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An Assessment of Printed Oral Cancer Materials from Local Health Departments in Illinois

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Local health departments can be resources for the public and health professionals to access educational materials on a variety of topics. Though the dental office is ideal, it should not be the only venue for obtaining oral cancer educational materials. As part of a cancer prevention and early detection project, this pilot study solicited printed educational materials concerning oral cancer from all local health departments (LHDs) in Illinois.

Sixty of the 94 health departments responded, for a response rate of 63.8%. Only 32 had printed oral cancer educational materials for public and professional distribution, and most focused on tobacco. Forty-eight different samples were received. At least one risk factor was identified in all materials. The most common was tobacco usage, present in 100% of the materials. Twenty-nine (61%) identified tobacco use as the only risk factor. Alcohol consumption, the second most frequently identified risk factor, was mentioned in only 12 (26%) of the materials. Few materials comprehensively covered areas such as signs and symptoms, risk factors, and the importance of examinations for early detection. Only five materials (11%) acknowledged that early lesions are often asymptomatic.

Local health departments are in an influential position to disseminate educational materials to the public and health professionals. Dental hygienists have the knowledge and expertise required to identify quality materials. They should be proactive in assisting LHDs with acquisition of appropriate printed materials and partner with them to advocate for prevention and early detection of oral cancer. In collaboration, the two can ensure that all LHDs have current and comprehensive printed materials about oral cancer to distribute to the public and other health professionals.

Keywords: oral cancer, printed educational materials, public, local health departments

Introduction and Review of the Literature

Dental hygienists must advocate for oral cancer awareness in their communities. As oral health care providers, they share a responsibility to ensure that the public and other health professionals have access to current and comprehensive printed educational materials about oral cancer. Materials disseminated from a variety of places, including the dental office, must outline risk factors, signs and symptoms, and the need for routine oral cancer examinations for early detection. Local health departments (LHDs) in Illinois serve as resources for printed materials about a multitude of health issues. Dental hygienists can play an important role in ensuring that LHDs have appropriate printed materials concerning oral cancer for distribution to the public and health professionals.

The American Cancer Society estimates that more than 28,000 Americans will be diagnosed with oral cancer in 2004, and 7,200 will die as a result of the disease.¹ Recent Surveillance, Epidemiology and End Results (SEER) data indicate there are 9.7 new cases per 100,000 in the United States per year, with little progress in the advancement of early diagnosis during the last decades.^{2,3,4} The five-year survival rate for oral cancer is only 17% for advanced stage disease and 81% for early localized disease.² The five-year relative survival rate is 56%.¹ Because of these statistics, *Healthy People 2010* and the Surgeon General's oral health report of 2000 both stress the need for earlier detection and diagnosis.^{5,6}

Major risk factors associated with oral cancer are tobacco usage and excessive alcohol consumption.^{3,7} The synergistic effect of tobacco and alcohol is particularly implicated in neoplasm development.^{3,4,7,8} Current smokers are six to 28 times more likely to develop oral cancer, and the combined use of tobacco and alcohol accounts for 75% to 90% of oral cancer cases in the United States.⁶ Long-term users of snuff (chewing tobacco) may face a 50-fold risk for oral and pharyngeal cancer development.³ Other risk factors associated with oral cancer include sun exposure for lip cancer, increased age, male gender, various viruses, lack of fruits and vegetables in the diet, and genetic predisposition.³ Males are twice as likely as females to develop oral cancer. Age is strongly associated with oral cancer, with 95% of the oral cancers occurring in individuals 40 years of age or older.³

The most common signs and symptoms of oral cancer are a white or red patch that does not go away, a sore that bleeds easily and fails to heal, and a lump or thickening of tissue. Signs such as difficulty chewing and/or swallowing or difficulty moving the tongue are usually those of advanced disease.¹ Because clinicians focus on patient-reported symptoms, rather than observed signs, and early oral cancer lesions are painless, diagnosis is often delayed.^{3,9}

