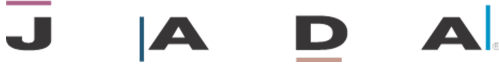


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Maryland adults' perspectives on oral cancer prevention and early detection

ALICE M. HOROWITZ, Ph.D.; MARIA T. CANTO, D.D.S., M.P.H.; WENDY L. CHILD, M.S.

An average of 30,000 new cases of oral and pharyngeal cancer are diagnosed in the United States annually, a pattern that has held for the past several decades.¹ These cancers represent approximately 3 percent of all cancers in the United States, most of which are diagnosed at late stages, and nearly 8,000 people die of these cancers each year.¹ Most oral and pharyngeal cancers are squamous cell carcinomas, which occur primarily in the floor of the mouth and on the tongue. These cancers also occur in the lip, gingivae, palate, buccal mucosa/ vestibule, tonsillar fossa, oropharynx, hypopharynx and salivary glands. The primary risk factors for oral cancers include all kinds of tobacco and alcohol use, unprotected exposure to sun (lip cancer), some viruses, lack of eating fruits and vegetables and marijuana use.^{2,3}

The findings from these focus groups suggest that a major effort in providing information and education about oral cancer prevention and early detection is needed.

Although the prevalence of oral and pharyngeal cancers in Maryland (27th among all states) is moderate, the state's mortality rate for these cancers is the seventh highest in the United States and sixth highest among African-American men.¹ The mortality rate has remained unchanged for decades, and most oral and pharyngeal cancers are diagnosed at late stages.⁴ Moreover, most oral and pharyngeal cancers in Mary-

Overview. In any given 12-month period, Maryland ranks 27th among all states and the District of Columbia in estimated new cases of oral cancer. The state also has the seventh highest overall mortality rate for oral cancer. Because of earlier research indicating that Maryland adults had little knowledge and many misconceptions about oral cancer, the authors undertook a study to obtain in-depth information from Maryland adults 40 years of age or older on oral cancer, oral cancer examinations and factors associated with having an oral cancer examination.

Methods. The authors conducted a qualitative descriptive study using information gathered from three focus groups consisting of nine, 10 and seven adults respectively, and which met at two locations. The authors hired a private focus group research firm, which randomly selected participants from a telephone list of local residents. A professionally trained moderator conducted all focus groups using a semistructured interview guide.

Results. Participants were struck by the fact that they rarely hear about this type of cancer. Many said that they never had had an oral cancer examination and did not know there was such a thing. Many participants also reported that they likely would be more comfortable discussing oral cancer with their physicians than with their dentists.

Conclusions. These findings provide additional in-depth insights to earlier work about Maryland adults' oral cancer knowledge, opinions and practices. The state plans to use this information to develop educational materials and interventions for the public to promote oral cancer prevention and early detection in Maryland.

Clinical Implications. Extensive public education about oral and pharyngeal cancers should be provided in dental offices and clinics, as well as in mass media of all types. More clinicians should include comprehensive oral cancer screenings in their oral examinations, and they should explain to patients what they are doing when they provide these screenings.

land are diagnosed by physicians.⁴ In light of these collective data, we initiated a statewide needs assessment of Maryland health care providers and the Maryland public regarding their knowledge, opinions and practices regarding oral cancer with the ultimate intent of increasing early detection and prevention of these cancers. A 1996 telephone survey conducted as part of this assessment showed that Maryland adults generally were ill-informed about oral cancer risk factors, prevention and early detection.⁶ Only 28 percent reported ever having had an oral cancer examination. Of those, 20 percent had had the examination in the preceding year.⁵ The American Cancer Society recommends that people 40 years of age or older or anyone of any age who is at high risk should have an annual oral cancer examination.⁶

The purpose of our study was to obtain and explore in-depth information on why Maryland adults did or did not receive oral cancer examinations, what they know about oral cancer and how best to inform the public about oral cancer prevention and early detection.

METHODS

We contracted with a private focus group research firm that recruited all participants. For the recruitment, the firm used primary and secondary inclusion criteria suggested by us and drawn from the previously conducted telephone survey of Maryland adults,⁵ as well as Maryland epidemiologic data on oral cancer.⁴

Inclusion criteria. *Primary.* We selected Baltimore and the Eastern Shore region as the target areas because of their high rates of oral and pharyngeal cancer prevalence and of mortality associated with these cancers.⁴ Therefore, we arranged to have two focus group meetings held in the Baltimore area and one in the Eastern Shore region. The focus group firm used a telephone list of residents to screen for the geographic criterion.

