Published in final edited form as:
J Health Care Poor Underserved. 2007 November ; 18(4): 833–846.

The Cultural and Social Context of Oral and Pharyngeal Cancer Risk and Control among Hispanics in New York

Gustavo D. Cruz, DMD, MPH, **Lawrence C. Shulman, MSW, ACSW**, **Jayanth V. Kumar, DDS, MPH**, and **Christian R. Salazar, MPH**
GUSTAVO CRUZ is an Associate Professor at the New York University College of Dentistry, Department of Epidemiology and Health Promotion, with which CHRISTIAN SALAZAR is also affiliated. LAWRENCE SHULMAN is affiliated with Sociomedical Resource Associates in Westport, Conn. and JAYANTH KUMAR with the New York State Department of Health, Bureau of Dental Health Services in Albany.

Abstract

New York City (NYC) has one of the highest incidence and mortality rates of oral and pharyngeal cancer (OPC) for Hispanics of any major U.S. city. This qualitative assessment explores OPC awareness, attitudes, and screening practices among at-risk Hispanics, health care providers, and community leaders in a Hispanic neighborhood of NYC. Four focus groups (N=39) were conducted with at-risk Hispanics. Structured interviews were conducted with ten health care providers (four physicians, four dentists, two dental hygienists) and three key community leaders. Results showed major gaps in OPC awareness across all key stakeholders. Focus group participants expressed difficulty in accessing appropriate health care. Health care providers were not familiar with OPC prevention and early detection practices. Community leaders lacked the knowledge and resources necessary for advocating prevention and early detection for their constituencies. All participants reported cultural, social, and structural barriers to prevention. There is a need for developing a comprehensive, culturally competent health communication program that targets all key stakeholders in the at-risk Hispanic community of NYC.

Keywords

Oral cancer; Hispanics; cancer; culture

It is estimated that 34,360 new cases of oral and pharyngeal cancer (OPC) will be diagnosed in the U.S. and 7,550 will die of the disease in 2007.[1] The overall five-year relative survival rate for diagnosed cases of OPC from 1996 to 2003 was 59.1% and has not changed significantly over the past 30 years.[2,3] Although racial and ethnic disparities in the incidence and mortality from OPC are well documented,[3–6] very little is known about the risk of OPC among Hispanics in the U.S. Recent studies have shown that Hispanic men in New York State (NYS), and New York City (NYC) in particular, exhibit much higher incidence and mortality rates of OPC than Hispanic men nationally.[7] Furthermore, early stage diagnosis for these cancers is lower in NYC than for the country as a whole and even lower within counties and neighborhoods where Hispanics constitute the majority.[7] Understanding the factors associated with disparities in cancer incidence and mortality in the U.S. is a fundamental goal sought by health care policymakers, providers, payers, and other stakeholders who strive to develop effective cancer control interventions for all populations with disproportionately high risks.

Please address correspondence to Gustavo D. Cruz, DMD, MPH, NYU College of Dentistry, Department of Epidemiology and Health Promotion, 345 East 24th Street, New York, NY 10010; (212) 998–9970, gustavo.cruz@nyu.edu..

The etiology of OPC is complex. Cigarette smoking and the consumption of alcoholic beverages are the primary behavioral risk factors for OPC, and their joint use can have multiplicative rather than additive effects; the risk is 6–15 times greater for smokers who are also heavy drinkers than for individuals who neither smoke nor drink.[8] In terms of dietary intake, the most consistent finding has been a protective effect associated with a high consumption of fruit, although a number of studies have also suggested that the consumption of some vegetables may be inversely associated with these types of carcinomas.[9,10] Other risk factors include certain human papilloma virus infection and sun exposure (for lip cancer).[11]

Lack of public awareness of the signs, symptoms, and risk factors associated with oral malignancies have been hypothesized to be potent barriers for the early detection and prevention of OPC.[12] National and local studies have shown that awareness of OPC tends to be lower among Hispanics than among non-Hispanics.[13,14] In addition, findings from the 1998 National Health Interview Survey (NHIS) and other recent studies conducted in NYS show that fewer Hispanics than non-Hispanics receive oral cancer examinations.[14–15]

The main objectives of this study were to assess qualitatively: a) OPC awareness, attitudes, and screening practices among Hispanics at high risk, b) knowledge and attitudes about OPC among health care providers who serve large Hispanic populations in NYC, and c) knowledge and attitudes about OPC among community leaders in Hispanic areas of NYC. This qualitative assessment focusing on at-risk Hispanics in NYC expands on the authors' previous quantitative studies conducted in NYS.[7,13,14,16]

Methods

Investigators conducted focus groups among at-risk Hispanics and a total of thirteen one-on-one interviews with health care providers and community leaders. All guides were developed by the investigators of this study, based on their previous work and an extensive review of the literature.

