Exploring awareness, attitudes, and perceived role among oral health providers regarding HPV-related oral cancers

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Abstract

Objectives: Human Papillomavirus (HPV), the most common STI in the United States, is increasingly being associated with a number of cancers, including oral cancers (OC). This may change the approach of oral health providers (OHP) towards screening and identifying OC in their patients.
Methods: Five focus groups were conducted in February and March 2009 with dentists and dental hygienists. Participants were recruited via presentations at monthly meetings of local dental and dental hygiene professional associations, and through association mailing and telephone lists.
Results: A total of 38 OHP participated in the focus groups (17 dentists and 21 hygienists). Analysis of focus group data was framed by three general content areas regarding HPV-related OC and the HPV vaccine, including: a) knowledge; b) attitudes; and c) perceived roles. Sub-themes that emerged included issues related to the HPV vaccine, the role of professional organizations, and concerns with gender roles and confidentiality.
Conclusions: As public awareness of the link between HPV and OC increases, OHP play an important role in addressing this issue with their patients. The current study clearly identified areas that must be addressed among OHP in order for effective and comfortable communication regarding the HPV-OC link and the potential uses of the HPV vaccines to take place, including: a) increasing knowledge of the HPV-OC link and HPV vaccine; and b) clarifying screening procedures, role, and expectations.

Introduction

Human Papillomavirus (HPV) is the most common sexually transmitted infection (STI) in the United States (1). The US Centers for Disease Control and Prevention estimate that at least 50 percent of sexually active men and women will acquire genital HPV infection in their lifetime (1). The virus is typically asymptomatic and transient, and 90 percent of HPV cases are naturally cleared by the body's immune system within 2 years of infection (1). "Low-risk" HPV types cause genital warts, while "high-risk" HPV types can cause cancer. With 99.7 percent of all cervical cancer cases attributed to HPV infection, it is widely accepted that HPV is the necessary cause of cervical cancer (1). High-risk HPV types are also linked to other anogenital cancers, including cancers of the vulva, vagina, penis, and anus, as well as non-anogenital cancers, including non-melanoma skin cancer and increasingly oral cavity cancer (OC) and oropharyngeal cancer (OPC) (2).

In 2009, an estimated 28,500 new cases of OC and OPC were diagnosed in the United States, with an estimated 6,100 deaths due to these cancers (3). Of these cancers, more than 90 percent are oral squamous cell carcinomas (OSCC) (3). Although there has been an overall decrease in incidence of OSCC over the last 30 years due to public health successes in reducing tobacco exposure among Americans (4), the incidence of HPV-related OSCC is on the rise (5). A recent review of the literature reported that HPV was present in ~22-26 percent of OSCC, of which ~90-95 percent were attributable to HPV-16 and -18 (the two types responsible for 70 percent

of all cervical cancers) (6). Moreover, much higher proportions (38-65 percent) of HPV-related OSCC have been observed in other studies (7,8).

Increases in HPV-related OSCC are attributed to increasing oral HPV infections (4). Oral HPV infection is likely acquired through sexual behavior, particularly through oral sex. However, other possible modes of transmission include autoinfection, mouth-to-mouth contact or kissing, and perinatal transmission (9). Thus, rather than tobacco and alcohol consumption, the risk profile for HPV-related OSCC consistently includes a greater number of oral and vaginal sex partners, a history of genital warts, and younger age at first intercourse (10).

To address the increasing incidence of HPV-related OSCC, researchers have cited the potential of existing HPV vaccines (7,9,11). Currently, two HPV vaccines are Food and Drug Agency-approved, both of which protect against HPV-16 and -18 – the HPV types that are responsible for 90-95 percent of HPV-related OSCC (1,6). Although studies have yet to establish that HPV vaccines are effective in preventing HPV-related OSCC, research has demonstrated their effectiveness in preventing other non-cervical cancers, specifically vulva and vaginal cancers (12).

Among the most frequently visited health care providers in the United States (13), oral health providers (OHP) are well-positioned to play a critical role in primary, secondary, and tertiary HPV-related OSCC prevention. As both scientific evidence and public awareness of the link increases, OHP may be expected to address the HPV-OSCC relationship with patients – hence, forward referred to as the HPV-OC link. Yet, to date, no other known studies have examined the OHP role regarding HPV-related OC. Accordingly, the current study presents qualitative findings from a larger mixed methods study that explored the capacity of OHP to engage in primary and secondary prevention of HPV-related OC. The aims of this phase of the larger study were to: 1) assess awareness among OHP regarding the HPV-OC link; and 2) elicit OHP attitudes and perceived role regarding willingness to a) screen for HPV-related oral lesions; b) discuss HPV as a contributing risk factor for OC; and c) discuss the HPV vaccine with their adult patients or parents of minor patients. Because of the exploratory nature of the study, a specific theoretical model was not applied.