Several studies indicate that dentists and physicians do not routinely perform adequate oral cancer examinations and are remiss in diagnosis of and referral for early oral cancers.^{4,9-18} Yellowitz and Goodman found that 82% of physicians and 17% of dentists did not perform an oral cancer examination on most of their patients.¹⁸ Prout et al. found that 77% of patients with advanced stage oral cancer were under a physician's care within three to 24 months of diagnosis.¹⁹ Another study found that 94% of patients with advanced stage oral cancers were seen by a physician within one year of diagnosis.^{20,21}

A national study of dental hygienists found that 66% of dental hygienists reported providing screenings 100% of the time for adults over age 40 at their initial appointment. Only 25% reported routinely palpating lymph nodes all of the time, and half did not palpate lymph nodes at all.²² Data from the 1998 National Health Interview Survey (NHIS) Cancer Control Supplement found that fewer than 10% of adults aged 18 or older reported having had an oral cancer examination within the last three years.^{23,24}

It is well documented that the public lacks adequate knowledge about oral cancer risk factors, signs and symptoms, and methods to facilitate early detection.^{6,7,10,11,16} The public, as well as other non-dental health professionals, must be informed of the need for oral cancer examinations as part of routine preventive care and of the risk factors and signs and symptoms associated with the disease. Horowitz and Nourjah expressed the need for implementation of vigorous oral cancer education for the public.¹⁰

In 1998, Chung and colleagues examined educational materials that focused on oral and pharyngeal cancers and were available to American adults.²⁵ They surveyed national and state organizations or agencies and requested copies of oral cancer materials they produced. Brochures, videotapes, posters, fact sheets, and leaflets were collected. Only 59 items included oral cancer in the content, and only 20 focused specifically on oral cancer. They called for a variety of new materials, particularly ones aimed at persons with low reading ability, and a brief list of steps for performing oral cancer examinations, similar to brochures currently available for breast examinations.²⁵

Canto and colleagues examined the coverage and quality of oral cancer information in the popular press. They discovered not only a lack of coverage, but inaccuracies in the content as well. More than 50% of the articles did not mention warning

signs, and only 6% mentioned the absence of pain associated with early lesions. Fourteen percent recommended clinical examinations by a professional, and only 8% suggested the need for self examinations.²⁶

Because local health departments are important resources for health materials, more studies are warranted to examine states' oral cancer materials, ensuring that health departments have accurate and comprehensive resources for the public and health professionals they serve. This pilot study assessed the printed oral cancer materials that are available from local health departments in the state of Illinois for the public and health professionals. The intent was to determine the types and comprehensiveness of printed oral cancer materials that were available from these public service agencies.

Methods and Materials

This study was conducted as part of a larger study, "Oral Cancer Prevention and Detection: The Illinois Model," for which the overall objective was to develop a statewide model for implementing oral cancer prevention and early detection in Illinois. Surveys were mailed to all 94 Illinois local health departments (LHDs) in April 2001, after permission for the study was granted by the Southern Illinois University at Carbondale institutional review board. Included in the survey was a request for samples of oral cancer printed materials provided to the public and health professionals. The surveys were addressed to the administrators of each LHD, and a return envelope was enclosed to facilitate the return. LHDs were given three weeks to return surveys and materials. No second mailing was included.

To evaluate the printed oral cancer materials received from the LHDs, an instrument was designed by combining elements from Chung et al.²⁵ and Canto et al.²⁶ with elements developed by the researchers. One of the researchers, an oral pathology professor in a baccalaureate dental hygiene program, examined and evaluated all of the printed materials. Among the areas evaluated were coverage of risk factors, warning signs and symptoms, the need for annual clinical and self-examinations, prevention, and early detection. Content was scored dichotomously as either present or not present in the materials. Results from other areas evaluated for inclusion in the materials, such as location and treatment for the disease, are not included in this short report but are available upon request.