Focus groups

Hispanic outreach workers recruited participants (N=39) face-to-face for all four focus groups during 2003–2004, primarily through community contacts in New York City: one large cooperative residential development in the Bronx, one prominent drug and alcohol treatment agency in the South Bronx, and one social and advocacy organization in Upper Manhattan. Men composed three of the focus groups and women the fourth (see Table 1). All participants were Hispanic (mostly of Puerto Rican descent), smokers (current or past), and alcohol users. All recruited focus group participants spoke both English and Spanish. Therefore, all discussions were conducted in English. Nevertheless, a bilingual co-facilitator was available for assistance if needed. All focus groups were conducted in the area where the participants were recruited. Each session lasted approximately 90 minutes.

A trained focus group moderator first distributed and answered questions about the informed consent document, stressing risks and benefits, confidentially of the group discussion, the voluntary nature of participation, and participants' rights to further information. Afterwards, participants completed a short sixteen-item anonymous questionnaire in English to collect data about age, ethnic background, tobacco and alcohol use, socio-demographic information, whether or not they had ever had signs or symptoms of oral cancer, and whether or not they had ever had an oral cancer examination. All participants received a $30 incentive for their participation. Approval was obtained from the New York State Department of Health institutional review board prior to the study.

Focus group participants were asked a series of 26 questions that probed into their perceptions of general health in their respective communities, health concerns facing men and women their age, their views of smoking and drinking, and their smoking experience and behaviors. Participants were also asked whether they had heard about *oral* (*mouth*) *cancer*, followed by a series of additional questions about both their oral cancer-related behaviors (e.g., behavior in response to symptoms) and what they perceived as influencing those behaviors (e.g., perceived susceptibility to oral cancer, perceived severity of oral cancer, perceived barriers to seeking care for oral cancer), Participants were also asked what they thought could be done to increase awareness of OPC in their community and what the main message(s) about oral cancer should be.

At the end of each session, a co-facilitator described oral cancer's risk factors, signs, and symptoms, and the importance of seeing a health care provider early if symptoms arise or persist. Oral cancer brochures and health information were distributed to all.

Health care providers

Thirty-six providers practicing in the same neighborhoods as the focus group participants were contacted from various referral sources including professional colleagues and members of the projects professional advisory group. Seventy percent responded to telephone solicitation. Ten providers were recruited and interviewed: four physicians, four dentists, and two dental hygienists. A uniform semi-structured interview guide was developed for all health care providers. The guide included questions regarding years in practice; practice characteristics; perceptions of social/structural factors and cultural beliefs that affect care-seeking behaviors of their patients; awareness of oral cancer epidemiology, signs, symptoms, and examination techniques; and current practices regarding counseling for tobacco and alcohol use. Each participant received $100 honorarium for his or her interview.

Community leaders

Three community leaders were recruited and interviewed: two Hispanic advocates with many years of health care advocacy and a Health Liaison for one of the NYC Borough Presidents. A semi-structured interview guide was developed and utilized; its content was similar to that used with the health care providers but with emphasis on their own and their community's knowledge, attitudes, and perceptions about oral cancer. Two community leader interviewees received $50 honoraria for their participation. (The Health Liaison, who was a public official, did not receive an honorarium.)

Data analysis

All 4 focus groups and 7 of the 13 interviews were tape-recorded. In addition, extensive field notes were taken for all. Audiotapes were transcribed and analyzed. Relevant patterns or themes of data were coded and organized into larger categories using Folio Views v4.3.[17]

Results

At-risk Hispanics' perspectives

Four significant themes emerged from the focus groups: Major health concerns facing men and women their age in their communities and social issues that contribute to poor health, social/cultural issues regarding their cigarette smoking and alcohol use, general awareness of oral and pharyngeal cancer, and perceived barriers in obtaining timely medical and oral health care.