Secondary. Other criteria included age of 40 years or older, lack of background in the health professions or pharmaceutical industry, being a representative of one of several racial/ethnic groups (especially black) and, preferably, past or current use of tobacco. The table shows the participants' characteristics.

Focus group settings. The two Baltimore focus groups were conducted in a professional focus group conference room, which adjoined a

TABLE

CHARACTERISTICS OF ORAL CANCER FOCUS GROUP PARTICIPANTS.	
CHARACTERISTIC	NO. OF PARTICIPANTS
Sex	
Male	13
Female	13
Age Range (Years)	
40-49	6
50-64	13
≥ 65	7
Tobacco Use Status	
Nonuser	5
Current or former user	21
Oral Cancer Examination Experience	
Yes	7
No	17
Don't know	2
Race/Ethnicity	
African-American	11
Hispanic	1
White	14
Time of Last Dental Visit	
< 12 months ago	11
1-2 years ago	3
≥ 3 years ago	11
Never	1
Level of Education	
Some high school	3
Completed high school	10
Some college	11
Completed college	2

room equipped with a one-way mirror for observers. The participants were advised that there were observers who were responsible for note-taking behind the one-way mirror. The Eastern Shore region focus group took place in a hotel meeting room in Easton, Md. In this setting, the observers sat in the same room with the participants and were introduced as summary note-takers. All three focus groups were audio-recorded. A light meal was served to all participants. Those in the Baltimore area were paid \$50 for participation; participants on the Eastern Shore were paid \$75 because of the longer distance they had had to drive to participate.

Data collection and analysis. The same professionally trained focus group moderator conducted all three group interviews, each of which lasted approximately one and one-half hours. The moderator used a semistructured interview guide with discussion items and identical sequences for each focus group. The guide was

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generated from the results of a previous survey of Maryland adults,⁵ as well as guides we had developed previously for health care providers on the same subject.

The moderator (W.L.C.) prepared a summary report for the three sessions, which contained selected quotes, while a second research team member (A.M.H.) prepared verbatim transcriptions from the audio recordings. We compared the two documents to ensure that they were consistent with the audio recordings. We then used qualitative content analysis methods to develop themes with supporting quotes from the verbatim transcriptions.⁷⁻⁹ We then prepared a qualitative descriptive profile of the participants on the basis of the combined findings from the three focus groups.

RESULTS

Five major themes emerged from the three focus groups. The information obtained helped explain from a patient’s perspective why the majority of these adults reported that they had not had an oral cancer examination in the past year. It also provided valuable insight into how this problem might be solved.

Theme 1: awareness of oral cancer and reactions to facts about it. Each group included participants who had never heard of oral cancer, and most of the others did not know very much about it. Participants were struck by the fact that they rarely hear anything about this type of cancer. Among their comments:

- “I haven’t heard much other than about that ballplayer ... you never see it written up.”
- “Occasionally, you see it written up. You see more of lung cancer [and] prostate cancer.”

Most participants thought that chewing tobacco causes oral cancer. They did not seem to realize that cigarette smoking is the primary risk factor. Participants asked several questions about oral cancer and why the public does not hear more about it if it is so prevalent:

- “Why haven’t we been more informed?”
- “If it’s that bad, why hasn’t it been publicized?”

Most of the participants tended to agree with one person who said, “You don’t hear a lot of publicity about oral cancer compared to breast cancer—and all other kinds of cancer. You never hear about oral cancer on TV or about cautions

you should take on how to prevent it or how often you should be checked or at what age.”

Participants also were interested in knowing the symptoms for which to look and whether insurance pays for the examination.

Theme 2: recollections from last visit to the dentist regarding health history taken and performance of an oral cancer examination.

When asked by the moderator, several participants in each group remembered completing some type of health history when they first visited their dentist. The moderator usually had to ask specifically whether anyone remembered the health history’s including questions about tobacco use. Participants most often mentioned being asked about their own or their parents’ medical history and about their insurance status:

- “I had to fill out a long form asking me about what kind of medication I was on. Did I have sugar [diabetes], cancer, high blood pressure? Was I allergic to anything? ... [It asked for the details of my] mother’s [health] history, [the details of my] father’s [health] history. ... It was because it was the first time I went to that clinic.”
- “I remember something about, of all things, the credit cards and health insurance.”

