at least 10 times the number of independent variables used in the model. Table 2 has a list of eligible covariates, along with the reason for their selection for, or exclusion from, the list.

Funding and IRB Status

An application for the Delta Dental of Iowa Foundation Graduate Student Award was submitted August 30, 2011 and grant funding for the project was approved October 4, 2011. An application also was made to the University of Iowa Institutional Review Board (IRB) for permission to conduct this study. On September 23, 2011, the IRB chair stated “the activity does not meet the regulatory definition of human subjects research since the University of Iowa (UI) researchers will not interact with the subjects nor have access to identifiable subject information. Thus, the project will not receive formal IRB review and approval and may proceed without it.”

Table 2. Reason for Selection or Exclusion of Covariates

p<0.10 in bivariate analysis	Conceptually relevant	Excluded despite having p<0.10
Gender	Education	Timing of last OC exam (due to low cell size)
Health advice from dentist	Age	12 OC risk factor questions (because the individual questions were used as a component of the outcome variable)
Heard about OC	Health advice from doctor	
Heard of exam for OC	Alcohol use status	
Know one early sign of OC	Last time at dentist	
Smoking status	Dentist ever ask you about alcohol	
Smokeless tobacco status	Last visit to doctor	
Dentist ever ask you about tobacco	Doctor ever ask you about tobacco	
Doctor ever ask you about alcohol	Lost all permanent teeth	
	Someone help you read health information	
	Problems learning about health conditions	

CHAPTER IV

RESULTS

Telephone Responses

A total of 10,100 telephone numbers from the sampling lists were available to be called at random for the survey (Table 3). Of these, 2,060 were working, connected, non-business numbers from the cell phone sampling list. Of all the people contacted from this frame (477), 155 (33%) completed the survey. There were 3,977 working, connected non-business numbers from the land phone sampling list. Of all the people contacted from this frame (1,136), 345 (30%) completed the survey. There were 500 completed surveys total, with 69% from the land phone frame and 31% from the cell phone list. About 16% of the total 500 completed telephone numbers were from cellular phone only households, and 11% were from land phone only households. The total survey response rate was 31% and Table 3 represents a summary of telephone distribution for the sampling frames.

Table 3. Summary of Telephone Responses

	Cell Phone	Land Phone	Total
Sample Universe	2700	7400	10100
“Bad” Sample (non-working, disconnect, business)	640	3423	4063
“Good” Sample	2060	3977	6037
Tried to contact but couldn’t reach	1583	2841	4424
Contacted but person refused to take the survey	303	765	1068
Contacted and the person started the survey but didn’t finish it	19	26	45
Contacted and the person completed the survey	155	345	500

Univariate Analysis

Demographics

The results of the univariate demographic analysis are shown in Table 4. Of the respondents the largest age group (31%) was those 65 years or older, and 95% self reported as White. There were roughly equal numbers of male (48%) and female (52%) participants. The education distribution was scattered with the greatest number (37%) of participants with either a college, graduate or professional degree.

Table 4. Univariate Analysis of Demographic Variables

Variable	Frequency	Percent (%)
Age		
18-34	75	15.2
35-44	56	11.4
45-54	84	17.0
55-64	124	25.2
65+	154	31.2
Race		
Non-White	23	4.7
White	470	95.3
Gender		
Male	240	48.0
Female	260	52.0
Education		
Less than HS/HS	152	30.6
Some college or vocational school	162	32.7
College graduate/Post grad/ Professional	182	36.7
Sampling Frame		
Land phone sampling	345	69.0
Cell phone sampling	155	31.0

Behavioral Health Practices

About 13% of respondents reported being a current smoker (smoking at least one cigarette every day for the last 30 days) (Table 5). About 6% reported using smokeless tobacco within the last 30 days. Over half (52%) of respondents reported drinking alcohol currently. The majority of respondents (65%) said they had seen a dentist within the previous six months. During their dental visit more than half of the dentists (58%) were reported to have asked about tobacco usage.

Eighty percent of respondents said they had a visit to their physician within the previous 6 months. During their visit, 85% reported being asked about tobacco use and 82% reported being asked about alcohol use. Only 9% of respondents said they had been vaccinated for HPV and 12% said they had lost all their permanent teeth.

Source of Health Advice

Respondents were asked ‘from whom or what place do you get advice about health?’ Respondents were read a list of options and were urged to check all that apply. The health advice variables are shown in Table 6. The majority (87%) of respondents said they obtained health advice from a physician, while about 39% said they obtained health advice from a dentist. Other interesting sources of health information mentioned (but not read as choices) included the Internet, other health professionals (such as a pharmacist or hygienist) and insurance wellness consultants.

Information about Oral Cancer

When asked, “Have you ever heard of oral or mouth cancer?” 88% of participants reported they had heard of OC (Table 7).

Table 5. Univariate Analysis of Behavioral Health Practice Variables

Variable	Frequency	Percent (%)
Smoke status		
Never	294	58.9
Ex	142	28.5
Current	63	12.6
Smokeless tobacco status		
Never	464	94.3
Current	28	5.6
Alcohol status		
Never	239	47.9
Current	260	52.1
Last time at dentist		
Within the last 6 months	323	65.1
Within the last 12 months	63	12.7
Within 1-3 yrs.	65	13.1
Never or more than 3 yrs.	45	9.1
Dentist ever ask you about tobacco		
Yes	257	58.0
No	186	42.0
Dentist ever ask you about alcohol		
Yes	170	39.3
No	263	60.7
Last visit to doctor		
Within the last 6 months	385	80.0
Within the last 12 months	66	13.7
More than one year - within the last 3 yrs.	30	6.3
Doctor ever ask you about tobacco		
Yes	405	85.3
No	70	14.7
Doctor ever ask you about alcohol		
Yes	382	81.6
No	86	18.4
Been vaccinated for HPV		
Yes	39	9.2
No	384	90.8

Table 6. Univariate Analysis of Source of Health Advice Variables

Variable	Frequency	Percent (%)
Health advice from doctor		
Yes	433	86.6
No	67	13.4
Health advice from dentist		
Yes	193	38.6
No	307	61.4
Health advice from TV		
Yes	129	25.8
No	371	74.2

Most people (89%) did not cite the dentist as providing knowledge about this cancer. In addition, the majority of respondents (94%) did not cite the doctor as providing knowledge about OC (Table 7).

Table 7. Univariate Analysis of Information about Oral Cancer Variables

Variable	Frequency	Percent (%)
Heard about OC		
Yes	443	88.6
No	57	11.4
Learn about OC from dentist		
Yes	55	11.0
Other	445	89.0
Learn about OC from doctor		
Yes	30	6.0
Other	470	94.0
Learn about OC from TV		
Yes	96	19.2
Other	404	80.8

Knowledge of Oral Cancer Exams

Although 87% reported having heard of oral cancer, over three-quarters (77%) of respondents said they had never heard of an OC exam (Table 8). Less than half (45%) said they had a test or exam where "the doctor or dentist pulls on your tongue, sometimes with gauze wrapped around it, and feels under the tongue and inside the cheeks?" (Note: In this Results chapter, a respondent was considered to have had an exam if they said "yes, I'm sure" (40%) or "yes, I think so" (5%) versus "no or don't know"). Of those who had an OC exam, more than three-quarters (83%) said they had an exam within the past year, as part of their routine dental exam by either their dentist or hygienist. Sixty-one percent of respondents said when they had an OC exam, the health professional explained what they were doing. For those who did not have an OC exam, just about half (47%) provided the following reasons for not having one: 1) no particular reason, 2) they never thought about having an exam, or 3) they did not know they should have an OC exam. Even if a doctor or dentist recommended the OC exam only 28% of all respondents said "yes", they would actually have the exam.

Oral Cancer Exam Sites

When asked who they would see if they found a "lump" in their mouth, 40% said they would see a physician; about 18% said they would see a dentist; and others responded they would not see a doctor or dentist (Table 9). Some said they would pray about it, seek advice from family or friends, or treat it themselves (data not shown). Even if a free OC exam were provided, just about half (48%) said they would still not utilize the service.

Table 8. Univariate Analysis of Knowledge of Oral Cancer Exam Variables

Variable	Frequency	Percent (%)
Heard of exam for OC		
Yes	112	23.1
No	373	76.9
Have you had a test where the doctor wraps gauze around your tongue?		
Yes or Yes, I think so	223	44.6
No or Don't know	277	55.4
Your last OC exam		
Within past yr.	159	64.4
Between 1-3yrs. ago, or over 3 yrs. ago	65	26.3
Never had an oral cancer exam	23	9.3
Main reason for having OC exam		
Specific problem, follow up to a previous oral problem	13	5.8
Part of a routine physical exam	25	11.2
Part of a routine dental exam	186	83.0
Who examined you for your last OC exam		
Doctor/physician	29	12.8
Dentist and dental hygienist	197	87.2
Did they explain what they were doing		
Yes, I'm sure or Yes, I think so	143	61.1
No or Don't know, Not sure	91	38.9
Most important reason for not having OC exam		
No reason/never thought about it/didn't know I should	110	47.0
Not needed/haven't had any problems	51	21.8
Put it off/laziness or doctor/dentist didn't recommend	49	20.9
Costs too much /no insurance or don't go to doctors /dentist/don't like or other	24	10.3
Would have an OC exam, if recommended by a doctor		
Yes	138	27.6
No or Other	362	72.4
Would have an OC exam, if recommended by a dentist		
Yes	123	24.6
No or Other	377	75.4

Of those who responded to not participating in the free OC exam, some said they would not take advantage due to time constraints and scheduling. Those who chose not to participate in the free exam said they felt there was no need (no signs/symptoms), many said they just did not like going to doctors for exams, or did not worry about cancer due to religious belief. About 26% said they would not go to a free exam because they were under the care of a private doctor or dentist and 8% said they felt they had no risk of oral cancer. If a free oral cancer exam were to be held some said they felt the most appropriate place for the exam would be at a community center (40%), while a majority said they had other ideas including the health department, community center church, school, senior center, work or a private medical or dental office.

