Oral Cancer Educational Materials for the General Public: 1998

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Abstract

Objectives: *Previous studies have shown that US adults are not well informed about oral cancers and only 15 percent ever have had an oral cancer examination. This study sought to determine the quantity and adequacy of educational materials designed to inform or educate US adults about risks for, and signs and symptoms of, oral cancer and the need for an oral cancer examination.* ***Methods:*** *Letters requesting copies of oral cancer educational materials produced by the organization or agency—leaflets, fact sheets, pamphlets, videos, posters—were sent to 172 national and state organizations or agencies. To determine the adequacy of the items, a previously developed, tested, and used form based on current science was adapted for this study. In addition, the SMOG index was used to determine readability for printed items.* ***Results:*** *Seventy-seven percent or 132 of the selected organizations responded to queries. A total of 59 items were received that focused on or included the topic of oral cancer. Twenty of these 59 items focused specifically on oral cancer; the balance, on other topics, but mentioned oral cancer. The readability ranged from sixth to 13th grade.* ***Conclusions:*** *This study demonstrates a dearth of educational materials about oral and pharyngeal cancers; most are written at too high a grade level for the general public. These findings may help to explain why the public is so uninformed about these neoplasms. [J Public Health Dent 2000;60(1):49-52]*

Key Words: oral cancer, educational materials, public.

Oral and pharyngeal cancers, including those of the lip, tongue, pharynx, and mouth, can be devastating both because the treatment often is physically disfiguring and psychologically handicapping and because the disease has a high mortality rate. The five-year relative survival rate of patients diagnosed with oral and pharyngeal cancer is one of the lowest (52%) of all major cancers (1). Most of these cancers are diagnosed at a late stage, yet chance of survival is better when the neoplasm is detected early (2). These cancers kill more Americans than cervical cancer or malignant melanoma (3-5). Although major risk factors for these malignancies have been established and signs and symptoms are known, results from state and national studies demonstrate that the US public is generally uninformed about these aspects of oral cancer (6-8). The American Cancer Society recommends that adults 40 years of age or older have an annual oral cancer examination (9). Yet, nationally, only 15 percent of adults ever have had an oral cancer examination. Of those who had an exam, less than half had it within the past 12 months (10). Ironically, this examination is one of the least intrusive of available cancer examinations.

While the role of information is often maligned, its potential power in stimulating the public to seek protective health services cannot be underestimated. An integral component of health promotion is the acquisition of accurate information. Access to reliable health information is crucial for progress toward reducing morbidity and mortality resulting from these cancers. Thus, health literacy—sometimes defined as the capacity of an individual to obtain, interpret, and understand basic health information and services and the competence to use or not to use such information and services in ways that are health enhancing (11)—is not only feasible, but also necessary. Studies in the mass media suggest that the public uses educational materials such as leaflets, fact sheets, posters, and videos among their major sources of health information (12,13). Access to factual health information is important in enabling individuals to protect themselves from risk factors for diseases and conditions and in keeping abreast of existing cancer examinations or tests. The most important general barrier to cancer screening appears to be a lack of awareness of a given test or examination and the failure of health care providers to recommend the procedure (8,14).

Because relatively little progress has been made in the war against oral cancer (15), a strategic plan for the prevention and early detection of these cancers was spearheaded by the Centers for Disease Control and Prevention, the National Institute of Dental and Craniofacial Research, and the American Dental Association (16,17). Resultant recommendations include implementing an effective national campaign for the prevention and early detection of oral cancers. One of the specific recommendations in the area of public education is the "Assessment of the quality, quantity, and availability of educational materials directed to the public about oral cancer" (16). The rationale for this recommendation was that such an assessment was necessary to document the kinds and quality of materials available and thereby to determine the needs of the general public for information regarding oral cancer prevention and early detection. Thus, the objectives of this study were to determine the quantity

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and adequacy of educational materials designed to inform or educate the adult public about: (1) oral cancer risks, signs, and symptoms; (2) the need for oral cancer examinations; and (3) the components of a comprehensive oral cancer examination.

