

# Perspectives of Maryland Adult and Family Practice Nurse Practitioners on Oral Cancer

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## Abstract

**Objectives:** Because oral and pharyngeal cancer mortality in Maryland ranks seventh among states and sixth for black males, a statewide oral cancer needs assessment was conducted. The purposes of this qualitative descriptive study were to obtain indepth information on nurse practitioners' awareness and opinions of oral cancer, oral cancer examinations, and related factors. These findings were intended to supplement a previous survey conducted among Maryland nurse practitioners. **Methods:** A professional focus group moderator conducted one face-to-face focus group with 11 nurse practitioners and one telephone focus group with eight nurse practitioners. Criterion-purposeful sampling and qualitative content analysis were employed. **Results:** Findings showed that oral cancer is a neglected public health problem and, based on their formal training, not one considered by nurse practitioners to be their responsibility. Although aware of other cancers, none of the nurse practitioners recognized that oral cancer was a public health problem in the state. Numerous barriers were cited for this neglect, including their lack of training and, in one case, unpleasant feelings about examining the mouth. Participants concluded that oral cancer is part of their responsibilities and that they are interested in related continuing education courses. **Conclusions:** The focus groups of nurse practitioners provided rich and insightful suggestions for future strategies to help solve the oral cancer problem in Maryland, which supplemented the quantitative mail survey conducted earlier. [*J Public Health Dent* 2001;61(3):145-49]

**Key Words:** oral cancer, focus groups, qualitative descriptive study, nurse practitioners.

In 1999 oral cancer accounted for more than 8,000 deaths of Americans, which surpassed both the number of deaths and the mortality rates for either melanoma or cervical cancer (1-3). Although the incidence and the mortality rates of oral cancer are on a slight decline in the United States, as they are for most other cancers, the five-year survival rate of oral cancer unfortunately has been unchanged since the early 1970s. In contrast, there have been significant improvements in the five-year survival rates of melanoma and cervical cancer. This discrepancy is because most oral cancers are detected at later regional or distant stages rather than at an early, localized stage, while most melanoma and cer-

vical cancers are detected at early or localized stages (3). Over the past 20 years the average five-year survival rate of oral cancer patients has been approximately 50 percent in the US population, 55 percent in whites, and only 32 percent in blacks. Likewise, during 1989 to 1994 only 38 percent and 18 percent, respectively, of oral cancers in whites and blacks were diagnosed at an early, localized stage (1,2). Findings from a 1992 survey among Americans also confirm that only 15 percent of people aged 40 years or older reported ever receiving an oral cancer examination. Furthermore, of those who had such an examination, only 48 percent had one during the past 12 months (4), even though

the American Cancer Society recommends that this age group receive a yearly oral cancer examination (5).

In the United States, the mortality rate of oral cancer for the state of Maryland ranked seventh among all states in 1996, which was up from the eighth since the early 1970s (2,6,7). In addition, from the latest available data in 1996, Maryland ranked sixth among all states for the oral cancer mortality rate in black males, which has likely increased since the early 1970s (Chu KC. Personal communication, Senior Researcher, Office of Special Populations Research, NCI, January 12, 2001).

As part of a systematic statewide oral cancer needs assessment, two focus groups (8) of Maryland adult and family practice nurse practitioners were conducted after a mail survey in the same group. The objective of this study was to obtain more indepth information on why these primary care professionals do not routinely perform oral cancer examinations for their adult patients by exploring barriers obtained from the previous quantitative mail survey (9). These barriers were: (1) awareness and opinions of Maryland adult and family practice nurse practitioners about oral cancer, and (2) skills and other factors affecting their provision of oral cancer examinations for the public. This study also probed other possible barriers perceived by nurse practitioners and sought their suggestions to help solve this problem in Maryland.

## Methods

This qualitative description was generated from two focus groups with Maryland adult and family practice nurse practitioners. These two focus groups were conducted with different methods at two geographical locations

in the summer of 1998: a face-to-face focus group in the Baltimore area and a telephone focus group in the Eastern Shore region. Criterion-purposeful sampling was used as the sampling strategy (10). Qualitative content analysis was selected as the method for data analysis (11,12).