Results

Sixty (64%) of the 94 health departments responded, with 32 (53%) of those sending printed materials. Twenty-eight (46%) of the LHD respondents indicated they had no printed oral cancer materials to send. Forty-eight different samples were received from the 60 responding LHDs. Some materials were duplicates, and some health departments had a larger variety of different types than others, but those numbers were not recorded.

The types of printed materials included 34 brochures, nine booklets, two posters, two fact sheets, and one bookmark. Three materials (coloring booklet, comic booklet, game/puzzle brochure) were appropriate for children. Only 11 (22%) of the materials were specifically about oral cancer. Thirty-two materials (65%) were primarily about tobacco but addressed oral cancer in varying degrees. Eight (16%) of the publications were targeted at older children or early adolescents as determined by title, content, and/or appearance. One brochure was designed for health care professionals but could be distributed to the public as well. Publication dates ranged from 1978 to 2001, including one from 1978, one from 1982, two from 1987, and the remainder from the 1990s and 2000s. Seven publications were not dated. One brochure, written in Spanish, was not included in the evaluation process.

Publications were evaluated for presentation of risk factors (Table I). At least one risk factor was identified in all materials. The most common was tobacco usage, present in 100% of the materials. Twenty-nine (61%) identified tobacco use as the only risk factor. Alcohol consumption, the second most frequently identified risk factor, was mentioned in only 12 (26%) of the materials. All other risk factors were identified in one to seven (2% to 15%) of the materials.

Risk Factors	# of materials that included the risk factor N=47	% of materials including the risk factor
Tobacco	47	100%
Alcohol	12	26%
Age	7	15%
Sun exposure	6	13%
Lack of fruits and vegetables	5	11%
Gender	5	11%
Race	3	6%
Virus-HPV	1	2%
Genetics	1	2%

Table I. Presentation of risk factors in 47 different printed oral cancer materials received from 32 of 94 Illinois LHD's.

Each publication was evaluated for presentation of nine different warning signs and/or symptoms of oral cancer. The most frequently cited warning sign was the occurrence of a red and/or white lesion in the mouth, reported in 29 (62%) of the publications. Mention of an ulcer or sore appeared in 26 (55%) of the materials. Thickness or swelling was cited in 18 (38%) of the materials, and change in color was included in the fewest publications. Difficulty swallowing was identified in 20 (43%). A "lump" and throat discomfort were described as symptoms in 21 (45%) and 19 (40%), respectively. Nineteen (40%) recommended seeking care if any of the signs were recognized. Fifteen of the publications (32%) failed to incorporate even one warning sign. Twenty-two (47%) included no potential symptoms. Only five materials (11%) acknowledged that early lesions are often asymptomatic (Table II).

Warning Sign/Symptom	# of materials that included the sign/symptom N=47	% of materials including the sign/symptom
White/Red lesion	29	62%
Ulcer/Sore	26	55%
Lump	21	45%
Difficulty swallowing	20	43%
Discomfort of throat	19	40%
Thick/Swelling	18	38%
Difficulty with jaw/tongue	17	36%
Numbness	16	34%
Bleeding	14	30%
Sustained sign	12	26%
Discomfort of dentures	8	17%
Hoarseness	5	11%
Change in color	3	6%
Burning	3	6%

Table II. Presentation of warning signs and symptoms in 47 different printed oral cancer materials received from 32 of 94 Illinois LHDs.

Materials were further evaluated for inclusion of recommendations for clinical and/or self-examination procedures and whether the areas to examine were noted, including lymph nodes, gingiva, cheeks, lips, tongue, palate, oropharynx, and the floor of the mouth. Fifteen (32%) of the materials suggested the importance of clinical oral examinations in detecting cancer of the mouth. Only one brochure included anatomical structures such as lymph nodes that should be examined by a professional. Eight (17%) of the 47 publications encouraged self-examinations, but only one publication identified anatomical structures of the oral cavity that should be examined.