Knowledge of Oral Cancer Risk Factors

Of the 12 listed potential risk factors for oral cancer (Table 10), most people (98%) said they knew chewing tobacco increased one's risk. The question on cigar use as a risk factor had 96% of respondents answer correctly. For the use of marijuana as an increased risk for OC, respondents who chose an increase or said they don't know were considered correct, and about 87% answered this correctly. Eating spicy foods does not increase one's chances of oral cancer, and 78% of the respondents said they knew this to be correct. Too much coffee does not increase the risk, and 68% of respondents were correct. Smoking beedies does increase the chances of OC, and 61% answered correctly. Having a virus increases the chance, and 60% responded correctly.

Lip biting does not increase the risk of oral cancer (52% answered correctly), however, too much sun exposure increases the risk, and only 48% answered correctly.

Table 9. Univariate Analysis of Oral Cancer Exam Site Variables

Variable	Frequency	Percent (%)
If found “lump” respondent would see doctor		
Yes	200	40.0
Other	300	60.0
If found “lump” respondent would see dentist		
Yes	89	17.8
Other	411	82.2
If free OC exam given, would you go?		
Yes	231	52.0
No or Don't know, Not sure	213	48.0
Reason would not go - private provider*	128	25.6
Seek care from private health care provider	372	74.4
Other		
Reason would not go - no risk*		
Not at risk for oral cancer	40	8.0
Other	460	92.0
Good place to have OC exam at community center		
Yes	201	40.2
Other	299	59.8
Good place to have OC exam at health department		
Yes	129	25.8
Other	371	74.2
Good place to have OC exam at private dentist		
Yes	151	30.2
Other	349	69.8
Good place to have OC exam at private doctor		
Yes	165	33.0
Other	335	67.0

Note: * “Other” includes those respondents who a) said yes, they would have a free OC exam if it were provided; or b) gave other reasons for not having a free OC exam if it were given.

Too much alcohol increases the risk of OC and 44% answered correctly. Many people (60%) said oral sex does not increase the risk of OC. Regarding poor oral hygiene as a risk factor for OC, only 17% had a response of does not increase or do not know, which was considered correct. For the purposes of subsequent bivariate and regression analyses, 52% of respondents answered at least eight of the 12 risk factor questions correctly, and thus were categorized as having high OC risk factor knowledge.

Knowledge of One Early Sign of Oral Cancer

Seventy-eight percent of people knew one early sign of OC (Table 11). Correct responses included white or red patches in the mouth which are not painful, and a sore or lesion in the mouth which does not heal.

Health Literacy

When asked, 'How often do you have someone help you read health materials?', the majority of respondents (88%) answered rarely or never (Table 12). Similarly, the majority of respondents (78%) said they were very or extremely confident in filling out medical forms. Respondents also said they had no problem learning about health conditions as 83% reported they rarely or never had a problem.

Table 10. Univariate Analysis of Knowledge of Oral Cancer Risk Factor Variables

Variable	Frequency	Percent (%)
Chewing tobacco increases risk		
Does not increase- wrong	11	2.2
Increase chance- correct	489	97.8
Cigar increases risk		
Does not increase- wrong	18	3.6
Increase chance-correct	479	96.4
Marijuana increases risk		
Does not increase- wrong	67	13.4
Increase chance/don't know- correct	433	86.6
Eating spicy food increases risk		
Does not increase- correct	392	78.4
Increase chance- wrong	108	21.6
Too much coffee increases risk		
Does not increase- correct	340	68.0
Increase chance-wrong	160	32.0
Smoking beedies increases risk		
Does not increase- wrong	193	38.6
Increase chance- correct	307	61.4
Having a virus increases risk		
Does not increase- wrong	202	40.4
Increase chance- correct	298	59.6
Biting lip increases risk		
Does not increase- correct	262	52.4
Increase chance- wrong	238	47.6
Too much sun increases risk		
Does not increase- wrong	261	52.2
Increase chance- correct	239	47.8
Too much alcohol increases risk		
Does not increase- wrong	281	56.2
Increase chance- correct	219	43.8
Having oral sex increases risk		
Does not increase- wrong	302	60.4
Increase chance- correct	198	39.6
Poor oral hygiene increases risk		
Does not increase/don't know- correct	87	17.4
Increase chance- wrong	413	82.6
Category for knowledge of risk factor		
Low (7 or fewer questions correct)	241	48.5
High (8 or more questions correct)	256	51.5

Table 11. Univariate Analysis of Knowledge of One Early Sign of Oral Cancer Variable

Variable	Frequency	Percent (%)
One early sign of OC		
# Wrong responses: 4, 97, 98	112	22.4
* Correct responses: 1,2,3	388	77.6
*1 = White patches in the mouth which are not painful		
*2 = Red patches in mouth which are not painful		
*3 = Sore/lesion in mouth which does not heal		
#4 = Bleeding in mouth		
#97 = Other		
#98 = Don't know/no answer		

Table 12. Univariate Analysis of Health Literacy Variables

Variable	Frequency	Percent (%)
Someone help you read health material		
Always/very often/sometimes	58	11.6
Rarely/never	441	88.4
Confident filling out medical forms		
Not at all/slightly/moderately	111	22.3
Very/extremely	386	77.7
Problems learning about health conditions		
Always/very often/sometimes	87	17.5
Rarely/never	411	82.5

Bivariate Analysis

Bivariate analyses for characteristics of respondents are shown in the following tables. The tables in this section have four columns, with the second and third columns representing the number and percentage of respondents with low and high OC risk factor knowledge, respectively, described as follows: Two categories of knowledge of OC risk factors were constructed with roughly equal numbers of respondents in each category. With a total of twelve potential OC risk factor questions, a score of eight or higher answered correctly was defined as a high level (51.5%) of knowledge, while a score from zero to seven was defined as a low level (48.5%).

Demographics

Age group was not statistically significantly associated with knowledge of OC risk factors. Of the respondents in the age group 35-44 years, 63% had high knowledge about OC risk factors, followed by the 65 year or older age group (54%) (Table 13). Race was not significant, however, there was a statistically significant difference in knowledge of risk factors between males and females ($p=0.003$), as females (58%) were more likely to have high OC risk factor knowledge compared to males (45%). Among the college graduate, post graduate, and professional education group, 55% had high OC risk factor knowledge compared to 46% among those with less than or equal to high school education and 53% among those with some college or vocational training. The relationship between sampling frame and knowledge of OC risk factors was not statistically significant.

Behavioral Health Practices

The responses pertaining to smoking status were statistically different ($p=0.012$) (Table 14). Those who said they never smoked were more likely to have high knowledge of OC risk factors (54%) compared to those who considered themselves current smokers (34%) ($p=0.012$). Results for smokeless tobacco were also significant ($p=0.010$); those who said they never used smokeless tobacco were more likely to have high knowledge about OC risk factors (53%) compared to the group of current smokeless tobacco users (25%).

Table 13. Bivariate Analysis of Demographic Variables

Variables	Knowledge of Risk Factors		
	Low N= 241 (%)	High N= 256 (%)	P-value
Demographics			
Age			0.538 [‡]
18-34	35 (46.7)	40 (53.3)	
35-44	21 (37.5)	35 (62.5)	
45-54	44 (53.0)	39 (46.9)	
55-64	67 (54.4)	56 (45.5)	
65+	71 (46.4)	82 (53.6)	
Race			0.435 [†]
Non-White	13 (56.5)	10 (43.5)	
White	225 (48.2)	242 (51.8)	
Gender			0.003 ^{†**}
Male	132 (55.5)	106 (44.5)	
Female	109 (42.1)	150 (57.9)	
Education			0.098 [‡]
Less than HS/HS	81 (54.4)	68 (45.6)	
Some college or vocational school	76 (46.9)	86 (53.1)	
College graduate/Post grad/Professional	82 (45.1)	100 (54.9)	
Sampling Frame			0.092 [†]
Land phone sampling	175 (51.0)	168 (49.0)	
Cell phone sampling	66 (42.9)	88 (57.1)	

Among those who said they saw a dentist within one to three years, 55% had high OC risk factor knowledge compared to 39% among those who stated they never had a visit or it was more than 3 years ago. Among those who reported that the dentist asked them about tobacco use, 55% had high knowledge of OC risk factors, compared to only 47% among those whose dentist did not ask about tobacco use. None of the above comparisons showed statistical significance. The difference between levels of OC risk factor knowledge for the question regarding whether the dentist ever asked about alcohol were not significantly different. Fifty-four percent of respondents who said they were asked about alcohol use by their dentist had high knowledge of OC risk factors compared to those who said they were not asked (49%).

Respondents who said they had visited the doctor within the last 12 months included 58% with high OC risk factor knowledge; however, results were not statistically significant compared to their counterparts (Table 14). Of those who said they visited the doctor within the last 6 months, 51% had high OC risk factor knowledge compared to 50% among those who said they visited the doctor more than one year ago or within the last three years.

No significant differences in the levels of OC risk factor knowledge were found for questions that asked the respondents if the doctor asked about tobacco and alcohol use. Of those who reported the doctor never asked about tobacco, 54% had high OC risk factor knowledge compared to 53% among those who said the doctor had asked. Of respondents who said the doctor asked about alcohol use, 54% had high risk factor knowledge compared to 44% among those who said the doctor did not ask about alcohol use. Respondents also were asked if they ever have been vaccinated for HPV, but this

variable was not significantly related to OC risk factor knowledge. Among those who said they were vaccinated for HPV, 59% had high risk factor knowledge compared to 53% among those who said they had not been vaccinated.