Social and health concerns—Participants cited cancer (especially lung, prostate, and colon cancer), asthma, diabetes, hypertension, heart disease, high cholesterol, depression, and obesity as major health issues in their communities. However, HIV/AIDS was their most pressing concern. Social issues related to poverty, homelessness, substance abuse, smoking, and alcohol abuse were all mentioned as factors contributing to poor health.

Social/cultural issues regarding cigarette smoking and alcohol use—Current smokers reported smoking from less than half a pack per day to more than two packs, with the majority reporting smoking between a half and one pack per day. All members agreed that smoking was a considerable problem in their neighborhoods. Initiation of smoking at a very early age (as early as 7–8 years old) was described as having a cultural and familial pattern. Most reported having a parent who smoked cigarettes. One participant said, "My mother smoked, my grandmother smoked. Everybody smoked." Another interjected, "They don't smoke now but they smoked then. That's how we started. I saw them smoke and I was taking cigarettes from them".

One of the older participants reminisced:

> When we would go for a drive (in Puerto Rico), my father would ask me to light him a cigarette. I was about nine and I would take a few puffs myself.

Another added:

> I used to [do] that with my stepfather. I used to like it.... it used to get me all dizzy and everything.

Another participant remarked, "Puerto Ricans smoke a lot." One of the younger men chimed in, "Yes, I would say 100%. They are not playing, they smoke 24/7. . . . They learn it from their parents . . . . " A young man stated, "By the time I was 13, I already had permission from my mother to smoke." A few of the group participants likened cigarette smoking to heroin addiction. Stress and anxiety were cited by many as precursors to smoking or to resuming smoking after a period of cessation.

Several participants described the interaction between smoking, alcohol, and drug use, especially among the young. One said, "… there are a lot of kids that smoke cigarettes and marijuana. I have seen a lot of 12, 13 year olds actually sitting there, and asking people for a cigarette. Especially when they go clubbing … they smoke marijuana and whatever liquor they are drinking … and then they have to have a cigarette." Another participant added, "They could smoke from a pack to three packs a day depending on their stress . . . . It is the atmosphere too. They just buy a pack and sit there and blow."

Cigarette smoking was associated with many emotional stressors (brought forth by social and economic factors) experienced by Hispanic men and women. A male participant summarized his social concerns:

> I just live in the ghetto. I don't have nothing to do, no school, no job. I don't get involved with no kind of community anything, What am I going to do? Develop a habit or a hobby. I have idle time. . . . What I am going to do? I am going to pick up a bad habit. Drink and smoke … is like a product of the environment. You know? That's serious . . . .

Cigarette smoking was believed by many participants to be associated with lung cancer and emphysema but not with OPC. When probed further, most stated that smoking, particularly heavy smoking, would probably increase a person's risk for OPC. They identified smokeless tobacco (chewing tobacco or snuff) as a probable risk factor for OPC, but believed that smokeless tobacco users were typically baseball players or people in rural areas, as well as

older, poor people, "… like those living in the mountains of Puerto Rico." Nevertheless, most participants saw no direct relationship between heavy smoking, alcohol abuse, and oral cancer.

Oral and pharyngeal cancer awareness—Most participants lacked bask knowledge of OPC and were unfamiliar with the term *oral cancer.* They needed clarification that oral cancer was cancer of the mouth (including lip) and throat. No participant mentioned oral cancer at the beginning of the discussion. Fewer than 30% of the participants said that they had heard of OPC. When asked what they had heard, most speculated about the causal factors. Three participants described OPC as "… not very pleasant, painful," "loss of the voice box, the tongue, the jaw bone" and "disfiguring," respectively. Two participants said they had family members (one a grandfather and the other an uncle) who died from OPC.

When told about the prevalence of OPC in their community as well as risk factors and early signs, most participants expressed outrage at the lack of information available in their communities. Most of the participants emphasized the need to "get the facts out to the people" in order to increase awareness of OPC in their community. Monetary incentives to be examined and to encourage follow-up were thought to be useful. Nevertheless, most recognized that money alone would not overcome denial or the sense of fatalism (the belief that events are determined by an impersonal fate and cannot be changed by human beings), which many described as "cultural" among Latinos. Most participants agreed, "It's up to God if you gonna get it."