Information from the previous mail survey of nurse practitioners (9) and the latest available data from the Maryland Cancer Registry (13) helped identify the inclusion criteria. First, the research team selected Baltimore and the Eastern Shore region as the two localities in Maryland for study because of their high incidence and mortality rates of oral cancer. Only persons currently employed for at least 20 hours per week as adult or family practice nurse practitioners in these two areas were eligible for participation. Only participants who served mostly middle- or low-income adult or elderly patients were recruited. The last two inclusion criteria were to obtain a diverse mix of years of practice experience and a mix of public and private primary place of employment. A private firm hired by the focus group leader recruited all nurse practitioner participants. The firm used the telephone list of adult and family practice nurse practitioners registered in those two areas provided by the Nurse Practitioners Association of Maryland to identify potential participants. The other inclusion criteria were verified with the participants.

Eleven nurse practitioners participated in the Baltimore focus group. Their experiences as nurse practitioners ranged from one year to more than 15 years, serving a wide range of clients in both public and private settings. These practice settings included hospitals, home care agencies, community health clinics, and freestanding clinics. This focus group session was completed in one hour and 40 minutes after the participants' working hours. It was conducted in a professional focus group facility, with conference-style seating for participants and adjacent viewing room for observers and recording equipment, at the office of the Assistance in Marketing Research Services Network in Towson, MD. A trained professional focus group moderator with extensive experience in conducting health-related qualitative research facilitated the focus group. The moderator used

a semistructured questionnaire guide formulated by the research team. The focus group was audiotaped and observed by the researcher team through a one-way mirror in an adjacent room. One research team member also took notes of the focus group's discussions. At the beginning, all participants were thoroughly informed of the focus group procedures. A light dinner and refreshments were provided before the focus group started.

Because of the wide geographic distribution of nurse practitioners in the Eastern Shore region, a telephone focus group was conducted rather than a face-to-face focus group. Participants were eight nurse practitioners whose experiences ranged from less than one year to more than 15 years in public and private settings. Their practice settings included community health center clinics, student health centers, private practices, and a psychiatric hospital. The Eastern Shore region telephone focus group was conducted for 70 minutes in the evening after the participants' working hours. The same moderator facilitated this telephone focus group using a semistructured questionnaire guide similar to that used for the Baltimore focus group with only slight changes to accommodate the different mode of data collection. The session was audiotaped and monitored by the research team. One research team member also took notes of this session. At the beginning, all participants were thoroughly notified about the telephone focus group process.

The semistructured questionnaire guides used in both sessions included specific discussion items and exact sequences. These questionnaire guides were adapted from a questionnaire guide used in the focus groups with other types of health professionals on the same subject (14). However, the guides for this study were not pretested specifically among nurse practitioners. Discussion topics incorporated the participants' awareness and opinion concerning oral cancer statistics in Maryland and oral cancer's risk factors, their training to provide oral cancer examinations, their opinions about doing oral cancer examinations and their actual practices, their priorities for doing these examinations and factors that influence their priorities, their reactions to results from some other related surveys among other

professional groups and the public, and their suggestions for improving oral cancer services for the public. A summary sheet of Maryland oral cancer statistics, relevant practice procedures for detecting oral cancer, and highlights of previous surveys among health professionals was disseminated to all participants at the end of the Baltimore focus group. The same fact sheet was mailed to all participants in the Eastern Shore region prior to the telephone focus group session. All participants of the second group confirmed receiving this fact sheet. Highlights in the fact sheet also were provided verbally by the moderator as background for the questions discussed at the beginning of each focus group.

Each research participant was briefed on the study's objectives and the participant's role in the study during the recruitment phase and just prior to the conduct of each focus group. Each participant gave verbal informed consent before each session was conducted. Only the first name of each participant was used during and after the sessions. Participants in the face-to-face focus group were provided a light supper before the session. Each participant was compensated \$100.