Source of Health Advice

The difference in knowledge of OC risk factors was not statistically significant regarding respondents' reported source of health advice. Of those who stated they obtained health advice from their doctor, 50% had high OC risk factor knowledge compared to those who responded they did not receive health advice from their doctor (60%). Of those who stated they obtained health advice from their dentist, 56% had high OC risk factor knowledge compared to 49% among those who responded they did not receive health advice from their dentist; these results were not statistically significant (Table 15). There was no statistically significant difference in knowledge of OC risk factors between those who responded they received health advice from the TV primarily (51%) and those who stated otherwise (52%).

Information on Oral Cancer

There was a significant difference in OC risk factor knowledge between those who said they had heard about OC and those who said they had not ($p=0.003$) (Table 16). Among respondents who answered yes when asked if they had ever heard of OC, 54% had high OC risk factor knowledge, while among those who said they had never heard of OC, 33% had high knowledge. The type of healthcare provider from whom respondents learned about OC was not statistically significant. Of those who said they learned about OC from their doctor, 60% had high OC risk factor knowledge compared to 51% among those who said they learned about it from other sources. Among those who said they

learned about OC from their dentist, 58% had high OC risk factor knowledge compared to 51% among those who said they learned about it from other sources.

Knowledge of Oral Cancer Exams

There was no significant difference in the levels of OC risk factor knowledge between those who said they heard of an exam for OC and those who said they had not heard of an exam for OC ($p=0.061$). There was a significant difference in OC risk factor knowledge based on whether respondents had undergone an OC exam ($p=0.002$). Those who said they had an OC exam performed were more likely to have high OC risk factor knowledge (59%) compared with those who answered no or don't know to having had an exam (45%) (Table 17). There was a significant difference in respondents' knowledge of risk factors based on when they had received their last OC exam ($p=0.009$). For those who said they never had an OC exam, 30% had high risk factor knowledge compared to 61% of those who said they had an OC exam within the past year or between 1 and 3 years or over 3 years ago (54%).

Oral Cancer Exam Sites

Among those who reported that if they found a "lump" they would see someone other than a dentist, 53% had high knowledge of OC risk factors compared to 46% among those who reported they would see a dentist. These results were not statistically significant ($p=0.256$) (Table 18). The difference between levels of OC risk factor knowledge for the question pertaining to reasons one would not go for a free OC exam if they had a private health care provider were statistically significant ($p=0.013$). Among respondents who reported they would not go for a free OC exam because they sought care from a private health care provider, 61% had high knowledge of OC risk factors

Table 14. Bivariate Analysis of Behavioral Health Practice Variables

Variables	Knowledge of Risk Factors		
	Low N= 241 (%)	High N= 256 (%)	P-value
Behavioral Health Practices			
Smoke status			0.012 ^{‡**}
Never	133 (45.6)	159 (54.4)	
Ex	67 (47.2)	75 (52.8)	
Current	41 (66.1)	21 (33.9)	
Smokeless tobacco status			0.010 ^{‡**}
Never	203 (46.6)	233 (53.4)	
Ex	14 (56.0)	11 (44.0)	
Current	15 (75.0)	5 (25.0)	
Alcohol status			0.612 [‡]
Never	103 (54.8)	85 (45.2)	
Ex	22 (44.9)	27 (55.10)	
Current	34 (61.8)	21 (38.2)	
Last time at dentist			0.157 [‡]
Within the last 6 months	150 (46.4)	173 (53.6)	
Within the last 12 months	33 (53.2)	29 (46.8)	
Within 1-3 years	29 (45.3)	35 (54.7)	
Never or more than 3 years	27 (61.4)	17 (38.6)	
Dentist ever ask you about tobacco			0.088 [†]
Yes	115(44.8)	142 (55.3)	
No	97 (53.0)	86 (47.0)	
Dentist ever ask you about alcohol			0.285 [†]
Yes	78 (45.9)	92 (54.1)	
No	133 (51.2)	127 (48.8)	
Last visit to doctor			0.640 [‡]
Within the last 6 months	188 (49.2)	194 (50.8)	
Within the last 12 months	28 (42.4)	38 (57.6)	
More than one year- within the last 3 years	15 (50.0)	15 (50.0)	
Doctor ever ask you about tobacco			0.860 [†]
Yes	192 (47.5)	212 (52.5)	
No	32 (46.4)	37 (53.6)	
Doctor ever ask you about alcohol			0.071 [†]
Yes	174 (45.7)	207 (54.3)	
No	48 (56.5)	37 (43.5)	
Been vaccinated for HPV			0.459 [†]
Yes	16 (41.0)	23 (59.0)	
No	180 (47.2)	201 (52.8)	

Table 15. Bivariate Analysis of Source of Health Advice Variables

Variables	Knowledge of Risk Factors		
	Low N= 241 (%)	High N= 256 (%)	P-value
Source of Health Advice			
Health advice from doctor			0.149 [†]
Yes	214 (49.8)	216 (50.2)	
No	27 (40.3)	40 (59.7)	
Health advice from dentist			0.093 [†]
Yes	84 (43.8)	108 (56.2)	
No	157 (51.5)	148 (48.5)	
Health advice from TV			0.927 [†]
Yes	63 (48.8)	66 (51.2)	
No	178 (48.4)	190 (51.6)	

Table 16. Bivariate Analysis of Information about Oral Cancer Variables

Variables	Knowledge of Risk Factors		
	Low N= 241 (%)	High N= 256 (%)	P-value
Information about OC			
Heard about OC			0.003 ^{***}
Yes	204 (46.2)	238 (53.8)	
No	37 (67.3)	18(32.7)	
Learn about OC from doctor			0.337 [†]
Yes	12 (40.0)	18(60.0)	
Other	229 (49.0)	238 (51.0)	
Learn about OC from dentist			0.294 [†]
Yes	23 (41.8)	32 (58.2)	
Other	218 (49.3)	224 (50.7)	
Learn about OC from TV			0.301 [†]
Yes	42 (43.8)	54 (56.2)	
Other	199 (49.6)	202 (50.4)	

Table 17. Bivariate Analysis of Knowledge of Oral Cancer Exam Variables

Variables	Knowledge of Risk Factors		
	Low N= 241 (%)	High N= 256 (%)	P- value
Knowledge of Oral Cancer Exams			
Heard of exam for OC			0.061 [†]
Yes	45 (40.2)	67 (59.8)	
No	186 (50.3)	184 (49.7)	
Have you had a test where the doctor wraps gauze around your tongue?			0.002 ^{†*}
Yes or Yes, I think so	91 (40.8)	132 (59.2)	
No or Don't know	150 (54.7)	124 (45.3)	
Your last OC exam			0.009 ^{†*}
Within past yr.	62 (39.0)	97 (61.0)	
Between 1-3yrs ago or over 3 yrs. ago	30 (46.2)	35 (53.8)	
Never had an oral cancer exam	16 (69.6)	7 (30.4)	
Main reason for having OC exam			0.145
Specific problem, follow up to a previous oral problem	8 (61.5)	5 (38.5)	
Part of a routine physical exam	11 (44.0)	14 (56.0)	
Part of a routine dental exam	74 (39.8)	112 (60.2)	
Who examined you for your last OC exam			0.706 [†]
Doctor/physician	11 (37.9)	18 (62.1)	
Dentist and dental hygienist	82 (41.6)	115 (58.4)	
Did they explain what they were doing			0.485 [†]
Yes, I'm sure or Yes, I think so	60 (42.0)	83 (58.0)	
No or Don't know, Not sure	34 (37.4)	57 (62.6)	
Most important reason for not having OC exam			0.188
No reason/never thought about it/Didn't know	67 (62.6)	40 (37.4)	
Not needed/haven't had any problems	24 (47.1)	27 (52.9)	
Put it off/laziness or doctor/dentist didn't recommend	27 (55.1)	22 (44.9)	
Costs too much /no insurance or don't go to doctors /dentist/don't like or other	12 (50.0)	12 (50.0)	
Would have an OC exam, if recommended by a doctor			0.359 [†]
Yes	71 (51.8)	66 (48.2)	
No or Other	170 (47.2)	190 (52.8)	

Table 17. Bivariate Analysis of Knowledge of Oral Cancer Exam Variables Continued

Would have an OC exam, if recommended by a dentist			0.313 [†]
Yes	64 (52.5)	58 (47.5)	
No or Other	177 (47.2)	198 (52.8)	

Note: Symbols used in tables

** Statistically significant ($p < 0.05$)

[†] Chi-square test

[‡] Cochran-Mantel-Haenszel Statistics

[#] Fisher's exact test

Table 18. Bivariate Analysis of Oral Cancer Exam Sites Variables

Variables	Knowledge of Risk Factors		
	Low N= 241 (%)	High N= 256 (%)	P- value
Oral Cancer Exam Sites			
If found “lump” respondent would see doctor			0.119[†]
Yes	105 (52.8)	94 (47.2)	
Other	136 (45.6)	162 (54.4)	
If found “lump” respondent would see dentist			0.256[†]
Yes	47 (54.0)	40 (46.0)	
Other	194 (47.3)	216 (52.7)	
If free OC exam given, would you go?			0.259[†]
Yes	116 (50.7)	113 (49.3)	
No or Don't know, Not sure	96 (45.3)	116 (54.7)	
Reason would not go -Private Provider*			0.013[†]
Seek care from private health care provider	50 (39.1)	78 (60.9)	
Other	191 (51.8)	178 (48.2)	
Reason would not go- no risk *			0.429[†]
Not at risk for oral cancer	17 (42.5)	23 (57.5)	
Other	224 (49.0)	233 (51.0)	
Good place to have OC exam at community center			0.120[†]
Yes	153 (51.3)	145 (48.7)	
Other	88 (44.2)	111 (55.8)	
Good place to have OC exam at health department			0.119[†]
Yes	54 (42.5)	73 (57.5)	
Other	187 (50.5)	183 (49.5)	
Good place to have OC exam at private dentist			0.405[†]
Yes	68 (45.6)	81 (54.4)	
Other	173 (49.7)	175 (50.3)	
Good place to have OC exam at private doctor			0.994[†]
Yes	79 (48.5)	84 (51.5)	
Other	162 (48.5)	172 (51.5)	

compared to only 48% among those who reported “other” reasons for not going for a free OC exam if given.