Methods

To achieve these objectives, letters requesting two copies of all educational materials—printed, video, or slides—produced by the respective agency dealing specifically with oral cancer or tangentially with it as part of other specific topics, such as tobacco use cessation or more general oral health educational materials for the public, were sent to 172 individuals or institutions in the summer of 1998. The agencies included the National Cancer Institute, National Institute of Dental and Craniofacial Research, the American Cancer Society, the American Dental Association, the American Association of Oral and Maxillofacial Surgeons, the American Dental Hygienists' Association, American Medical Association, recognized comprehensive cancer centers (such as Sloan Kettering), cancer support groups (such as SPOHNC), major cancer research hospitals, health education publishers, all state dental directors, and other individuals to whom we were referred. Agencies were requested to respond within two weeks. If they had no such educational materials, they were asked to so advise. Three weeks after the initial letter was sent, all nonresponders were contacted by phone. When calls could not be completed because a specific person had not been identified previously, a FAX was sent to the original address.

Responses were logged in using a spreadsheet, noting the type of educational material (leaflet, video, fact sheet), intended audience (general public or health care provider), primary focus, and date of publication.

To analyze the content of the educational items, a previously developed, tested, and described form was adapted for use (18). Two investigators independently assessed several different educational materials in testing and modifying the form for this study. Differences were discussed and resolved until standardization was reached. Each educational item was assessed to determine whether specific content areas about oral cancer were included. These content areas were based on the scientific literature and included: risk factors, signs and symptoms, prevention, anatomic locations of oral cancers and the components of a clinical oral cancer examination (Figure 1), and self-examination. Also recorded was whether the item included statistics regarding oral cancers and mentioned the importance of early detection. When incorrect information regarding risk factors was found, that also was recorded about the item.

The SMOG formula was used to estimate the readability (reading level that refers to the number of years of education required for a person to understand a written item) of the 19 printed educational items that focused on oral cancer. This formula has been used for decades to evaluate educational materials, including those for other cancers. This procedure was applied by counting the number of words with three or more syllables in the first 30 successive sentences of the publications and then determining the estimated grade level on the SMOG conversion table (19).

FIGURE 1
Components of a Clinical Examination for Oral Cancer

1. Check lymph nodes in the neck and under the lower jaw
2. Check cheeks and lips
3. Check gums
4. Pull tongue forward
5. Check palate
6. Check oropharynx
7. Check floor of mouth

Results

The combined response rate from the state dental directors and the organizations and institutions surveyed was 77 percent. A total of 59 items that focused on or mentioned the topic of oral cancer were received. Twenty of the 59 items specifically addressed oral cancer. They included leaflets, brochures, fact sheets, and one video. The other 39 items focused on other topics, but mentioned or included information about oral cancer. Of these 39 items, 19 focused on smokeless tobacco, 9 focused on smoking cigarettes, 3 focused on use of cigars, 4 addressed tobacco in general (where the focus was not soley on either smoking or smokeless tobacco, 3 items were on oral health care in general and simply included mention of oral cancer, and 1 item was on general cancer prevention in which oral cancer was mentioned several times.

Overall, educational materials with a specific oral cancer focus were obviously more comprehensive in the scope of their attention to the manifold aspects of oral cancer than were materials in which the primary theme was essentially another topic (such as smoking cessation or oral health in general), where only brief attention was given to oral cancer, typically in the form of a simple mention. Accordingly, the remaining section of the study results focus on the adequacy of the 20 items with a specific focus on oral cancer prevention and early detection, which accounted for 36 percent of all the materials received.

Risk Factors. As shown in Figure 2, tobacco and alcohol were mentioned most often as risk factors (in 19 items), followed by sun exposure for lip cancer (in 12 items). The combination of tobacco and alcohol was mentioned as a synergistic risk factor in nearly half of the educational materials, as were age and sex. Race was mentioned in the context of being a risk factor in nine of the educational materials. The lack of consumption of fruits and vegetables was mentioned in four of the 20 items. Viruses as potential risks were mentioned only once.