Methods

Participants

Five focus groups were conducted in February and March 2009 with OHP. Participants were recruited for the current study via two procedures: a) presentations at monthly meetings of local dental and dental hygiene professional associations located in Hillsborough and Alachua County, FL; and b) through association mailing and telephone lists. Inclusion criteria for participation in this study were: a) possession of a current dental or dental hygiene license; and b) graduation from an accredited US program. The current study was approved by the Institutional Review Boards of the collaborating universities.

Table 1 Sample Items from the Focus Group Moderator Guide

What have you heard about the link between HPV and oral cancer?
What do you perceive is your role or responsibility in screening for oral cancers?
What sorts of oral cancer risk factors do you look for?
What do you perceive is your role or responsibility in educating your patients about oral HPV infections?
What do you know about HPV vaccines?
What are your thoughts about recommending HPV vaccines to your patients?

HPV, Human Papillomavirus.

Instruments

A semi-structured moderator's guide was developed by the co-principal investigators (Daley, Dodd) in collaboration with the research team. Prior to implementation, the moderator's guide was reviewed for comprehension and face validity by five OHP and was revised accordingly (see Table 1). The semi-structured nature of the moderator's guide allowed for flexibility for responding with additional probes to new and/or unexpected responses.

Procedures

Three focus groups were conducted with practicing dentists (D), and two with practicing dental hygienists (DH). Of the three focus groups with practicing D, one was held in Gainesville, FL (Alachua County) and two in Tampa, FL (Hillsborough County). A focus group comprised of practicing DH was held in each of the above referenced Florida cities. Based on tenets of qualitative research methodology, focus groups were stratified by profession. Also, key informants recommended separating D and DH focus groups during the initial round of focus group moderator guide revisions. Because the perceived role of the OHP with regards to oral cancer screening was one of the main constructs to be examined, coupled with the differing nature of dental and dental hygiene practice roles and responsibilities, stratification of groups by profession was necessary. Each focus group consisted of 4-13 participants. All of the focus groups were held in the evening to accommodate practice hours. The Co-PIs, both of whom are experienced in focus group procedures, moderated the groups. Prior to beginning each group, participants were asked to read and sign a consent form describing the procedures and purposes of the study. Upon providing consent, participants were asked to complete a demographic profile. No

Table 2 Focus Group Participant Demographics

	Dentists	Dental hygienists	Total
N	17 (45%)	21 (55%)	38
Male	9	1	10 (26%)
Female	8	20	28 (74%)
Age range	28-66 years	23-60 years	23-66 years
Mean age	45 years	44 years	44 years
Years in practice (range)	3-43 years	<1-40 years	<1-43 years
Years in practice (mean)	19 years	16 years	18 years

identifying information was collected. Focus groups ranged in time from 60 to 120 minutes. D and DH were compensated with gift cards for their participation in this study.

Data analysis

All focus groups were audio-recorded and transcribed verbatim for analysis. Any potentially identifying information was removed from the transcripts prior to analysis. A coding guide was developed that focused on the key items of elicitation (e.g., knowledge, attitudes, and perceived role). Data were then coded iteratively in NVivo® (QSR International, Cambridge, MA, USA), a qualitative software package, using the constant comparative method. Codes were compared for inter-rater consistency, and inconsistencies were resolved through research team meetings and ongoing discussion. Passages were sorted by category and reviewed for recurring themes and diversity in responses.

Results

Participant demographics

A total of 38 OHP participated in the focus groups (D = 17; DH = 21). Participants ranged in age from 23 to 66 years. The majority (84 percent) self-identified as Caucasian. More detailed information regarding specialty training among OHP was not collected systematically; however, it was revealed during the course of the focus groups that a variety of specialties were represented. Table 2 depicts demographic characteristics by profession.

Analysis of focus group data centered on the three major themes as explored in the focus group moderator's guide, namely: a) knowledge; b) attitudes; and c) perceived role regarding HPV-related OC and HPV vaccines. Sub-themes within these three main content areas emerged during the analysis (see Table 3). The following sections present general and sub-theme findings.