Oral Cancer Risk Factors

Statistically significant differences were detected between each potential OC risk factor and the levels of knowledge of OC risk factors ($p < 0.002$ in all instances) (Table 19).

Knowledge of One Early Sign of Oral Cancer

Among those who correctly reported one early sign of OC, 55% had high knowledge of OC risk factors, compared to 41% among those who incorrectly reported one early sign of OC; this comparison was statistically significant ($p = 0.009$) (Table 20).

Health Literacy

There were no significant differences in knowledge of OC risk factors for any of the three questions relating to health literacy. Among those who said they always, very often or sometimes needed assistance with reading health material, 59% had high OC risk factor knowledge compared to 51% among those who said they rarely or never needed assistance (Table 21). Among those who said they were very or extremely confident filling out medical forms, 54% had high OC risk factor knowledge compared to 45% among those who said they not at all, slightly or moderately needed help. Among those who said they rarely or never have problems learning about health conditions, 53% had high OC risk factor knowledge compared to 45% among those who said they always, very often or sometimes have problems learning about health conditions.

Table 19. Bivariate Analysis of Oral Cancer Risk Factor Variables

Variables	Knowledge of Risk Factors		
	Low N= 241 (%)	High N= 256 (%)	P-value
Oral Cancer Risk Factors			
Too much sun increases risk			<0.000 ^{†***}
Does not increase- wrong	163 (62.7)	97 (37.3)	
Increase chance- correct	78 (32.9)	159 (67.1)	
Too much alcohol increases risk			<0.000 ^{†***}
Does not increase- wrong	167 (60.1)	111 (39.9)	
Increase chance- correct	74 (33.8)	145 (66.2)	
Too much coffee increases risk			<0.000 ^{†***}
Does not increase- correct	112 (70.4)	47 (29.6)	
Increase chance-wrong	129 (38.2)	209 (61.8)	
Cigar increases risk			<0.000 ^{###}
Does not increase- wrong	18 (100.0)	0 (0.0)	
Increase chance-correct	223 (46.6)	256 (53.4)	
Chewing tobacco increases risk			0.001 ^{###}
Does not increase- wrong	9 (100.0)	0 (0.0)	
Increase chance- correct	232 (47.5)	256 (52.5)	
Smoking beedies increases risk			<0.000 ^{†***}
Does not increase- wrong	126 (65.6)	66 (34.4)	
Increase chance- correct	115 (37.7)	190 (62.3)	
Having a virus increases risk			<0.000 ^{†***}
Does not increase- wrong	141 (70.2)	60 (29.8)	
Increase chance- correct	100 (33.8)	196 (66.2)	
Marijuana increases risk			<0.000 ^{†***}
Does not increase- wrong	53 (79.1)	14 (20.9)	
Increase chance/don't know- correct	188 (43.7)	242 (56.3)	
Eating spicy food increases risk			<0.000 ^{†***}
Does not increase- correct	74 (69.2)	33 (30.8)	
Increase chance- wrong	167 (42.8)	223 (57.2)	
Biting lip increases risk			<0.000 ^{†***}
Does not increase- correct	154 (64.7)	84 (35.3)	
Increase chance- wrong	87 (33.6)	172 (66.4)	
Poor oral hygiene increases risk			0.002 ^{†***}
Does not increase/don't know-correct	212 (51.7)	198 (48.3)	
Increase chance- wrong	29 (33.3)	58 (66.7)	
Having oral sex increases risk			<0.000 ^{†***}
Does not increase- wrong	187 (62.3)	113 (37.7)	
Increase chance- correct	54 (27.4)	143 (72.6)	

Table 20. Bivariate Analysis of One Early Sign of Oral Cancer Variable

Variables	Knowledge of Risk Factors		
	Low N= 241 (%)	High N= 256 (%)	P-value
One Early Sign of OC			
One early sign of OC # Wrong response: 4, 97, 98 * Correct response: 1, 2, 3 *1 = White patches in the mouth which are not painful *2 = Red patches in mouth which are not painful *3 = Sore/lesion in mouth which does not heal #4 = Bleeding in mouth #97 = Other #98 = Don't know/no answer	66 (59.5) 175 (45.3)	45 (40.5) 211 (54.7)	0.009^{†**}

Note: Symbols used in tables

** Statistically significant (p<0.05)

† Chi-square test

‡ Cochran-Mantel-Haenszel Statistics

Fisher's exact test

Table 21. Bivariate Analysis of Health Literacy Variables

Variables	Knowledge of Risk Factors		
	Low N= 241 (%)	High N= 256 (%)	P-value
Health Literacy			
Someone help you read health material			0.242 [†]
Always/very often/sometimes	24 (41.4)	34 (58.6)	
Rarely/never	217 (49.5)	221 (50.5)	
Confident filling out medical forms			0.097 [†]
Not at all/slightly/moderately	61 (55.5)	49 (44.5)	
Very/extremely	179 (46.5)	206 (53.5)	
Problems learning about health conditions			0.155 [†]
Always/very often/sometimes	47 (55.3)	38 (44.7)	
Rarely/never	192 (46.8)	218 (53.2)	

Note: Symbols used in tables

** Statistically significant (p<0.05)

[†]Chi-square test

[‡]Cochran-Mantel-Haenszel Statistics

[#] Fisher's exact test

Logistic Regression Analysis

To initially evaluate whether having had an OC exam or having high health literacy were significantly associated with knowledge of OC risk factors (Research Questions 1 and 2, respectively), two simple logistic regression models were developed. Table 22 shows the results of both models in a single table. The results of the first model indicated that the levels of knowledge of OC risk factors were significantly associated with having had an OC exam ($p=0.002$). The odds of high knowledge of OC risk factors for those who reported having had an OC exam were 1.76 (95% CI = 1.23-2.51) times the odds of those who reported having had no OC exam. The second model showed that confidence filling out medical forms was not associated with the level of knowledge of OC risk factors ($p=0.098$).

Table 22. Simple Logistic Regression Models for Knowledge of Oral Cancer Risk Factor Variables

Variable	Knowledge of Risk Factors		Odds Ratio (95% Confidence Interval)	P- value
	Low (n=241) %	High (n=256) %		
Have you had a test where the doctor wraps gauze around your tongue?				0.002
Yes or Yes, I think so	91 (40.8)	132 (59.2)	1.76 (1.23, 2.51)	
No or Don't know	150 (54.7)	124 (45.3)	1.00	
Confident filling out medical forms				0.098
Very/Extremely	179 (46.5)	206 (53.5)	1.43 (0.94, 2.19)	
Not at all/slightly/moderately	61 (55.4)	49 (44.6)	1.00	

Table 23 shows the final multivariable logistic regression model that evaluated the association between OC risk factor knowledge and having had an OC exam (Research Question 1), adjusted for other covariates. Those who said they had an OC exam were significantly more likely to have high OC risk factor knowledge compared to those who said they did not have an OC exam ($p=0.021$), controlling for gender, smoking status, health advice from the doctor, having heard about OC, sampling frame, and health advice from the dentist. The following respondents were more likely to have high OC risk factor knowledge compared to their counterparts: females ($p=0.003$), those who said they were a never or ex-smoker ($p=0.011$), those who said they did not obtain advice from the doctor ($p=0.015$), those who said they had heard about OC ($p=0.016$), those called from the cell phone sampling frame ($p=0.017$), and those who received health advice from a dentist ($p=0.039$).

Controlling for these other predictors, those who said they had an OC exam were 1.57 times as likely to have high knowledge of OC risk factors compared with those who said they did not have an exam. The odds of high OC risk factor knowledge for females were 1.74 times that for males, while nonsmokers and former smokers were associated with a 1.13 greater odds of high OC knowledge compared to current smokers. Participants who did not receive their health advice from a doctor were 2.04 times as likely to have high OC knowledge compared with those who received health advice from a doctor. Those who said they heard about OC were 2.13 times as likely to have high OC knowledge compared to those who did not hear about OC. Those from the cell phone frame were 1.64 times as likely to have high OC risk factor knowledge compared to those from the land phone list. Those who said they received health advice from a dentist were

1.51 times as likely to have high OC risk factor knowledge compared with those who didn't receive advice from a dentist.