When tobacco was addressed specifically as a risk factor, smoking was mentioned most often (in 19 items), followed by use of cigarettes, cigars, and chew tobacco, each of which was mentioned in over half of the 12 items of the materials. Pipes, snuff, and smokeless tobacco were mentioned, respectively, in 10, eight, and two of the items. An ill-fitting denture was incorrectly identified as a risk factor in four of the educational materials. Poor oral hygiene also was incorrectly mentioned as a risk factor in three items.

Signs and Symptoms. Virtually all (n=19) of the oral cancer focused materials mentioned an ulcer or sore as an early warning sign. Seventeen items mentioned a sustained sign—that is, one that remains beyond the normal self-limiting time period—and 16 mentioned a thickening or swelling. Both red and white patches were men-

tioned in over two-thirds of the educational materials. The absence of pain and the need to seek care each were mentioned in 13 of the publications and the video. A white patch or leukoplakia both were mentioned in four of the items. Difficulty in chewing or swallowing was mentioned in 12 of the 20 items; change in color, in 10 of them; and hoarseness, in one-third of the specific oral cancer educational materials. The most common named symptom was a lump (n=18), followed by bleeding (n=13). The fact that a person with an early oral cancer lesion would typically be asymptomatic was mentioned in nearly half of the materials. Numbness, pain, discomfort in the throat, and difficulty moving the jaw or the tongue were mentioned in nine of the items. Discomfort wearing dentures was identified in nearly one-third of the materials.

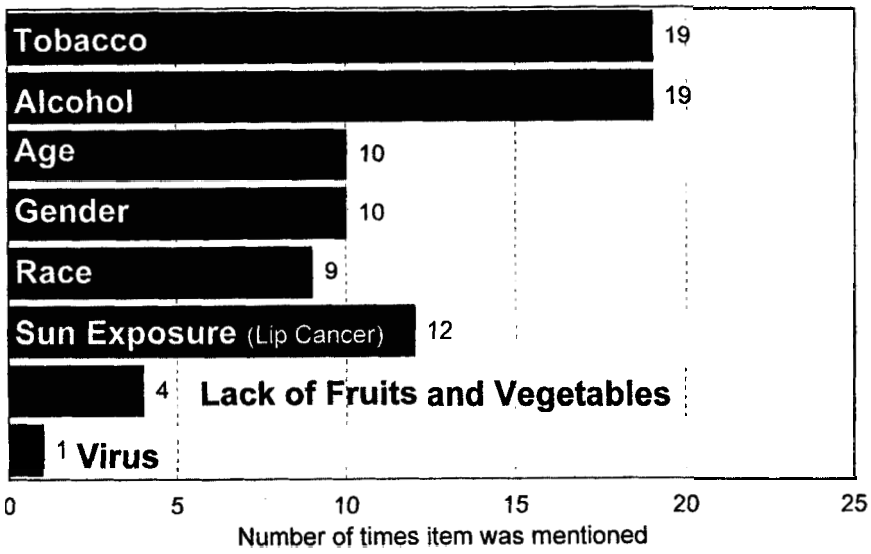
Primary Location of Oral Cancer Lesions. The tongue was mentioned as a primary site for oral cancers in nearly three-fourths of the items, followed by lip (n=14), cheek (n=11), floor of mouth (n=10), gingiva (n=9), throat (n=9), and palate (n=8).

Methods of Prevention. The most commonly mentioned mode of preventing oral cancer was tobacco use cessation (n=12), followed by smoking cessation (n=10). Decreasing the amount of alcohol intake (n=10), and protection from the sun either by staying in the shade or by protecting the lips with lip screen or protective clothing (such as hats) both were mentioned in one-third of the items. Finally, eating fruits and vegetables to protect against these cancers was addressed by five of the items.

Clinical and Self-examination. Generally, most information about a clinical oral cancer examination was incomplete, mentioning only a few components. One-third of the materials mentioned checking lymph nodes in the neck and floor of the mouth, and checking cheeks and lips.