Many participants cited lack of knowledge about signs or symptoms of OPC, denial of the consequences of risky behaviors (i.e., smoking and alcohol abuse), and faith in "God's will" as reasons for not considering themselves at high risk. One participant expressed a fatalistic view this way: "What will happen, will happen, I can't control it."

Most participants believed that a diagnosis of OPC would be very serious. Some were concerned about length of life with a diagnosis of OPC; others seemed more concerned about disfigurement and other quality of life issues. Only a few had seen anyone with disfiguring surgery. Interestingly, when asked about their self-perceived risk for OPC, most participants perceived their risk to be none to low.

When asked about the type of provider they would seek, should symptoms of oral cancer appear, many replied that they would seek a physician, whereas only a few indicated that they would seek a dentist. Many suggested they would try to ignore any symptoms unless they became very painful or severe. The vast majority of participants reported that they had never received an oral cancer exam (that they were aware of) from a doctor or a dentist. Most participants did not see dentists as the most appropriate health providers to see for oral cancer. Most agreed with a male participant who stated, "Dentists only drill and fill cavities and pull teeth to make bridges. They don't talk about oral cancer."

Barriers to health care—Very few participants sought preventive medical or dental care. Most admitted delaying a visit to the doctor or dentist "… until things get real bad, and I really feel lousy" (as one participant said). Cited barriers to accessing health care included absence of signs or symptoms; denial; treating themselves with over the counter medications or with other remedies obtained from *botánicas* [retail stores selling alternative medicines and goods] or from *curanderos* [healers]; "fatalism"; cost; lack of health insurance; and communication difficulties with the providers who "don't speak my language or understand my culture."

Most participants felt they had access to some level of medical care specifically for emergencies (generally, the public health care system). Clinics and emergency services were cited as places where participants frequently received care. All of the participants who had visited a health

care provider in the past year said that their providers had not discussed OPC risks, signs, and symptoms with them, despite their having a history of tobacco and/or alcohol use.

Health care providers

Physicians' perspectives—Four physicians practicing in the same area where the focus group participants lived were interviewed. Many agreed that there is a lack of appropriate access to health care in the communities where they practice. All cited a lack of compliance by their patients as well as communication difficulties with their patients as barriers for preventive regimens. Many patients, they said, only return if the same condition gets worse or a new condition arises. Most physicians described little understanding about cancer in general and OPC in particular among their patients. Low awareness of OPC was attributed to many factors, including little knowledge of its signs, symptoms, and risk factors and the perceived fact that Latinos tend to "avoid hearing about cancer because they associate it with death and pain."

Only two of the physicians reported routinely checking for signs of OPC as part of a general medical workup. One physician stated, "If the problem is below the neck, I rarely check for oral cancer." Three were not sure who is "primarily responsible" for examining for OPC, a dentist or a physician. Nevertheless, two agreed it should be a shared responsibility. All refer their patients to a dentist if they find potential mouth lesions. All indicated they routinely counsel their patients about smoking cessation; only two stated they had counseled patients about excessive drinking. All confirmed they had had very little clinical training on OPC in medical school. They learned "a bit [to examine the mouth] but there was little emphasis on cancers of the mouth and throat. The emphasis was on looking for swollen glands."

Oral health care providers' perspectives—Four dentists and two dental hygienists were interviewed. They identified the major oral/dental health problems of their populations as cavities, gum infections, poorly made dentures, soft tissue abnormalities, and lack of prior dental care. They said that very few patients had knowledge of OPC and that most had little general knowledge about oral diseases. All but one of the dentists had received training about OPC after graduating from dental or dental hygiene school. Interestingly, most cited time pressures associated with practicing in low-income communities, lack of reimbursement and the relative low yield of oral cancer examinations as strong barriers for adherence to recommendations. All dentists indicated they talk to their patients about smoking cessation but "we know it's not going to happen," They all agreed that more continuing medical/dental education courses should be available on the subject to "refresh their knowledge." None evaluated their patients for alcohol abuse or discussed alcohol as part of their initial dental exams. All stated they have communication difficulties with patients who speak another language (only one of the oral health providers interviewed was Hispanic and spoke Spanish). Most tried to resolve the problem by having family members or others to interpret during the examination, adding undue stress to the patient-doctor encounter. The two dental hygienists felt they were more "attuned to patients and patients' responses to illness and disease [than the dentist]." They suggested that dental hygienists are underutilized in OPC control. Both said they performed routine oral cancer examinations on their patients.