There were five steps in the data analysis process. First, after each session, the research team discussed strengths and weaknesses of the data collection process and a possible data analysis framework. Second, the moderator prepared a summary transcription (15) for each session with selected quotes from the audiotapes, and another research member prepared a written summary of each session. Third, another research team member listened to the audiotapes together with a review of the moderator's summary transcriptions and the observer's/listener's notes to ensure descriptive validity (16) and to get a whole sense of the collected data (17). The same member of the research team used the qualitative content analysis method to extract major themes and quotes pertinent to the objective of the study from the moderator's summary transcriptions, audiotapes, and the observer's/listener's notes (18). Fourth, members of the research team discussed and agreed on those theme categories. The research team was confident that they inter-

preted the participants' responses and the group dynamics correctly. This confidence was justified because the topic was fairly straightforward. Moreover, ambiguous issues were rechecked at the end of both sessions. Ten minutes before each session ended, the research team member who observed the face-to-face focus group and monitored the telephone focus group supplied the moderator with additional questions and unclear points to be probed before each session was terminated. Thus, this study likely had interpretive validity (16). The research team concluded that the Baltimore focus group and the Eastern Shore region telephone focus group did not provide different information. Therefore, the research team decided to prepare one qualitative descriptive profile based on patterns and themes that emerged similarly from both sessions.

## Results

"... when you look at the mouth, there is everything right there: poverty, lack of care, history of IV drug use, abuse, ... look into the eye and the mouth, we can see the whole person...."

This participant's quote reflected the view of most participants that the mouth was an integral part of the body. Moreover, they indicated that they had decided to participate in this study because of their interest in oral cancer. However, almost all admitted that an oral cancer examination was not a high priority in their practice settings and that they had rarely performed these examinations for their patients. One participant revealed:

"I can't remember the last time I put a finger in someone's mouth. ... I am feeling that it is almost confession time. Because I think how many patients I have seen who have a history of alcohol or drug abuse and I can't say that I did these tremendous oral exams ... I would say I fall short of thinking of that. Certainly lung cancer but I can't say that I would think of oral cancer."

To help explain why Maryland adult and family practice nurse practitioners were unlikely to perform oral cancer examinations in adult patients, four main themes were summarized

and explained. The first two themes elucidated two barriers identified from the previous mail survey. The third item summarized the participants' perceived barriers to this issue. The last category elaborated the participants' suggestions to help solve the obstacles.

**Theme 1: Insufficient Knowledge about Oral Cancer.** Two areas of oral cancer knowledge were explored and discussed in the focus group and the telephone conference. These areas were oral cancer statistics and risk factors. First, perception of oral cancer statistics was discussed. None of the participants in either group recognized that oral cancer is a public health problem in the United States and in Maryland. All members of the Baltimore group were surprised at the high incidence and high mortality rates for oral cancer in the United States. Furthermore, they were amazed at Maryland's unexpectedly high ranking among other states for oral cancer death rates, even though most participants were well aware of the high incidence of other types of cancers in Maryland. Similarly, most members of the Eastern Shore group were astonished at the Maryland oral cancer statistics. Many participants enthusiastically asked several related questions after the moderator revealed the information. Typical reactions from participants were:

"No, I had no idea of those statistics at all."

"We never hear about oral cancer."

"We are high up on all cancers; we are leading the nation on all cancers, but I didn't realize that oral cancer was a specific problem."

Second, inadequate recognition of oral cancer risk factors was discussed. Most participants could not identify the risk factors of oral cancer. Most participants of the Baltimore focus group could identify only tobacco use and alcohol consumption for oral cancer and sun exposure for lip cancer, whereas nearly all participants of the Eastern Shore group put emphasis only on the use of smokeless tobacco. Both groups did not include age, family history, previous oral cancer history, inadequate consumption of fruits and vegetables, and certain viral infec-

tions as risk factors (19). Some questioned whether pharyngeal cancer should be included in a definition of oral cancer. The Baltimore focus group agreed to one participant's suggestion that, "If you can reach it [in the oral cavity] with a finger, it is included." This definition was similar to the terminology of oral cancer, which includes cancers of the lips, tongue, floor of the mouth, palate, gingival and alveolar mucosa, and oropharynx (20).

**Theme 2: Uncertain, Uncomfortable, and Unclear about Oral Cancer Exams.** Most participants in both groups were highly confident of their skills in palpating head and neck lymph nodes—an extraoral part of an oral cancer examination. In contrast, nearly everyone was uncertain, uncomfortable, or unclear about performing an intraoral part of an oral cancer exam. In short, they believed they had inadequate skills to perform oral cancer examinations. They were uncomfortable because of their unpleasant feelings about examining their patients' oral cavities. They were unclear about the line of responsibility with dental professionals on this intraoral examination.