Knowledge

Knowledge regarding the HPV-OC link

Participants were asked about their level of knowledge regarding the link between HPV and OC. Overall, participants' responses ranged from a complete lack of knowledge to understanding *some* intricacies of the HPV-OC link, as represented by the following quotes:

Table 3 Matrix of Themes

Knowledge	Attitudes	Perceived role
Limited knowledge regarding the HPV-OC link	(Dis)comfort discussing the HPV-OC link with patients	Role of OHP in discussing the HPV-OC link with patients
Limited knowledge regarding the HPV vaccines	Concerns with confidentiality issues related to discussing the HPV-OC link with patients	Role of OHP in discussing the preventative potential of HPV vaccines with patients
Shifts in dentistry practice resulting from emerging HPV-OC link	Concerns with gender roles related to discussing the HPV-OC link with patients	Role of professional oral health organizations in raising awareness about the HPV-OC link
Summary: Limited knowledge about the HPV-OC link and HPV vaccines, coupled with changing risk factors for OC, results in new OC screening challenges and some uncertainty among OHP	Summary: Concerns about the appropriateness of HPV-OC discussions with patients due to confidentiality and gender roles results in some OHP discomfort	Summary: OHP responses varied regarding whether or not their role should be to discuss the HPV-OC link and/or HPV vaccines with patients. Accordingly, many cited the need for professional organization support to raise public and disciplinary awareness about the link

HPV, Human Papillomavirus; OC, oral cancer; OHP, oral health providers; OPC, oropharyngeal cancer.

"I thought I had a decent oro-patho education but, it just seemed like there was just no connection made. I personally don't know. I kind of made an assumption, but beyond that I don't know much else." (D)

". . . When that [the link between HPV and OC] started coming out . . . they were making some connection between the HPV. I think it's [strains] 16, 18, 41, or something like that . . ." (D)

A few participants expressed a strong desire to learn more about the HPV-OC relationship:

". . . I'm interested to learn a lot about the link because I wasn't aware there was a great link with the oral cancer." (DH)

Knowledge regarding HPV vaccines

Similarly, most participants reported not being well-informed about HPV vaccines. For example, one female dentist reported: "I'll be honest. I don't know much about the vaccine. I don't." Misinformation and uncertainty of associated risks, monetary cost, and number of required vaccine doses emerged during the group discussion, as illustrated in the following quotes:

Participant 1: "How often do you have to have the vaccine?" (D)

Participant 2: "Once, I believe, is all you need." (D)

Several OHP expressed strong professional and personal reasons for acquiring more information about the risks associated with HPV vaccines:

"I don't know enough about the vaccine. I'm therefore afraid to give it to my daughter right now . . . And I would really like to know more about it or if it's a time thing for it to be out . . ." (DH)

Shifts in practice

Another important sub-theme emerging from the discussion relating to knowledge was a frequent acknowledgement that the HPV-OC link and its accompanying new risk factors are dramatically shifting current understandings of OC risk. For example, one OHP reported the following:

"We do the exam, and we behave like what we were trained . . . We are taking age and risk factors and stuff into [account] . . . HPV throws all that out the window. How do we check HPV visually? We're not. We're not going to catch it early." (D)

OHP frequently indicated that this new information underscores the need to screen everyone for OC, not just those with the traditional risk factors:

"Well it's also shifted due to the fact that it's not just your smokers and your tobacco users anymore . . . So, it's gotten to the point where you need to do it on everyone." (DH)

In addition, OHP spoke at length about their desire for additional guidance from their professional organizations on ways to manage screening for HPV-related OC:

"We need standard of care . . . The potential for negativity there without saying, 'this is standard of care. ADA's been informing people. I have a brochure in my waiting room that explains this.' I can't branch out like that unless I've got that support for me." (D)

Attitudes

(Dis)comfort

Focus group participants described varying levels of comfort pertaining to patient-provider discussions of the HPV-OC link. Findings suggest that while some OHP could easily engage with their patients on this topic, most were more hesitant:

"I'm in a small town, and if I bring that stuff up, not only it'd be the kiss of death [. . .] it ain't gonna fly." (D)

OHP frequently made connections between patient-provider communication about HPV-related OC and other sensitive oral health topics, such as domestic violence, drug use, or eating disorders. Attitudes toward these other sensitive topics and their connections to HPV-related OC were described extensively. A participant explaining the similarities between broaching the topics of HPV-related OC and domestic violence reported:

"Several years ago, we had to go into the whole domestic violence thing. We had to start being comfortable about recognizing those things and being able to ask a patient . . . We're always jumping hurdles with the new things that come out and how to address patients." (D)

Another participant drew a comparison between the sexual aspects of both HPV-related OC and HIV, and the lingering effects of the latter on their profession:

"Let me say this is not the first time. HIV hit dentistry hard, scared people hard. And we still ignore it. We still don't discuss anything with our patients. We just hope to God they will proclaim that they have it if they do." (D)

Concerns with confidentiality

Most participants expressed concerns with confidentiality in relation to "sensitive" discussions with patients. These concerns were especially strong when they involved discussing sensitive topics with minor patients. Other concerns included constraints of the physical environment, such as operatories without doors, which preclude patient privacy during visits. With regard to the structure of offices, one participant stated:

"If you're going to ask [patients] a question which most people consider an invasion of privacy, the other issue in most dental offices is we are not behind a closed door.