Community leaders' perspectives

Three community leaders were interviewed: Two were Hispanic advocates who had 15 and 21 years of health activism experience, respectively, in the Bronx neighborhoods. In addition, they served as volunteers or staff members for a community-based organization in the Bronx. The third community leader was a Health Liaison for one of the city's Borough Presidents. All cited very poor access to health care, particularly oral health care, for residents of low socioeconomic status in their Bronx and upper Manhattan communities; they all shared the

impression that OPC is largely unknown in their communities. All were aware that cigarette smoking was a cause of lung cancer, but none had knowledge of the risk factors for OPC. They believed that heavy smoking and drinking, especially among Latino men, is prevalent in their communities. The leaders cited many social and economic barriers to proper awareness of health care issues and access to health care. These included poverty, discrimination, homelessness, family dysfunction, low literacy, and social isolation. One leader said:

> … Folks who are poor and illiterate tend to keep to themselves. They do not go to medical providers unless they are very sick. The emergency departments are the doctors of choice since they cannot be turned away for lack of money or insurance if they are sick … they ignore follow up recommendations …

Community leaders raised the issue of the large numbers of immigrants in their communities. They stated that many residents are worried about immigration (*la migra*) and that immigrants fear the hospitals and/or doctors will turn them over to the Immigration and Naturalization Service (INS). Dental care is even more difficult to get than medical care. According to all leaders, immigrants' knowledge of health and illness is very limited. Cultural attitudes about cancer equate it with death. One summarized the prevalent view on cancer this way: "Forget about treatment, your number is up, you're going to die."

For a summary of major themes elicited by all key stakeholders please see Table 2. Key recommendations for OPC control by all stakeholders are summarized in Box 1.

Discussion

As far as we can ascertain, this study is the first to examine community-level perspectives on OPC in a Hispanic community in the U.S. Results shed light on the prevalent perceived barriers for OPC control among all key stakeholders (health care providers, community leaders and individuals at high risk). Although social and cultural influences related to smoking and alcohol use among Hispanics have been reported previously,[18–20] no studies have explored these behaviors in the context of OPC risk.

Alarmingly, there was a general lack of awareness on the high incidence of this disease in all sectors of the community. Individuals at high risk mentioned multiple social, cultural, and economic factors that influence risky behaviors for OPC (i.e. smoking and alcohol abuse) as well as their care-seeking behaviors. Culturally influenced factors such as early initiation of cigarette smoking, fatalism, and the importance of family and community identification were often mentioned by focus groups participants. It is interesting that despite the serious efforts of several organizations to curb smoking rates among New Yorkers, this community had little knowledge of one of the most devastating effects of smoking in their community (oral and pharyngeal cancers). Although all stakeholders acknowledged the relationship of cigarette smoking to many cancers, its association with OPC was often unrecognized. Furthermore, the role of alcohol in increasing the risk of OPC was unknown to most participants.

Box 1. KEY STAKEHOLDER RECOMMENDATIONS FOR OPC CONTROL

1. Develop a high profile, creative and consistent educational and advertising campaign to increase public awareness of the serious risks associated with this cancer.
    - **a.** Develop educational materials that are at an appropriate reading level for distribution in community fairs, beauty parlors, bars, barbershops, churches, and community centers.

- **b.** Utilize various media (billboards, posters on public buses and subways, taxis, population-specific magazines, newspapers, photonovelas, ethnic newspapers, local radio stations and TV).
- **c.** Utilize public figures in the advertising (entertainment, music, sports, movie stars)

2. Propose mandated school-based educational programs for tobacco and alcohol control.
   - **a.** Target High School and elementary school students, particularly since smoking is initiated at earlier ages.
   - **b.** Target college students, where the risk level rises significantly for smoking and drinking.
3. Develop efforts to reach the immigrant populations, many of whom exhibit high rates of smoking and alcohol use.
4. Test the use and efficacy of an "Oral Cancer Van," to deliver educational materials and oral cancer screening services to various sectors of their communities and populations.