Information provided on oral cancer self-examination was more complete than was the information on a clinical oral cancer exam provided by a health care provider. One-third of the educational pieces mentioned checking cheeks and lips. Six of the items also mentioned checking gums, tongue, palate, and floor of the mouth. Checking lymph nodes in the neck and floor of the mouth was mentioned in only two items. The importance of early detection was mentioned in nearly three-fourths of these materials. Statistics about oral cancer were mentioned in two-thirds of them.

FIGURE 2
Risk Factors for Oral Cancer Mentioned in Health Education Materials



Readability. The estimated reading level using the SMOG readability formula for the 19 printed educational items ranged from the sixth to 13th grade. Five of the items tested at the sixth or seventh grade level; nine at the eighth and ninth grade levels; and five tested at grades 10, 11, 12, or 13.

Discussion

The limitations of this study include the fact that some sources of educational materials on oral and pharyngeal cancers may have been missed. However, it is likely that those groups who had materials or knew of materials produced by others were pleased to respond. Further, the search was limited to print or video materials; materials from Web sites were not gathered. Despite these limitations, the findings are useful in clarifying the need and determining the content of additional materials.

Overall, few materials are designed to inform or educate the public specifically about oral cancer. Of all the oral diseases, oral and pharyngeal cancers have the highest mortality. Thus, the fact that only 20 items on oral cancer prevention and early detection were identified as a result of contacting 172 individuals and agencies is disappointing. This conclusion is especially true considering that numerous kinds of educational materials are available for the public in other oral-related content areas, such as toothbrushing and flossing, dental caries, periodontal diseases, orthodontia, and tooth whitening. The sheer lack of educational materials partially explains the public's lack of knowledge of these malignancies. Interestingly, a lack of coverage about oral cancer in the popular press in the past decade also was found in another study (18). For self-protection the public needs to know what oral cancer is, its risk factors, its signs and symptoms, the components of an oral cancer examination, and the recommended frequency for having one (17). The need is clear—more oral cancer educational materials for use in a variety of settings, including waiting rooms and for health care providers to share with patients. Concomitantly, health educators need additional educational/informational materials to help educate the public about oral and pharyngeal cancers.

With few exceptions, most of the 20 items that specifically addressed oral cancer were fairly comprehensive and accurate. Three of the more comprehensive items were available from state health departments. This finding means that while these fact sheets would be available for use in these respective states, generally such materials would not be provided for out-of-state residents. These fact sheets were prepared on desktop computers and

were informative, with the readability level generally being high. Thus, every state could and should have such a fact sheet available. While most of the educational materials correctly identified smoking and the use of alcohol as the major risk factors for these neoplasms, the role of diet (consuming fruits and vegetables) and viruses were rarely mentioned. This latter information about fruits and vegetables and viruses is more recent, which may explain why it was not included in more of the materials. A few of the educational materials contained misinformation regarding risk factors. Such inaccuracies likely contribute to misinformation or confusion on the part of the public as well as health care providers.

Further, most of the 20 items were written at a reading level likely too high for many target groups, especially those with lower levels of education. What is needed, for example, is a publication written and designed similar to "The Pap Test: It Can Save Your Life!" (20). This publication is colorful, is written in simple language in large print, and is available in Spanish. Only one of the 20 items that focused on oral cancer was available in Spanish and there were no posters about oral cancer.

Clearly lacking is a brief publication that would delineate the steps of an oral cancer examination, similar to that now available for a good mammogram (21). This kind of information is important for individuals to be able to determine whether their health care providers are providing a comprehensive oral cancer examination.

Based on the results of our search for educational materials on oral and pharyngeal cancers, it is clear that a variety of new materials are needed, especially those that are for use with persons of low literacy. Because low health literacy may impair individuals' understanding of health messages and limit their ability to act responsibly, it is important to develop appropriate materials. Moreover, materials should be produced in Spanish and in other languages, as well as English. The general need for accessible educational materials about oral cancer prevention and early detection is heightened by the fact that the aging US population is increasing the number of persons at risk for oral and pharyngeal cancers.

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