Few participants recalled being counseled by a dentist about anything in particular, including smoking or use of other forms of tobacco. One person mentioned being advised about a diet healthy for teeth and how to brush and floss her teeth. A few participants said that they had been advised to stop smoking, but did not indicate that they had been told much about why or how to do so.

Each of the focus groups included adults who said that they visited dentists regularly for routine checkups and cleanings. When asked to describe their recent dental visits in detail, participants remembered things like reading magazines in the waiting room, having their teeth cleaned or radiographed by a dental hygienist and the dentist’s “looking at” their teeth. No one mentioned having undergone an oral cancer screening examination. In fact, after being told what the examination consists of, quite a few participants were relatively certain that they never had had such an examination and that they would remember if they had. Among the comments to this effect:

.....
Each group included participants who had never heard of oral cancer, and most of the others did not know very much about it.

— “If someone had grabbed my tongue and looked [at it], I would have known or remembered it.”

— “I would remember if someone pulled a piece of cotton out to work on my tongue.”

Still, a few people wondered if they might have had an examination at some point of the dental visit but simply did not know what the dentist was doing:

— “Maybe dentists do this, and we just didn’t know.”

— “Your dentist might be looking, and you don’t know it. I want to be told. I’m paying him to do what is best for me. I want to know what he is doing.”

But a few people distinctly recalled having had such an examination when the moderator described it (“You mean the cancer check?” one said).

Four participants said that they had the examination but had not thought to mention it in their descriptions of recent visits to their dentists. In each group, at least one person did recall having had the examination after hearing the moderator’s description of it. Their comments included the following:

— “[The dentist] takes his finger and feels around all over the place.

He checks my glands around here and up there. I was concerned about cancer, but he didn’t find anything. Every time I go, he checks all around.”

— “They look around. [The dentist] told me before he did it. He put a tissue on my tongue and looked around. When he was done, he said I was cancer-free.”

Among participants who thought they had had the examination, most people said that they were not told it was a cancer screening before it was done:

— “They checked the inside of my cheeks and pulled out my tongue and felt my neck. They didn’t tell me what they were doing.”

— “I don’t remember them saying that they were checking for cancer, but [rather] for gum disease.”

Several participants said that their regular physicians, not their dentists, perform the examination:

— “I’ve only had it done by medical doctors.”

— “My regular doctor [physician] does it every year.”

— “The doctor checks my neck and down my throat. I don’t think any of the dentists I have

been to did anything but use the mirror and pick at my teeth.”

Furthermore, each group included a participant or two who avoided going to a dentist unless they were in pain. Several of the participants had lost all or most of their teeth and assumed that they did not need to see a dentist unless they had a problem.

Theme 3: what people need to know about oral cancer and oral cancer screening. After learning some facts about risk factors for and signs and symptoms of oral cancer, several participants in each group said that the following information is important for the Maryland public to learn:

— how common oral cancer is;

— Maryland’s oral cancer statistics, including the number of people who develop it and how many die of it;

— the impact of tobacco and alcohol use on oral cancer;

— symptoms and signs of oral cancer;

— the importance of looking in one’s mouth;

— how easy the oral cancer examination is;

— that oral cancer disfigures a person, but it can be prevented.

One participant wanted to know whether there is an oral cancer self-examination like the one for breast cancer. She said, “If you knew the symptoms to look for, you could check yourself. If you saw one of those changes, then that would be the alarm that something is wrong.”

Another participant commented, “People who like the way they look, they do not want their face[s] torn up. This information just might scare them. They might get more concerned.”

Some of the participants developed opinions about oral cancer examinations because of information they gained from taking part in the focus group. For example, several participants said that they would ask about the oral cancer screening as a result of the focus group discussion. However, a few people said that they would ask only if they happened to be at the dentist’s office but would not make a point of going just to be screened.

One participant who indicated that he was unlikely to go for a screening said it would make a difference if he could find a dentist whom he likes and with whom he could feel comfortable talking.

Several of the participants had lost all or most of their teeth and assumed that they did not need to see a dentist unless they had a problem.

Theme 4: whether information would motivate people to seek an oral cancer examination, and the type of health provider with whom they would be most comfortable undergoing the procedure.

Several participants in each group thought they would ask about an oral cancer examination as a result of the information discussed:

- “I think when I have to go, I will request it, probably. I probably will leave here and look in my mouth to see if I can find anything, but I probably wouldn’t make an appointment just for that examination.”
- “I feel sure that I have had it [an oral cancer examination], but I’ll be sure to ask now.”
- “I will ask next time. I want to know what he is doing.”