Table 23. Multivariable Logistic Regression Model for Exploring the Association Between Knowledge of OC Risk Factors and Having Had an OC Exam, Adjusted for Other Variables

Parameter	Odds Ratio (95% Confidence Intervals)	P-Value
Have you had a test where the doctor wraps gauze around your tongue? Yes or Yes, I think so No or Don't know	1.57 (1.07, 2.30) 1.00	0.021
Gender Female Male	1.74 (1.20, 2.52) 1.00	0.003
Smoke status Never & Ex Current	2.13 (1.18, 3.84) 1.00	0.011
Health advice from doctor No Yes	2.04 (1.15, 3.62) 1.00	0.015
Heard about OC Yes No	2.13 (1.15, 3.97) 1.00	0.016
Sampling frame Cell phone sampling Land phone sampling	1.64 (1.09, 2.47) 1.00	0.017
Health advice from dentist Yes No	1.51 (1.02, 2.25) 1.00	0.039

Table 24 shows the final multivariable logistic regression model that evaluated the association between OC risk factor knowledge and confidence in filling out medical forms (Research Question 2), adjusted for other covariates. Results showed that high OC risk factor knowledge was not associated with confidence in filling out medical forms ($p=0.182$) controlling for gender, smoke status, test where doctor wraps gauze, having heard about OC, sampling frame, and health advice from the doctor. However, this analysis suggested participants who were female ($p=0.006$), said they never or former smokers ($p=0.010$), had an OC exam ($p=0.016$), heard about OC ($p=0.023$), were from the cell phone sampling frame ($p=0.028$) or did not receive health advice from a doctor ($p=0.040$) were more likely to have high OC risk factor knowledge compared to their counterparts.

In this model, the odds of high OC risk factor knowledge among female participants were 1.68 times that of males. Participants who stated they were never or ex-smokers were 2.17 times as likely to have high OC risk factor knowledge compared to current smokers. Those who said they had an OC exam were 1.60 times as likely to have high OC risk factor knowledge compared to participants who said they did not have an OC exam. Those who had heard about OC were 2.05 times as likely to have high OC risk knowledge compared to those who said they had not heard about OC. Participants from the cell phone sampling frame were 1.58 times as likely to have high OC risk factor knowledge compared to those from the land phone sampling list. Participants who said they did not receive advice from their doctor were 1.79 times as likely to have high OC risk factor knowledge compared to those who said they received advice from their doctor.

Table 24. Multivariable Logistic Regression Model for Exploring the Association Between Knowledge of OC Risk Factors and Confidence in Filling Out Medical Forms, Adjusted for Other Variables

Parameter	Odds Ratio (95% Confidence Intervals)	P-Value
Confident filling out medical forms Very/extremely Not at all/slightly/moderately	1.36 (0.87, 2.12) 1.00	0.182
Gender Female Male	1.68 (1.16, 2.43) 1.00	0.006
Smoke status Never & Ex Current	2.17 (1.20, 3.92) 1.00	0.010
Have you had a test where the doctor wraps gauze around your tongue? Yes or Yes, I think so No or Don't know	1.60 (1.09, 2.34) 1.00	0.016
Heard about OC Yes No	2.05 (1.10, 3.82) 1.00	0.023
Sampling frame Cell phone sampling Land phone sampling	1.58 (1.05, 2.37) 1.00	0.028
Health advice from doctor No Yes	1.79 (1.03, 3.14) 1.00	0.040

CHAPTER V

DISCUSSION

The study described in this thesis (“The Iowa study”) confirms the hypothesis that there was a positive association between having had an OC exam and knowledge of risk factors for OC. Those who had an OC exam had 1.57 times the odds of having high OC risk factor knowledge compared to those who did not. The study did not support the hypothesis that there was a positive association between confidence in filling out medical forms (which be used as a proxy measurement for health literacy) and knowledge of risk factors ($p=0.1828$).

Phone Response Summary

The 2003-2012 national cell phone trends suggest an increase in the number of people living in cell phone only households (106). Based on national studies, the percentage of cell phone only households among adult households in 2012 was about 34% (106). Adults living in the Midwest (38%) were more likely than adults living in the Northeast (23%) to live in cell phone only households. Due to more people in the Midwest being likely to use cell phones it was very important that the Iowa study included cell phone users. Most health studies prior to 2007 did not include cell phone users, which produced coverage bias. Coverage bias can occur when people in the same population are not in the same sampling frame (108). The inclusion of cell phone only households in the Iowa study minimized coverage bias and allowed the investigators to survey a broader population.

In the Iowa study, of the 500 completed surveys, 69% came from the land phone list and 31% were from the cell phone list. Those who were from the cell phone list were

more likely than those from the land phone sampling list to have high OC risk factor knowledge (OR=1.64 and 1.58, Table 23 and 24). According to NHIS surveys, younger adults (18-29 yrs.) were more likely than older adults to have cell phone only households (106).

We conducted a limited exploration of potential differences between respondents from the cell phone and land phone sampling frames by comparing the two groups with respect to demographic variables, history of OC exams, smoking status, health advice from a dentist, and confidence in filling out medical forms. Significant differences were found only for age ($p < 0.000$), history of OC exams ($p = 0.002$), and smoking status ($p = 0.043$), with younger people, those who did not have an OC exam, and current smokers more likely to be from the cell phone list than their counterparts. An extensive discussion of factors related to cell phone versus land phone use is beyond the scope of this thesis so will not be further addressed here.

Demographics: Iowa Study vs. Iowa State Population

Comparing the demographics of the Iowa study sample to state of Iowa population demographics, the Iowa study was similar with regard to race and gender (Table 25). The Iowa study had 25% of respondents state they were in the 55-64 yr. group compared to Iowa 2011 Census data showing that the state average was about 17% (109). Thirty-one percent of respondents from the study stated they were 65 yrs. and older compared to the Iowa state average of 20%. In the Iowa study, educational levels were not similar to state of Iowa population. Responses from the Iowa study suggest participants on average were more educated than the Iowa population. For this study,

31% of respondents stated they had less than a HS education or a HS diploma compared to 43% of Iowans with this level of education.

Table 25. Demographics: Iowa Study vs. Iowa State Population

Variable	Iowa Study (Age 18 +) (%)	State of Iowa Census 2011* (%)
Age		
18-34	15.2	26.8
35-44	11.4	16.4
45-54	17.0	19.7
55-64	25.2	16.7
65+	31.2	20.4
Race		
Non-white	4.7	7.0
White	95.3	93.0
Gender		
Male	48.0	48.9
Female	52.0	51.1
Education		
Less than HS/HS	30.6	43.5
Some college or vocational school	32.7	21.7
College graduate/Post grad/ Professional	36.7	34.0

SOURCE: *Information in right column from US Census Bureau, 2011 American Community Survey

Note: The Iowa study age group 18-34 years is compared to the Census data that groups 20-34 year-olds. The Iowa state Census 2011 data for education are based on those 25 years and older. Iowa state Census 2011 data have been recalculated to apply to only those 18 years and older (73.1% of the state population).

Females were more likely than males to have high OC risk factor knowledge, even when other covariates were taken into account (OR=1.74 and 1.68, Table 23 and 24 respectively). This gender difference could be because females are generally more health conscious than males. According to the 2003 National Adult Literacy Survey (NALS) men had lower health literacy scores than women, as 16% of men had below basic scores compared to 12% of women (27). A study by Jones et al. suggested that men, minorities, the elderly, and the less educated were more likely to have health literacy difficulty (26). One could speculate that education and socioeconomic status are positively associated with high OC risk factor knowledge, as suggested by Patton et al. (69). However, this relationship was not observed in the Iowa study. Perhaps those who completed the Iowa survey represent those more aware of OC risk factors regardless of educational status.

Sources of Health Advice

Many people seek the health advice of their doctor (physician) who should review their health history and discuss any risky health behaviors, including risk factors for OC. In the Iowa study, 87% of respondents stated they obtained health advice from a physician. Of those who learned about OC from their doctor, 50% had high OC risk factor knowledge. Those who said they did not obtain health advice from their doctor were twice as likely as those who said they did obtain health advice from the doctor to have high OC risk factor knowledge (OR =2.04 and 1.79, Table 23 and 24). There are many sources of information people use to seek health advice and perhaps respondents to this survey had doctors who did not provide up to date information or did not discuss OC risk factors. In general, it could be because many doctors do not have much knowledge about the oral cavity.

Information about Oral Cancer

There are also many sources from which people can receive oral cancer information. In 1996, 20% of MD adults received an OC exam that was performed by a physician, not a dentist (110). In the Iowa study, 13% of Iowa adults received an OC exam from a physician, not a dentist. One reason may be that some adults do not routinely seek care from a dentist due to negative dental experiences (59). If people are unlikely to seek dental care, it would be difficult for them to obtain advice about oral cancer from a dentist. Another source besides dentists to obtain oral cancer information is the Internet; it has been reported that 80% of US adults use the Internet for general health related information and 15% use it for dental health advice (62), but similar information was not collected during the Iowa study.

Participants who said they obtained health advice from their dentist were more likely than those who said they did not obtain health advice from the dentist to have high OC risk factor knowledge (OR= 1.51, Table 23). This was the only covariate found in just one regression model (all other significant variables were found in both models). Specifically, it was found in the model that explored the association between knowledge of OC risk factors and having had an OC exam (Table 23). One could speculate that this covariate was not significant in both models because only the first model pertained to having had an OC exam and the variable, health advice from a dentist, is related to the first model since dentists typically perform OC exams. The second model pertains to health literacy and perhaps health advice from a dentist is generally not related to confidence in filling out medical forms.

In the Iowa study, 39% of respondents stated they received health advice from a dentist and 11% said they learned about OC from a dentist. Thus, people who obtain health advice from a dentist should freely ask questions and clarify anything confusing during their visit (58). Dentists should not only be concerned with the oral cavity, but also aware of the overall health of their patients (31). Horowitz and colleagues recommended that health care providers examine patient health behaviors and provide appropriate information on OC prevention (31). “Compared to physicians, dentists may be less likely to ask patients about their smoking and alcohol history, but may be more likely to transfer that information into an oral examination when the information is solicited” (83,111,112). Thus, it is important that dentists assess overall health, explain the OC exam and risk factors associated with OC. Patient education and counseling are important components for patient care. Some dentists at the time of the 2002 MD survey were not confident in tobacco counseling and they felt this was beyond their dental scope or was too intrusive (6). This should never be a reason health counseling is not given; more efforts are needed in dentist-patient communication as well as health counseling to discuss OC risk factors.