All health care providers and community leaders agreed that very few at-risk Hispanics seek preventive medical and dental care; episodic use of the health care system is the norm for a large sector of their community. Cited barriers to appropriate access to timely care included communication difficulties between providers and patients (because of both language differences and patients' low health literacy), lack of trust in health care providers, and attitudes and beliefs (on the part of both providers and patients) that undermine potential preventative efforts. For example, the focus groups participants blamed their providers for not informing them of the risk of smoking and helping them quit, for not conducting oral cancer examinations, and for not educating them on the signs and symptoms of OPC. On the other hand, providers blamed their patients' lack of compliance and episodic use of health care for the late detection of these cancers in their community.

All participants cited language barriers between providers and patients as contributing causes of deficient OPC knowledge and screening. Seemingly, however, providers, community leaders, and focus group participants were referring to different issues under the broad umbrella of language barriers. The providers and community leaders cited the need for translators and language-appropriate educational materials whereas focus group participants were also referring to providers' knowledge of culturally influenced behaviors and language nuances of bilingual individuals in their communities. Despite having the ability to speak English (with mixed proficiency) some participants cited communication difficulties with providers "… who don't speak my language or understand my culture."

In addition to the need for culturally congruent (or competent) providers, there seems to be a need for the utilization of trained medical interpreters in local health practices. Reliance on family members or friends to interpret during medical encounters has, for example, been found to be associated with low coronary heart disease risk knowledge among Spanish-speaking individuals.[21]

One of the most troubling findings of this study is the apparent lack of agreement on the part of both the public and medical health providers of what type of health professional is most appropriate to diagnose OPC; those at high risk say they would most probably go to a physician if they notice any signs or symptoms whereas the physicians think the dentist is the most appropriate health care professional to diagnose OPC. These different views are particularly

troubling because OPC can be easily diagnosed in its early stages; approximately 90% of all invasive oral and pharyngeal cancers arise from the surface mucosa[11] and are therefore readily visible to a clinician. With proper training, nurse practitioners, physician's assistants, physicians, dentists, as well as dental hygienists can identify OPC in its early stages with a simple ninety-second visual and tactile examination.[22]

According to all participants, the influence of social and cultural factors on harmful behaviors and timely care-seeking is compounded by stressors stemming from neighborhood characteristics including the high prevalence of drug and alcohol abuse; lack of affordable, culturally appropriate health care; the overall effects of poverty; and a sense of alienation from the community at large.

Our earlier quantitative studies showed that: a) Hispanics in New York City show the highest morbidity from OPC among all Hispanics in the U.S.;[7] b) NYS oral health care providers, although knowledgeable about the disease, need further training in certain examination techniques and recognition of some risk factors;[23] c) NYS Hispanics are less knowledgeable than non-Hispanics about the signs, symptoms, and risk factors for OPC;[14] d) Hispanics in NYS tend to have lower rates of oral cancer examinations than non-Hispanics;[14] e) NYS primary care physicians and nurse practitioners need training on OPC examination techniques and general awareness of the epidemiology of this disease in NYC (authors' unpublished findings). The present study expands on those findings and adds community level perspectives, which could inform future OPC control efforts. It shows the need for incorporating culturally specific beliefs (e.g., fatalism) and social concerns in preventative efforts, the need to address the lack of culturally competent health care, and the need to educate and raise the awareness of this disease in all sectors of the community.

Nevertheless, due to the qualitative nature of this study, its results cannot be generalized to the larger Hispanic Community in NYC. By design, all participants in the focus groups were individuals at high risk for OPC due to smoking and/or drinking and low socioeconomic status. Moreover, the health care providers and community leaders who were interviewed were all based in the same geographic area as the members of the focus groups, so their perspectives may differ from those of their peers in other areas of NYC or with a different patient population.

A previous national campaign to raise awareness of OPC was considered ineffective, especially among those at high risk, because it failed to account for the cultural context of the targeted communities.[24] Sadly, there are no OPC control programs specifically targeted to Hispanics in NYC or, as far as we know, in any other part of the U.S. Furthermore, the availability of patient educational materials that comprehensively addresses OPC risk factors for the general public is currently lacking.[25–26] As far as we could ascertain, there is also a lack of culturally appropriate OPC educational materials available for Hispanics. It is possible that the lack of awareness among health care providers, community leaders, and the public about the prevalence of these cancers in the Hispanic community may have led to an underestimation of the risk by this population and thus the lack of interventional programs.