Other participants, however, admitted that they were neither motivated to do so nor concerned about the issue:

- “Unless I was feeling ill, I wouldn’t go have this [examination] done.”
- “Out of sight, out of mind. When you leave here today, you will forget about it.”

Participants noticed that the background information they were provided during the discussion mentioned that one could ask a physician about oral cancer screening. One person thought he might ask about the oral cancer examination when he saw his physician for regular blood pressure checkups.

In one of the groups, most participants reported that they would probably be more comfortable discussing oral cancer with their regular physicians than with their dentists. Others thought they would be comfortable enough with either a dentist or a physician:

- “I’ll probably ask the doctor [physician]. He checks for all types of cancers.”
- “I would ask the physician as opposed to the dentist to do the exam.”
- “I am really close to my medical doctor. I tell her everything. She is my friend. As long as I have been going to this dentist, I am not close to him. I think you associate your dentist with pain. They have no bedside manner.”
- “I would probably ask the dentist, but I would be petrified the whole time.”
- “I would ask the dentist. I don’t think I would

worry because no one in my family has cancer.”

- “I would ask the doctor or dentist. My family doctor gives me a lot of information. I know there is some way you can identify lesions. Why isn’t there some self-taught thing [like breast self-examinations]?”

One participant planned to ask both his dentist and physician about the examination: “When I go for my annual [checkup], if he doesn’t do it, I’ll be sure to ask—both my physician and my dentist. It wouldn’t hurt to have them both do it.”

Theme 5: ways to communicate with the public. Participants suggested that information should be distributed through schools and various types of mass media, not just through dentists or physicians. Collectively, participants recommended that the following be used to disseminate information about oral cancer prevention and early detection: use of billboards; advertising on buses, trains and subway trains; health classes in schools; television talk shows; World Wide Web pages; and discussions in religious groups. Several participants suggested that the radio be used more frequently. One participant said, “A lot of work-

places have radios [on during the workday]. If you listen to something over and over, eventually it sticks in your mind that this is important.”

DISCUSSION

Overall, participants in these focus groups were not well-informed about oral cancers, and most believed that they had not had an oral cancer examination. These findings are consistent with a statewide telephone survey conducted earlier among Maryland adults.⁵ Participants thought it was strange and disturbing that oral cancer is rarely publicized and felt that efforts to increase awareness are needed. Their perceptions of a dearth of information for the public are consistent with studies that have confirmed this problem.^{11,12} Because many people do not see a dentist for routine care, efforts to educate the public about oral cancer and early detection are important.

Although dentists are considered physicians of the mouth, it is interesting that many of the focus group participants were more inclined to seek care regarding an oral soft-tissue lesion from their physicians rather than their dentists. In a related study that involved focus groups made up

Participants thought it was strange and disturbing that oral cancer is rarely publicized and felt that efforts to increase awareness are needed.

of Maryland family practice physicians, the participants were not surprised that in Maryland, most oral cancers are diagnosed by physicians. In these latter focus groups, physicians tended to believe that patients would be more likely to see them than dentists about oral cancer issues, because health insurance frequently does not cover dental treatment. In addition, some thought that patients were afraid of going to a dentist and tend to associate such visits with pain.¹³

Furthermore, the practice among dentists of not informing patients when they are conducting an oral cancer examination means that some people may have had the screening without realizing it. The examination itself is a valuable opportunity to explain why the screening is important, what the lesions look like and why it involves examining the tongue by having the patient extrude it and checking lymph glands intraorally and extraorally. This kind of information also would help prepare patients who are not accustomed to having the dentist be concerned with anything besides teeth.

Some dentists have seemed 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. However, there is good evidence that health care providers, including dentists, can be very influential in getting their patients to stop tobacco use. This concept may be of special importance in a tobacco-producing state such as Maryland.

CONCLUSIONS

The findings from these focus groups, combined with survey findings from the Maryland state⁵ and national^{13,14} studies, suggest that a major effort in providing information and education about oral cancer prevention and early detection

is needed. Furthermore, dentists and other care providers could be instrumental in increasing the public's awareness of and knowledge about these cancers. Most important is that dental professionals should be taking appropriate health histories, providing comprehensive oral cancer examinations and explaining the procedure to their patients. ■

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