Those who said they had heard about OC were twice as likely as those who said they did not hear about OC to have high OC risk factor knowledge (OR=2.13 and 2.05, Table 23 and 24). It is not surprising that if one has never heard about OC, there would be only a small chance that they would have high OC risk factor knowledge. Sources of information about OC include the Internet but there is a gap in OC knowledge on some of the Internet websites. The findings from an Irwin et al. study suggested patients usually could not discriminate the quality of health information given on the Internet, so it is

important that potential sources of OC knowledge, like the Internet, present quality user-friendly information.

In the Iowa study, 89% of respondents stated they had heard about OC. In a Horowitz et al. 2002 study, “many said that they never had had an oral cancer examination and did not know there was such a thing” (6). Some participants from that study thought it was interesting that OC was not highly promoted or discussed (6). The authors suggested more efforts towards higher risk populations, which encompassed the less educated, young adults, elderly, and tobacco users (6).

Knowledge of Oral Cancer Exams

Usually patients during their initial dental appointment will undergo an OC exam that consists of intra- and extra-oral palpations, which is the principal way of detecting OC (58). The OC screening could provide a chance to educate and counsel patients on OC behavioral risk factors (96). A 2002 Horowitz study highlighted that some dentists were not informing patients that an OC exam took place (6). Patients could have been screened and not be aware of it. In the Alfano et al. study, respondents stated examiners did not palpate possible lesions during their OC exam (30). The reported prevalence of OC exams (40%) in the Iowa study could have been overestimated if the exam was not done correctly and thoroughly or underestimated if the patient was not aware an OC exam took place (113). The Horowitz et al. study suggested that discrepancies between national and state data concerning the prevalence of ever having had an oral cancer exam could be linked to the type of interview, response rate, age of population, sex, education and dental utilization (31). National and MD data had different results concerning the lifetime prevalence of ever having had an OC exam (28). “In the 1992 NHIS, only 15% of adults

reportedly had ever had an oral cancer exam, whereas nearly 28% of MD adults claimed they had” (28). This 13% difference could have also been evident in the Iowa study if patients did not know they had an OC exam.

Participants who said they had an OC exam were more likely than those who said they did not have an OC exam to have high OC risk factor knowledge (OR=1.57 and 1.60 in Tables 23 and 24, respectively). In the Iowa study, about 40% of participants said “yes, I’m sure” to having had an OC exam (Note: In the Results section of this thesis, we also included an additional 5% who said “yes, I think so” to having had an OC exam because the analysis had already been completed by the time this inconsistency was noticed). Being able to access a dental provider to have an OC exam is multifaceted. There are many reasons people may not have had an OC exam, including no access to a health provider, lack of insurance and geographical barriers. Those who had an OC exam may have been more exposed to OC health materials and had regular access to physicians and dentists who could have explained what they did during the exam.

NHIS Studies

The Iowa study used questions from the NHIS and the following section reports previous national and state survey results. In the 1992 NHIS study, only 15% of adults reported having had an OC exam compared to 28% in the MD1998 study and 40% in the Iowa study. It has been 20 years since the 1992 NHIS study, and many factors could have influenced the increase in OC exam prevalence, such as dental schools doing a better job of educating students on OC exam, which translates into more dentists providing OC exams. The differences in OC exam prevalence between the two states suggest an increase in OC exams and possibly more discussion of OC risk factors in recent years.

Currently, older adults nationwide are living longer (114,115) and retaining their natural teeth, which should encourage increased national efforts to promote OC prevention and early OC detection in older adults who are considered high risk (116). During this time there also was a national campaign funded by the National Cancer Institute under the leadership of the ADA to increase OC awareness (117). This campaign could also have helped increase the use of OC exams and discussion of OC risk factors.

The 1992 NHIS survey asked adults 40 years and older about causes of oral cancer and the following percentages of participants correctly identified these: 67% smoking, 59% smokeless tobacco, 18% sun exposure, and 15% alcohol. Seventy-seven percent incorrectly identified coffee drinking as an OC risk factor (110).

In the Iowa study, 98% of respondents stated that they knew chewing tobacco increased the risk for OC. There was high knowledge of tobacco as an OC risk factor perhaps due to various media sources that emphasize tobacco as a cause of various cancers and chronic illnesses. Knowing the harm tobacco can cause could improve the health of the public if that knowledge motivates people to quit or never start smoking. When respondents were asked if they knew alcohol to be a risk factor for OC, 13% of Americans in 1995 (105) correctly identified it as a risk factor compared to 44% of Iowa respondents in 2012 (Table 26). The Iowa study had similar averages for dental utilization, as 29% of NHIS respondents did not have a dental visit within the past year compared to 22% of respondents from the Iowa study. In terms of health behaviors, according to 2011 NHIS data, 19% of Americans self-reported as current smokers and 52% said they were current regular drinkers. In the Iowa study, 13% considered themselves current smokers and 52% said they were currently a regular drinker. Iowa

respondents reported having more OC exams and were more knowledgeable about alcohol as an OC risk factor compared to national studies in the early 1990s.

Maryland Study

In a similar MD study (31), 85% of respondents said they had heard of OC compared to 89% of respondents from the Iowa study (Table 27). Thirty-six percent of MD respondents correctly identified sun exposure as an OC risk factor compared to 48% from the Iowa study. Thirteen percent of MD respondents knew alcohol could increase one's chances of OC compared to 44% from the Iowa study. In Maryland, 21% of respondents said they had heard of an OC exam compared to 23% from the Iowa study. When the OC exam was described as a "test where the doctor pulls on your tongue, sometimes with gauze wrapped around it, and feels under the tongue and inside the cheeks", 28% of MD respondents said "yes" they had an exam, compared to 40%

Table 26. NHIS vs. Iowa Comparisons

Survey Questions	NHIS	IOWA 2012
Had an OC exam	15% (1992)	40%
Knew alcohol as a risk factor	13% (1995)	44%
Did not have a dental visit within the past year	29% (2008)	22%
Said they were current smokers	19% (2011)	13%
Said they were current regular drinkers	52% (2011)	52%

from the Iowa study. Explaining and describing the OC exam could be beneficial to increase OC awareness and help with recalling if one ever had an OC exam.

Table 27. Maryland vs. Iowa Comparisons

Survey Questions	MD 1998 (%)	IOWA 2012 (%)
Had heard of OC	85	89
Correctly identified sun exposure as an OC risk factor	36	48
Correctly identified alcohol as an OC risk factor	13	44
Had heard of OC exam	21	23
Had an OC exam	28	40

North Carolina Study

The Patton et al. NC study can be used to compare OC risk factor knowledge to the Iowa study. The NC study used similar NHIS questions and included comparisons from the Maryland 1998 published OC study (69). One limitation of the NC study was its use of only respondents from land phones. In the NC study, education was associated with the level of OC knowledge. In the Iowa study education was not associated with OC knowledge. Like the Iowa study, the 2002 NC study had similar tobacco prevalence results compared to statewide estimates.

The MD study was conducted in 1996, the NC study in 2002 and the Iowa study in 2012. The reported OC exam rates were 28% in Maryland, 28% in NC (31), and 40% in Iowa. The rates were all higher than the national OC exam rates reported in the 1992

study (15%) suggesting an increased rate of OC exam utilization (110). Explanatory factors associated with oral cancer examinations in both the MD and NC studies included education and older age (69). In the Iowa study, education and age were not significant in the bivariate or multivariable analyses. In the MD study, the effect of race was evident, however in the Iowa and NC studies it was not significant.

Table 28 illustrates the state comparisons of correctly answered OC risk factors and non-risk factors. The difference in OC risk factor knowledge between the MD, NC and Iowa studies could be associated with a temporal trend in knowledge, differences in state educational systems, and differences in the wording of the survey questions, which could have led to interpretation differences (69). The OC risk factor assessments in the NC study asked if the responses were “related or not related.” In the Iowa study the respondents had to choose if a risk factor “increased or decreased” the chances of OC. In the MD study, the responses were “increases, probably increases, probably does not, and definitely does not increase” chances of OC.

In MD, overall knowledge of OC risk factors was described as low (31). It was concluded that there was moderate knowledge of signs and risk factors for OC among NC adults (69). The Iowa study did not categorize respondents based on their absolute level of OC risk factor knowledge, rather a cut point at the median was established to create two groups of roughly equal size.

Misconceptions and OC Risk Factor Scoring

There were some misconceptions and myths about OC risk factors. Many people incorrectly stated that potential factors were risk factors for OC when they truly are not.

For example, 83% of respondents said that poor oral hygiene was a risk factor for OC, but it is not.

Table 28. State Comparisons: MD, NC, and Iowa

OC Risk Factors	MD 1996 % Correct	NC 2002 (%) Correct	IOWA 2012 (%) Correct
Regular drinking of alcohol	13	49	44
Too much sun exposure	36	63	48
*Eating hot and spicy foods	32	82	78
*Cheek biting	16	65	52

Note: * Non-OC risk factors

Similarly, 48% of respondents stated that lip biting increases one's chances of OC, which it does not. One rationale for these results could be that respondents knew this survey was about OC risk factors and thus could have thought all the potential risk factors presented in the survey must have been risk factors. If this were the case, respondents would have said "yes" to all the potential risk factors and would have had a score of eight because there were eight correct risk factor questions and four incorrect risk factor questions. A score of eight would have put them in the high OC risk factor group, based on the cut point used in this analysis. It is important to correct these misconceptions about OC risk

factors to alleviate fear and anxiety about OC. Correcting these misconceptions could help people assess and put into perspective possible outcomes of their health behaviors.