In summary, this study suggests the need for a multi-sectorial health communication program that is culturally appropriate to increase awareness of OPC among all key stakeholders of this Hispanic community in NYC. Culturally appropriate messages that present the facts about oral cancer (i.e., definition, risk factors, signs, and symptoms); acknowledge the various cultural, social, and economic barriers to appropriate care; and emphasize early detection and prevention may help to reduce the morbidity of this disease among this population, which remains at high risk.

Acknowledgements

This study was supported by the National Institute of Dental and Craniofacial Research, National Institutes of Health, grants no. U54 DE 14257 and R21-DE 14425. We thank all participants of this study as well as the anonymous reviewers for their helpful and encouraging comments.

Notes

1. American Cancer Society (ACS). Cancer facts & figures 2007. Atlanta, GA: ACS; 2007.
2. Ries, LAG.; Krapcho, M.; Melbert, D., et al., editors. SEER cancer statistics review, 1975–2004. Bethesda, MD: National Cancer Institute; 2007.
3. Swango PA. Cancers of the oral cavity and pharynx in the United States: an epidemiologic overview. J Public Health Dent 1996 Fall;56(6):309–18. [PubMed: 9089526]
4. McLean A, LeMay W, Vila P, et al. Disparities in oral and pharyngeal cancer incidence and mortality among Wisconsin residents, 1999–2002. WMJ 2006 Sep;105(6):32–5. [PubMed: 17042417]
5. Shavers VL, Harlan LC, Winn D, et al. Racial/ethnic patterns of care for cancers of the oral cavity, pharynx, larynx, sinuses, and salivary glands. Cancer Metastasis Rev 2003 Mar;22(1):25–38. [PubMed: 12716034]
6. Morse DE, Kerr AR. Disparities in oral and pharyngeal cancer incidence, mortality and survival among black and white Americans. J Am Dent Assoc 2006 Feb;137(2):203–12. [PubMed: 16521387]
7. Cruz GD, Salazar CR, Morse DE. Oral and pharyngeal cancer incidence and mortality among Hispanics, 1996–2002: the need for ethnoregional studies in cancer research. Am J Public Health 2006 Dec;96(12):2194–200. [PubMed: 17077408]
8. Blot WJ, McLaughlin JK, Winn DM, et al. Smoking and drinking in relation to oral and pharyngeal cancer. Cancer Res 1988 Jun 1;48(11):3282–7. [PubMed: 3365707]
9. Winn DM. Diet and nutrition in the etiology of oral cancer. Am J Clin Nutr Feb;1995 61(2):437S–445S. [PubMed: 7840089]
10. Pavia M, Pileggi C, Nobile CG, et al. Association between fruit and vegetable consumption and oral cancer: a meta-analysis of observational studies. Am J Clin Nutr 2006 May;83(5):1126–34. [PubMed: 16685056]
11. Mayne, TS.; Morse, DE.; Winn, DM. Cancers of the oral cavity and pharynx. In: Schottenfeld, D.; Fraumeni, JF., editors. Cancer epidemiology and prevention. 3. New York: Oxford University Press; 1996. p. 674-96.
12. Horowitz AM, Goodman HS, Yellowitz JA, et al. The need for health promotion in oral cancer prevention and early detection. J Public Health Dent 1996 Fall;56(6):319–30. [PubMed: 9089527]
13. Cruz GD, Le Geros RZ, Ostroff JS, et al. Oral cancer knowledge, risk factors and characteristics of subjects in a large oral cancer screening program. J Am Dent Assoc 2002 Aug;133(8):1064–71. [PubMed: 12198985]quiz 1094
14. Kumar, J.; Oh, J.; Cruz, GD. Oral cancer examination: behavioral risk factor surveillance system (BRFSS) analysis; J Dent Res. 2006. p. 1564Available at www.dentalresearch.org
15. Blackwell DL, Tonthat L. Summary health statistics for the U.S. population: National Health Interview Survey, 1998. Vital Health Stat 2002 Oct;10(207):1–93.
16. Cruz GD, Ostroff JS, Kumar JV, et al. Preventing and detecting oral cancer. Oral health care providers' readiness to provide health behavior counseling and oral cancer examinations. J Am Dent Assoc 2005 May;136(5):594–601. [PubMed: 15966646]quiz 681–2
17. FolioViews. Nextpage 2.0 Web page. Draper, UT: 2006. Available at http://www.nextpage.com/resources/folio-views.htm
18. Unger JB, Shakib S, Gallaher P, et al. Cultural/interpersonal values and smoking in an ethnically diverse sample of Southern California adolescents. J Cult Divers 2006 Spring;13(1):55–63. [PubMed: 16696546]
19. Sanderson Cox L, Feng S, Cañar J, et al. Social and behavioral correlates of cigarette smoking among mid-Atlantic Latino primary care patients. Cancer Epidemiol Bio-markers Prev 2005 Aug;14(8):1976–80.