Factors that affected their skills were their lack of formal and continuing education. Most participants reported they had received no or brief and fragmented training on oral cancer examinations. Although several participants stated that an oral cancer examination was a part of their physical examination training, nearly all participants believed that they had inadequate skills for performing oral examinations, especially palpation in the oral cavity and examination of the tongue. A mainstream belief of the participants conformed to this participant's remark:

"It [training on oral cancer examinations] was covered as part of the physical [examination], but it wasn't covered in [the] depth that you [the focus group moderator] were speaking."

Another weakness addressed was that their oral examination training was likely neglected because it was considered solely a responsibility of the dental profession. A participant explained this disadvantage as:

"... After that we were sent off to practice [oral examinations] on

each other, I remember that nobody bothered to glove up and bothered doing this invasive mouth procedure ... They just said this [is] what you would do here and everyone just said all right."

Similar to their formal education, there was almost no continuing education on oral cancer reported by the nurse practitioners. A few participants of the Eastern Shore group noted that oral cancer was not included in the elective continuing education courses on cancers that they had attended during the past few years. Only a few participants had learned about an oral cancer examination from either the Internet (the National Oral Health Information Clearinghouse), informal training with a physician colleague, or a flowsheet physical examination protocol for nurse practitioners.

With regard to their lack of providing oral examinations, several participants felt that the oral cavity is a private and unclean part of the body. A few participants shared a sentiment expressed by one nurse practitioner:

"I remember how disgusting it was when you practiced on each other. You had the glove on your hand and [had to examine blindly inside the mouth.] Oooh, this is disgusting and it's terrible to have to do this on our patients."

Unfortunately, because of time constraints, this participant's response was not probed for a more in-depth meaning.

One issue was the unclear line of responsibility for intraoral examinations among nurse practitioners and dental professionals. Participants posited that:

"... We are back to this problem of who does the [oral cancer] exam and who takes care of the [oral cancer and oral health] problem."

"There seems to be a line between medical and dental follow-up, but the mouth is sort of a gray area. We inspect and palpate externally and we expect the dentist to go in and do the more internal stuff ... There seems to be this boundary, the teeth and the mouth, and nobody really knows who is supposed to be doing it."

The nurse practitioners perceived

that their training on oral examinations was superficial and that these examinations were mainly the responsibility of the dental profession. This perception reinforced the belief that the oral cavity should be reserved solely for dental professionals and that an oral examination was not a priority for nurse practitioners.

### **Theme 3: Other Perceived Barriers.**

Most participants in both groups agreed that there were several other barriers to their performing oral cancer examinations. Mainly, these obstacles were (1) time limitations for each patient in the current managed care system, (2) patients' not having dental insurance coverage, (3) unawareness of oral cancer in patients because of having little information on oral cancer, and (4) difficulties in convincing patients who had no symptoms or chief complaints in the oral cavity to have oral cancer examinations.

The barriers of time constraints and patients' lack of dental insurance were identified most often. Because approximately 15 minutes are allowed for each patient and there are so many activities to complete with each client, time constraints limited not only an oral cancer examination, but also patient education. Many participants piggybacked this participant's quote:

"Time is a constraint. You can't do a thorough oral exam in minutes, so I leave it to the dentist."

Participants also acknowledged that they see dental problems routinely, but little can be done because of patients' limited financial resources. Most patients, especially in the Eastern Shore region, were reported to not have dental insurance. Therefore, most participants felt that patients cannot visit a dentist directly when they have an oral health problem. Also, they felt that it would be highly unlikely for persons without dental insurance coverage to obtain an oral cancer examination from dental professionals. This participant's comment echoed most participants' responses:

"... I see dental problems every day, but there is nothing I can do for [patients] except hand them some Tylenol and Motrin because most of them have no [dental] insurance."

Some participants also mentioned the last two barriers. A few partici-

pants mentioned lack of awareness of oral cancer among their patients. They said:

"There is no information [on oral cancer] available, no brochure. Therefore, it is more likely to find oral cancer at the very late stage."