As expected the individual risk factors were strongly associated with the level of OC risk factor knowledge. There was low knowledge about the following correct OC risk factors: only 40% of respondents said oral sex was a risk factor for OC, only 44% of respondents said that too much alcohol was a risk and only 48% said that too much sun exposure increased risk. In Iowa, increased health promotion with respect to the previously mentioned OC risk factors is needed to help OC prevention. Knowledge of the harmful effects of sun exposure and OC risk is especially important in Iowa, which has a large population of farmers.

Health Literacy

Studies suggest that people with existing health problems generally have less knowledge about their health conditions and tend to have lower health literacy levels compared to those without existing health conditions (81). There are social stigmas associated with low health literacy, including that people may feel embarrassed and may not want to seek help when they do not understand something (28). In the Iowa study, only 6% of respondents said they learned about OC from a doctor (physician) and only 11% said they learned about OC from a dentist. This low percentage of knowledge from health care providers in the Iowa study could also be due to negative stigmas associated with healthcare providers, since over half (54%) of the Iowa study participants said they learned about OC from other sources including family and friends, their workplace, school, church, the Internet, and warning labels on tobacco products.

Healthcare providers have contributed to the challenge of health literacy by using medical terms patients are not familiar with; this practice adds a major source of miscommunication to the patient–provider relationship (28). Consequently, many patients rely solely on supplemental health educational materials to help clarify their medical concerns and misunderstandings (28). No transfer of information can take place if patients are not actively engaged in their health (28). Better efforts in healthcare provider communication should be made to increase discussion of OC risk factors in Iowa.

Those who said they were very or extremely confident filling out medical forms were not more likely than those not at all, slightly, or moderately confident filling out medical forms to have high OC risk factor knowledge (OR=1.36, Table 24). Having optimal oral health refers to being able to understand, interpret and communicate orally and in written form (100). The following are some reasons health literacy may not have been related to high OC risk factor knowledge in the Iowa study: 1) The health literacy screening questions originally were designed for use in a one on one setting or as part of a health intake form. It was not used this way in the Iowa study, which could have skewed the results since respondents could have answered differently on the telephone than in a one on one setting; and 2) The prevalence of OC exams could have been underestimated or overestimated due to misclassification if respondents could not remember whether they had an OC exam or not. Misclassification could also have been evident with the health literacy screening questions if respondents could not recall ever having trouble with health materials. When health literacy questions were asked regarding trouble or difficulty reading health materials, filling out medical forms, or learning about health

conditions, some respondents probably did not want to feel ashamed so they could have said they were very or extremely confident in those areas.

Since 83% of respondents stated they had no problem learning about health conditions, it is worth noting that 83% incorrectly answered that poor oral hygiene was a risk factor for OC. Although poor OH is not a risk factor for OC, due to inclusive scientific evidence two responses for this risk factor were considered correct. Further evaluation is needed on how healthcare providers discuss OC risk factors with their patients to determine if restructuring the content of OC health material is an effective strategy for OC risk factor promotion.

Health literacy requires a different set of skills beyond reading and completing a medical form. Additional skills include reading, numeracy, oral communication, listening, computer and media literacy (118). According to a Safer et al. study, the highest level of education completed did not necessarily correspond to a patient's health literacy level. Health literacy levels were generally lower than formal education levels (85). In the Iowa study, the association between the level of education and OC risk factor knowledge was not significant, which may have been related to the importance of the skill set needed to have adequate health literacy.

Adequate health literacy can help people make better health decisions. In the Chew et al. study, adequate health literacy levels were equivalent to the ninth grade or higher and those at this level were thought to understand information and perform most reading tasks in the healthcare setting (78). In the Iowa study, the relationship between education and OC risk factor knowledge was not statistically significant ($p=0.098$). More research is needed to determine the necessary level of health literacy needed by the public

to adequately function in health care settings. Ultimately, health materials should be presented in a manner the public can relate to and understand in order to improve OC risk factor knowledge and prevent OC.

Strengths and Limitations

The strengths of the Iowa study include the ability to confirm the association between knowledge of OC risk factors and having had an OC exam. The study gave descriptive information on Iowans' OC exam practices and knowledge of OC risk factors, and used primary data collection. The study included cell phone users and was adequately powered to detect reasonable effect sizes. Finally, the inclusion of NHIS study questions was helpful for comparative analysis of other state and national data.

Some limitations of the Iowa study include that the results were based on self-report, thus the occurrence of OC exams could not be verified with chart audits. Additionally, people who did not feel confident in their OC knowledge may have chosen not to participate in the study, thus biasing the results. There were only two categories of OC risk factor knowledge, low and high, which made it difficult to detect the actual prevalence of low OC risk factor knowledge. In addition, those with truly low health literacy may not have understood the questions asked. Last, the study may not be generalizable to other states.

Recommendations

There are several general recommendations commonly understood about OC examinations and health literacy. Some of the recommendations were also consistent with the Iowa study. In general, with better health literacy improved health outcomes are best seen (100). Health care providers can help increase the public's knowledge of OC risk

factors by explaining to patients what is being done during the OC examination. Explaining about the OC exam and OC risk factors is important. In addition, better understanding is needed about the importance of health literacy for high-risk and vulnerable populations that are likely to have low health literacy. Overall, health literacy should be addressed by structuring health materials that are appropriate for the public by evaluating current health materials in dental clinics and offices. Several interventions in the field of health literacy have been used to improve knowledge of health conditions (103,119,120). Iowa can learn from states that have actively made efforts in OC promotion like Maryland, New York and California.

An adequate level of health literacy is necessary for optimal health, but the challenge for healthcare providers is how to measure one's ability to navigate the healthcare system and understand health advice and counsel. To promote better OC risk factor knowledge, more efforts should be made in the curriculum of health professional students and reinforcement through continuing education courses are needed. The Iowa study reported that confidence in filling out medical forms was not associated with high OC risk factor knowledge. Future studies should investigate health literacy proxy measurements other than confidence in filling out medical forms. Findings from the Iowa study could be helpful in developing health literacy related interventions to reduce gaps in OC risk factor knowledge. With results available on OC risk knowledge, interventions can be tailored to stress specific OC risk factors of interest in the population.

To address deficiencies in OC risk factor knowledge, the public needs adequate health literacy, which requires accurate and up to date OC knowledge in a manner they can relate to and understand. To increase what the public knows about OC risk factors

dentists should have current evidence-based information and be able to translate that information into patient-centered language. In general, everyone could benefit from knowing more about OC risk factors. Based on the Iowa study findings, targeted populations should include those 55 years and older, high-risk individuals such as current smokers, alcoholics and those who have not been vaccinated for HPV.

Future studies should assess the OC risk factor knowledge of Iowa dentists. Every Iowa dentist should know how to perform an OC exam and how to address the health literacy needs of patients. Continuing education courses can be in the form of lectures, hands-on training or webinars. Dentists should explain the OC exam and communicate slowly in plain simple language especially when communicating with the older population as the cognitive skills of patients decline with increased age. The dentist and staff should also educate high-risk patients on the need for HPV vaccination.

To conclude, the Iowa study can be used to develop a state plan on OC prevention and early detection. Future research should involve collaborations between the University of Iowa College of Dentistry, Iowa Department of Public Health and the Iowa State Dental Association to develop an OC awareness program that could increase adult Iowans' OC risk factor knowledge.

APPENDIX

Knowledge of Risk Factors for Oral Cancer Among Adult Iowans

Hello, my name is (YOUR NAME). I'm calling from Opinion America. We are doing a short survey of residents of Iowa, who are at least 18 years old, in cooperation with the University of Iowa.

May I speak with a resident of Iowa who is at least 18 years old?

1. Yes
2. Yes, but call back
3. No, refuse

(READ AS NEEDED)

This survey is about mouth cancer. Your cooperation is voluntary and we'd greatly appreciate your help. The results of this survey will be used to develop educational programs about mouth cancer. We would like to find out what people already know about mouth cancer so we'll know how to better educate them. Are you willing to participate? A computer has generated your telephone number randomly. All of your responses are completely confidential. You may choose to stop the interview at any time or not to answer a particular question.

The interview will take about 10 minutes. Your responses are very important to the development of educational programs for adults about early cancer detection.

Q1. First, from whom or from what place do you get advice about health? (READ LIST, CHECK ALL THAT APPLY)

1. Doctor
2. Dentist
3. Nurse
4. Community Leader
5. Church
6. Local Health Department
7. Newspaper/Magazine
8. TV
9. Radio
10. Friend/Neighbor
11. Other
12. NONE – REFUSED

Q2. These first few questions are about oral or mouth cancer. Have you ever heard of oral or mouth cancer?

1. Yes
2. No
3. Don't know

(IF Q2=YES, ASK)

Q2b.

Where did you learn about it? (DO NOT READ LIST, RECORD ALL MENTIONS)

1. Billboard
2. Newspaper
3. TV
4. Radio
5. Bus
6. Subway/Metro
7. Light Rail
8. Health Fair
9. Dentist
10. Doctor
11. Other [SPECIFY]
12. Don't know/Not Sure

Q3. Have you ever heard of a test or exam for oral or mouth cancer?

1. Yes
2. No
3. Don't know/Don't Remember

Q4. Have you ever had a test or exam in which the doctor or dentist pulls on your tongue, sometimes with gauze wrapped around it, and feels under the tongue and inside the cheeks?