20. Kaplan CP, Nápoles-Springer A, Stewart SL, et al. Smoking acquisition among adolescents and young Latinas: the role of socioenvironmental and personal factors. Addict Behav 2001 Jul-Aug;26(4):531–50. [PubMed: 11456076]

21. Wagner J, Abbott G, Lacey K. Knowledge of heart disease risk among Spanish speakers with diabetes: the role of interpreters in the medical encounter. Ethn Dis 2005 Autumn;15(4):679–84. [PubMed: 16259493]

22. Kerr AR, Cruz GD. Oral Cancer, Practical prevention and early detection for the dental team. N Y State Dent J 2002 Aug-Sep;68(7):44–54. [PubMed: 12243093]

23. Gajendra S, Cruz GD, Kumar JV. Oral cancer prevention and early detection: knowledge, practices, and opinions of oral health care providers in New York State. J Cancer Educ 2006 Fall;21(3):157–62. [PubMed: 17371181]

24. Papas RK, Logan HL, Tomar SL. Effectiveness of a community-based oral cancer awareness campaign (United States). Cancer Causes Control 2004 Mar;15(2):121–31. [PubMed: 15017124]

25. Chung V, Horowitz AM, Canto MT, et al. Oral cancer educational materials for the general public: 1998. J Public Health Dent 2000 Winter;60(1):49–52. [PubMed: 10734617]

26. Canto MT, Kawaguxhi Y, Horowitz AM. Coverage and quality of oral cancer information in the popular press: 1987–98. J Public Health Dent 1998 Summer;58(3):241–7. [PubMed: 10101701]

Table 1

DEMOGRAPHIC CHARACTERISTICS OF STUDY POPULATION

Focus group participants	**Group 1 (n=10)**	**Group 2 (n=8)**	**Group 3 (n=8)**	**Group 4 (n=13)**
Sex	Female	Male	Male	Male
Age (yrs)				
Range	23–53	45–54	40–64	43–61
Mean	32.7	47	46.8	52.3
Providers		**Type of practice**		
Four (4) primary care physicians		Community-based group practice, HMO		
Four (4) dentists		Community-based group practice		
Two (2) dental hygienists				
Community leaders		**Community role**		
Two (2) Hispanic advocates		Health activism, CBO volunteer in the Bronx		
Public sector advocate		Health liaison for one of the City's Borough Presidents		

HMO = health maintenance organization

CEO = community based organization

Table 2

MAJOR THEMES RELATED TO OPC CONTROL BY KEY STAKEHOLDER GROUPS

	Focus groups	Health care providers	Community leaders
Smoking as a social/cultural issue			
1. Early initiation to smoking, often influenced by family member.	X		
2. Tobacco use associated with high rates of substance abuse, alcohol abuse and social distress.	X		
3. Acculturation plays a role among females.	X		
4. Lack of familiarity with tobacco and alcohol.		X	
5. High prevalence of smoking and alcohol use in the community.	X	X	X
Oral and pharyngeal cancer awareness			
1. Lack of knowledge about early signs, symptoms, risk factors, or the availability of an exam.	X	X	X
2. Most perceived no association between smoking, alcohol, and OPC.	X		X
3. Need for high profile community-based interventions.	X	X	X
4. Need more availability of culturally appropriate educational materials.		X	X
5. Low yield and reimbursement issues.		X	
Access to health care issues			
1. Few had history of regular medical or dental visits.	X	X	X
2. Lack of follow-up.		X	
3. Fatalistic view of cancer “Cancer = Death”.	X	X	
4. Social issues (e.g. poverty) as barriers for seeking care.	X		X
5. Poor access to oral health care.	X		X
6. Cultural and language differences as barriers.	X	X	X

OPC = oral and pharyngeal cancer