With a lack of available information, participants said that it was also very difficult to convince their patients to have oral cancer examinations and to refer them for further treatments. In connection with their negative feeling about examining the oral cavity, many participants also pointed out that their patients did not want their mouths to be examined, especially when they wore a denture or had poor oral hygiene.

**Theme 4: Need for Locally Organized Comprehensive Training and Other Suggestions.** Although almost all participants agreed that oral exams should be a part of their responsibilities and showed interest in continuing education on oral cancer, they suggested a more comprehensive course in which oral cancer is integrated with other relevant subjects, e.g., prevention and control of tobacco and alcohol consumption. They also preferred having oral cancer training together with other health professionals so that their roles and lines of responsibility could be discussed and determined. Moreover, most participants favored on-the-job training rather than a time-consuming continuing education course. Their suggestions were based mainly on a concern that oral cancer is a low priority among health care providers. Therefore, if a continuing education course were organized separately, they felt that few would be interested and participation would be low. Furthermore, it was noted that nurse practitioners in the Eastern Shore region would be highly unlikely to spend the lengthy six-hour commute to attend only a short continuing education course on oral cancer organized at a central location in Maryland. Finally, most participants preferred that such training courses offer continuing education credits and that fees should be minimal. The Eastern Shore region participants also suggested that the College of the Eastern Shore would be an appropriate venue for their training.

Participants suggested the follow-

ing topics that continuing education on oral cancer should cover: how oral cancer kills, review of complete oral examinations, lesions that need referral, typical versus atypical lesions, tongue examinations, risk factors, resources and specialists in the community for referral of patients, oral examinations in high-risk populations, and oral examinations in primary care settings.

Most participants also recognized the need to raise awareness of the burden of oral cancer for both the public and health professionals through various channels with various types of media such as the use of flyers, posters, and CD-ROMs.

### Discussion

This study provided insight into strategies to enhance a Maryland statewide oral cancer prevention program. Because poorer populations are more likely to have access to medical care than dental care, primary medical care providers, including nurse practitioners, should play a pivotal role in the implementation of oral cancer preventive programs. Based on information obtained from the previous mail survey (9), possible education interventions for nurse practitioners were assessed in this study. However, data from this study showed that there might be other essential areas that need further study. These include a perception that performing oral examinations is unpleasant for nondental health care providers, negative attitudes of both patients and health care providers toward the oral cavity, and an unwillingness of patients to be examined intraorally. These constraints may dramatically affect the success of a program that goes beyond an educational intervention.

Three weaknesses of this study need to be addressed: the disadvantages of a telephone focus group, whether the criteria for recruiting participants were appropriate (21), and whether the data obtained from only two focus groups were adequate (21).

Disadvantages of a telephone focus group have been discussed elsewhere (22,23). This study shared some of those weaknesses. However, possibly because of the nonsensitive nature of the topic of this study, group dynamics that occurred during the Eastern Shore telephone focus group were

similar to those that occurred in the face-to-face focus group. In addition to the participants' active discussions throughout the conference, they also interacted during a short absence of the moderator, who had to brief a participant who joined the group late. During this short period, participants mentioned that they enjoyed the telephone focus group and would like this kind of study done more often. In short, there were no shortcomings that seemed to affect the findings from the telephone focus group compared with the face-to-face focus group.

It has been suggested that focus group participants should not only have common experience with the focus of the research, but also similar cultural experience (8,24). Although a mix of participants' years of practice experiences and a mix of participants' public/private primary place of employment were included in the study, the first suggestion was not violated. From a previous survey, the data showed that most nurse practitioners rarely performed oral cancer examinations; therefore, their experiences with the research topic should have been similar. Concerning the second suggestion, there should not have been a problem because of the nonsensitive study topic. In short, the sampling strategy and criteria for recruiting participants for this study seem to have been appropriate.

Because of limited resources, only two focus group sessions were included. Nonetheless, little new information emerged from the second session. Therefore, the information from this study likely is adequate to guide relevant interventions that are needed for an initial phase of an oral cancer preventive program in Maryland. Moreover, the research team presumes that the process of studying this problem is appropriate and can be applied in other states or communities.

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