1. Yes, I'm sure
2. Yes, I think so
3. No
4. Don't know, not sure
5. Refused

IF "YES" TO EITHER Q3 OR Q4, ASK Q'S 5 THRU 8, OTHERWISE SKIP TO INSTRUCTION PRIOR TO Q9

Q5. When was your last oral cancer exam? (READ LIST IF NEEDED)

1. Within past year
2. Between 1 and 3 years ago
3. Over 3 years ago
4. Never had one (SKIP TO Q9)
5. Don't know, not sure

Q6. What was the main reason you had, for having this test/exam?

1. Specific problem
2. Follow-up to a previous oral problem
3. Part of a routine physical exam
4. Part of a routine dental exam
5. Other [SPECIFY]
6. Don't know, not sure

Q7. Who, that is, what type of medical care person examined you when you had your last checkup for oral cancer? (READ LIST, RECORD RESPONSE)

1. Doctor/Physician
2. Nurse/Nurse Practitioner
3. Dentist
4. Dental Hygienist
5. Other (SPECIFY)
6. Don't know, not sure

Q8. Did the health care provider explain to you what he/she was doing when providing the oral cancer exam?

1. Yes, I'm sure
2. Yes, I think so
3. No
4. Don't know, not sure
5. Refused

(DO NOT ASK Q'S 9-11, IF "1, 2, 3 or DK/Not Sure TO Q5)

Q9. What is the most important reason why you have not had an oral cancer exam in the past few years? (DO NOT READ, RECORD CLOSEST ANSWER)

1. Nor reason/never thought about it/didn't know I should
2. Not needed/haven't had any problems
3. Put it off/laziness
4. Costs too much/no insurance
5. Doctor/dentist didn't recommend it
6. Don't go to doctors or dentist/don't like
7. Other (SPECIFY)
8. Don't know, not sure

Q10. What would it take to get you to have an oral cancer exam? (ROTATE. READ LIST, RECORD ALL MENTIONS)

1. Recommendation from doctor
2. Recommendation from dentist
3. Oral cancer information on TV/Radio/Print
4. Talking with someone who has oral cancer
5. Knowing what causes oral cancer
6. Knowing that an exam is quick and painless
7. Knowing where you could get a free oral cancer exam
8. Other [SPECIFY]
9. Don't know, not sure

Q11. If you found a lump or sore in your mouth who would you go see? (READ LIST, RECORD ALL MENTIONS)

1. Doctor/Physician
2. Nurse/Nurse practitioner
3. Dentist
4. Dental Hygienist
5. Other (SPECIFY)
6. Don't know, not sure

(ASK EVERYONE)

Q12. If a free oral cancer exam was available in your area would you go and have an exam?

1. Yes
2. No
3. Don't know, not sure

(IF Q12=NO, ASK)

Q12b. What would you say is the primary reason you wouldn't take advantage of a free oral exam? (READ LIST, RECORD ALL MENTIONS)

1. Fear
2. Lack of transportation
3. Not at risk for oral cancer

4. Seek care from private health care provider
5. Other [SELECT AND RECORD]
6. Not Sure/Don't Know

(ASK EVERYONE)

Q12c. Where do you think would be a good place to hold a free oral cancer exam in your area? (READ LIST, SELECT ALL MENTIONED)

1. Health department
2. Community Center
3. Church
4. School
5. Senior Center
6. Offered at your workplace
7. Private Dentist
8. Private Doctor
9. Other (SPECIFY)
10. Don't know, not sure

Q13. Now I'm going to read a list of possible factors that may or may not increase a person's risk of getting oral cancer, that is, cancer of the lip, mouth, tongue, or throat. For each, please tell me if you think it increases a person's chance of getting oral cancer or does not. If you don't know, tell me that as well.

Would you say (INSERT FIRST FACTOR), increases chances of getting oral cancer OR does not increase chances? (REPEAT FOR ALL FACTORS)

(RESPONSE CHOICES FOR EACH OF THE ITEMS LISTED)

1. Increases Chances of getting oral cancer
2. Does not increase chances
3. Don't know

(ROTATE)

- a. Spending too much time in the sun
- b. Excessive drinking of alcoholic beverages
- c. Excessive coffee drinking -no
- d. Smoking cigarettes, cigars or a pipe
- e. Using chewing tobacco or snuff
- f. Smoking beedies
- g. From Viruses
- h. Smoking Marijuana
- i. Eating hot or spicy food-no
- j. Biting on your lip or cheek-no
- k. Poor oral hygiene
- l. Oral sex

Q14. What is one early sign of oral or mouth cancer?
(READ LIST, INDICATE THE ONE THAT BEST FITS RESPONDENT'S ANSWER)

1. White patches in mouth which are not painful
2. Red patches in mouth which are not painful
3. Sore/lesion in mouth which does not heal
4. Bleeding in mouth
5. Other [SPECIFY]
6. Don't know/No answer

Q15. Do you now smoke cigarettes every day, some days, or not at all?

1. Every day (FORCE PUNCH Q16=YES AND SKIP TO Q17)
2. Some days
3. Not at all
4. Refused

Q16. Have you ever smoked cigarettes regularly, that is, at least one cigarette every day for 30 days?

1. Yes
2. No
3. Don't know, not sure

Q17. Do you now use smokeless tobacco, chewing tobacco, or snuff, everyday, some days or not at all?

1. Every day (FORCE PUNCH Q18 = YES AND SKIP TO Q19a)
2. Some days
3. Not at all
4. Don't know, not sure
5. Refused

Q18. Have you ever used smokeless tobacco, chewing tobacco or snuff regularly, that is at least once a day for 30 days?

1. Yes
2. No
3. Don't know, not sure

Q19a. Do you now drink alcohol every day, some days, or not at all?

1. Every day (FORCE PUNCH Q19b = YES AND SKIP TO Q20)
2. Some days
3. Not at all
4. Refused

Q19b. Have you ever consumed alcohol regularly, that is at least once a day for 30 days?

1. Yes
2. No
3. Don't know, not sure

Q20. When was the last time you went to a dentist? Would you say...

1. Never
2. Within the last 6 months
3. Within the last 12 months
4. More than one year
5. Within the last 3 years
6. More than three years
7. Don't know/remember

Q21. Has your dentist ever asked you if you use tobacco?

1. Yes
2. No
3. Don't Recall

Q22. Has your dentist ever asked if you drink alcohol?

1. Yes
2. No
3. Don't Recall

Q23. When was the last time you went to a doctor? Would you say...

1. Never
2. Within the last 6 months
3. Within the last 12 months
4. More than one year ago
5. Within the last 3 years
6. More than 3 years
7. Don't know/remember

Q24. Has your doctor ever asked you if you use tobacco?

1. Yes
2. No
3. Don't Recall

Q25. Has your doctor ever asked if you use alcohol?

1. Yes
2. No
3. Don't Recall

Q26. Have you been vaccinated for H-P-V?

1. Yes
2. No
3. Don't Recall

Q27. Have you lost ALL of your permanent teeth?

1. Yes
2. No

3. Don't Recall

Chew Health Literacy Questions

Q 28. How often do you have someone help you read health materials?

- Always
- Very Often
- Sometimes
- Rarely
- Never

Q29. How confident are you filling out medical forms by yourself?

- Extremely
- Very
- Moderately
- Slightly
- Not at all

Q30. How often do you have problems learning about your health condition because of difficulty understanding written information?

- Always
- Very Often
- Sometimes
- Rarely
- Never

Q31a. What was your age at your last birthday?

ENTER AGE IN YEARS

(IF REFUSED, ASK)

Q31b. What year were you born?

ENTER YEAR

Q32. RECORD GENDER OF RESPONDENT (MOVE UP TO FRONT & CONFIRM IF NEEDED)

1. Male 2. Female

Q33. Which one of the following best describes your level of education? (READ LIST, RECORD RESPONSE)

1. Less than High School
2. High School Grad
3. Some College or Vocational School
4. College Graduate
5. Post graduate or professional degree
6. Refused

Q34. How would you describe your racial or ethnic background? (READ LIST)

1. White
2. Black or African American
3. Hispanic
4. Asian
5. Native Hawaiian or Other Pacific Islander
6. Native American
7. Other (SPECIFY)
8. Unknown
9. Refused

Q35. And finally, right now, are you now using a Cell phone or a Land phone?

1. cell phone – (ASK Q36a)
2. land phone – (ASK Q36b)

Q36a. (IF Q35 = CELL PHONE, ASK); In the past month -- would you say that you have used:

1. Only a cell phone (FORCE CODE 1)
2. Both a cell phone and a land phone, but you mostly use the cell phone (FORCE CODE 3)
3. Both a cell phone and a land phone, but you mostly use the land phone (FORCE CODE 4)
4. A cell phone and land phone -- but use both about equally (FORCE CODE 5)

Q36b. (IF Q35 = LAND LINE, ASK); In the past month – would you say that you have used:

1. Only a land phone, (FORCE CODE 2)
2. Both a land phone and a cell phone, but you mostly use the land phone (FORCE CODE 4)
3. Both a Land Line phone and a Cell phone, but mostly use the Cell phone (FORCE CODE 3)
4. A land phone and cell phone, but use both about equally (FORCE CODE 5)

(PROGRAMMER -- FORCE PUNCH FOR Q35-36 SERIES): RESPONDENT USES

1. Cell phone only
2. Land phone only
3. Both, primarily use cell phone
4. Both, primarily use land line
5. Both, use both about equally

THANK RESPONDENT FOR HIS/HER TIME AND COOPERATION

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