Discussion

It appears that many LHDs in Illinois lack printed materials that adequately present pertinent facts relevant to oral cancer. Because Americans are generally uninformed about risk factors, signs and symptoms, and the need for examinations, it is disconcerting that 28 (46%) of the 60 health departments which responded had no printed oral cancer materials to distribute.^{4,9-14} All LHDs should have an array of current printed oral cancer materials available for distribution to the public and health professionals promoting oral cancer awareness and education.

Several limitations of this pilot study should be noted and resolved in subsequent studies. The survey instrument did not provide an operational definition of printed oral cancer educational materials; thus, it failed to make an explicit distinction between tobacco materials and those addressing oral cancer. This interpretation was left up to the respondent. As a result, some departments may have failed to submit materials designed primarily for tobacco education, even though oral cancer information was included in the materials' content.

Due to deadlines beyond the researchers' control, the study was to be completed in a six-week time period. Therefore, no second mailing was sent to non-respondent LHDs. The time limitation was also a reason for the evaluation of materials by only one researcher; therefore, inter-rater reliability was not established. Having additional evaluators assess the materials would have strengthened the reliability of obtained data. However, the materials were examined as to whether specific elements were included or missing. The degree to which the specific elements were covered was not assessed.

A variety of free materials are available through the American Cancer Society and the National Oral Health Information Clearinghouse. Many Illinois local health departments distributed the same materials, and most were designed for anti-tobacco education. Caution must be exercised, however, to avoid sending the message that oral cancer is associated only with tobacco use. Most tobacco materials did not provide comprehensive coverage of oral cancer nor information on critical issues such as the need for exams to facilitate early detection.

Aside from tobacco, there was little mention of risk factors in the printed materials. Most materials primarily dealt with tobacco and alcohol and failed to discuss other risk factors. Increasing age, for example, is an important risk factor that should be identified in the materials. The public should be better informed about risk factors other than tobacco use that are associated with oral cancer.

Collected materials inadequately presented warning signs and symptoms. With the current emphasis on early detection, oral cancer materials should stress the absence of symptoms and painlessness associated with early lesions. Many of the materials listed signs and symptoms like difficulty swallowing, which is germane to advanced disease rather than early stage lesions. The American Cancer Society Facts and Figures lists difficulty swallowing as a symptom of advanced disease, which usually bears a poor prognosis.¹ To aid in early diagnosis, oral cancer materials should stress the lack of signs and symptoms, as well as those associated with early oral cancer lesions.

Clinical and self-examinations are necessary, especially for those at high risk, to diagnose oral cancer in its earliest stage. High-risk patients include tobacco users, alcohol abusers, and those over the age of 40. Most of the printed materials did not address the need for self-examinations. Izquierdo and Rozier⁹ discuss the tendency for clinicians to rely on patient-reported symptoms. While not all experts agree on the utility of self-exams, many encourage them in conjunction with regular clinical exams. Although the efficacy of self-exams is not documented in the literature, it seems rational to perform them, particularly for high-risk individuals, when considering the asymptomatic nature of early oral lesions. If printed materials address the painlessness of early oral cancers and the reduced morbidity with early detection, perhaps patients would recognize the need for clinical and self-examinations.

*Healthy People 2010*⁵ and the Surgeon General's oral health report⁶ both clearly address the importance of examinations for early detection, but the literature reveals a lack of routine oral cancer examinations by dentists and physicians alike.^{7,10,11,16} Silverman views performing oral cancer exams on all adult patients, as well as educating them about the need for such examinations, as a challenge for dental professionals, but one with great merit.⁴ As with self-exams, if the need for clinical examinations were better explained in printed oral cancer materials, patients could become proactive and request oral cancer examinations from their dentists or physicians.

Local health departments should have up-to-date printed materials for distribution. Publication dates of the collected materials ranged from 1978 to 2001. Although most of the information remains accurate, some content in dated publications may not be current. For example, it is accurate that difficulty swallowing is a symptom of oral cancer, but this symptom is now recognized as one of advanced disease.¹

To avoid the suggestion of negligence on the part of LHDs, one must recognize the vast array of health issues that confront these agencies. Faced with issues such as HIV infection, teen pregnancy, and the threat of bioterrorism, just to mention a few, it is not surprising that adequate supplies of printed materials about oral cancer may not be a top priority for the agencies. As oral health specialists, dental hygienists should assume a proactive role in partnering with LHDs to provide oral cancer materials to the public and other professionals. Volunteering to serve as oral health consultants is one way to contribute expertise and promote oral health awareness. When current and comprehensive materials are acquired by dental hygienists, a portion could be supplied to the local health department. It could be an ongoing project for local dental hygiene components to periodically examine LHD educational materials to ensure that quality oral health materials are available for distribution to the public. Dental hygienists could also assist in the development of educational materials, ensuring appropriate information is included in the content. It is the dental hygienist's professional responsibility to promote awareness of oral cancer and to monitor printed materials for public and professional distribution-not only in the dental office, but anywhere she/he can provide expertise concerning the disease.

Additional research into materials and their availability should be conducted. The examination of printed materials in all states could serve as a catalyst for ensuring that disseminated materials contain the most current, comprehensive, and useful information regarding oral cancer for the entire country. Further examination of local health departments could provide more insight into the reasons for the lack of printed materials about oral cancer. In this study, perhaps the health departments that sent materials were those with dental clinics in their facilities. All health departments should have materials available because clients may visit for immunizations or other services and pick up displayed oral cancer materials. Other oral health information could be displayed as well, encouraging patients to utilize oral health services, either at the health department or in the private sector.

Conclusions/Recommendations

The availability of oral cancer printed materials from LHDs in Illinois appears to be inadequate. Additionally, comprehensive educational materials must be developed for the distinct purpose of educating people about oral cancer, beyond just mentioning it in anti-tobacco materials. Risk factors, signs and symptoms, and the need for clinical and self-examinations must be stressed. Oral cancer has the highest mortality rate of any oral disease, but with early detection, morbidity and mortality rates improve significantly.

As oral health specialists, dental hygienists should be proactive and help agencies acquire comprehensive printed materials for public and professional distribution, promoting awareness and facilitating early detection of this life-threatening disease. Local dental hygiene components could develop ongoing projects in which members periodically examine printed materials at LHDs to ensure that comprehensive, accurate materials are available to the public. Suggestions for this type of project are included in Table III. Dental hygienists could offer to assist with all oral health materials, not just those concerning oral cancer, and collaborate with the agency for the overall oral health of its clients.

1. Ensure that the practice location contains oral cancer materials for distribution.
2. Identify the location of the local health department, community health center, and other publicly funded health services locations.
3. Visit the local health department and assess the types of educational materials available to distribute to the public.
4. If oral cancer materials are not evident, schedule a meeting with the health director or administrator to discuss mutual concerns.
5. Prior to the meeting, identify sources of materials and obtain copies for the facility.
6. During the meeting, specify sources of free or inexpensive, up-to-date materials.
7. Offer to assist with the acquisition of quality materials.
8. Work with local dental hygiene and dental components to evaluate and/or provide quality oral health materials, particularly if no dental clinic is associated with the agency.
9. Periodically reassess the materials available at the facility.
10. Notify the facility if additional materials become available.
11. Offer assistance to health care providers on how to best utilize materials.
12. Offer to provide continuing education programs on oral cancer for various health care providers.

Table III . Twelve Steps a Dental Hygienist Can Take to Prevent Oral Cancer in the Community.

Dental hygienists could also provide educational programs for other health care providers, incorporating suggestions on the use of printed materials and how to best utilize them with patients. Dental hygienists should stress the importance of oral cancer prevention, screenings, and support for patients during treatment of the disease. A collaborative approach among the various health care providers, drawing from different areas of expertise, should certainly be the best overall approach to care for the patient.

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Notes

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