We're in an open situation, so the confidentiality issue would be out right then. So I think that'd be another reason most people wouldn't feel comfortable asking or answering." (DH)

Regarding discussions with minor patients, another OHP commented:

"I think [discussing the HPV-OC link with patients] depends on the age of the patient . . . if the mother is waiting in the waiting room and you go, well what did you find? I think that's really delicate." (D)

Concerns with gender roles

The third sub-theme pertained to concerns with gender roles when discussing the HPV-OC link with patients. Many OHP alluded to the existence of gender roles, noting that DH, who are typically women, are better positioned to engage in sensitive discussions with both male and female patients:

"He [the dentist] is on a different level with the patient. But because he's on a different level, and we are more on their level, they talk with us more. Maybe it's because we are women mostly." (DH)

Male dentists often worried that any type of discussion involving sexual behavior places them at risk for being accused of sexual harassment or inappropriate behavior. A male participant commented on the challenges involved in discussing HPV-related OC with female patients:

"I think it would be very difficult for me to ask a 24-year-old college student girl if she's having sex and how many sexual partners she's had . . . I'd probably have to have somebody who is the same sex as her, so either a hygienist or somebody, filter the information, and then give me a risk factor." (D)

Perceived role

HPV-OC link

Although some participants stated that their profession had a clear role and responsibility in discussing the HPV-OC link with patients, others did not concur. The following quotes illustrate these contrasting points of view, though they are not reflective of wider professional differences between D and DH:

"It seems to fit in with our protocol." (D)

"I would not do it. I mean, I would not do it unless I was directly ordered to. Then I might have a problem." (DH)

HPV vaccines

Similarly, the reactions toward discussing and recommending HPV vaccines were varied. Positive reactions to HPV vaccine conversations were often in the context of educating patients:

"Definitely . . . I would definitely want to recommend. I think most dentists are preventative minded. That's how we are trained to be . . . Of course, allowing the parent to make the ultimate decision. But making them aware, most of them are just not aware . . . And again, if it is shown to prevent that problem and if they feel like their kid would be at risk, then absolutely you need to mention that." (D)

Most often, however, participants expressed more hesitation in relation to discussing and recommending HPV vaccines. Many attributed their reluctance to the limited information available about HPV vaccines in general, and their relationship to HPV-related OC specifically, as well as a lack of professional support:

"Do we have an obligation to push our patients to get vaccinated because they are not virgins or have had intercourse? I don't think that's our role. I don't think we think that's our role. It's certainly not our role yet. Right now we are just in this middle ground . . . we are just waiting for something to push it one way or the other as to what our obligation is . . . If we don't really have our ducks in a row on what's standard of care or not . . . For me, I'm just sitting back unless I'm directly asked." (D)

Finally, a number of OHP touched upon the importance of the difference between active versus passive vaccine recommendation. Some participants suggested they would feel differently about discussing the vaccine with a patient if that person asked them about it, rather than the OHP initiating this conversation. Overall, OHP demonstrated a much higher level of comfort when engaging in patient-initiated HPV discussion. These patient-led discussions could be facilitated, as suggested by one participant, by placing HPV vaccine materials in their offices:

"I'm not going to openly say, 'Hey, has your daughter had sex yet? No? Ok, great. How about this vaccine?' But if they asked me, 'Hey, what do you think about this vaccine?' I'd say, 'Yeah, it's great . . .' ." (D)

Role of professional organizations

Most OHP focus group participants strongly stated their belief that professional associations should play a role in increasing public awareness about the HPV-OC link. For example, one OHP remarked:

"I really think that if oral cancer becomes, first of all, more prominent, and second, HPV is the main thing causing it, ADA has to do a commercial campaign to inform people. . . . Then they will be prepared when they step through our doors that yes, this is part of caring for you. I don't think you could just decide tomorrow that I'm going to start talking about sexual preferences with Josephine Smith . . . when you are in business, and your business thrives on word of mouth, you run the risk of

really upsetting someone who is going to tell a thousand people." (D)

In addition to commercial campaigns, participants suggested various mechanisms through which the American Dental Association (ADA) could play a role. These included creation of brochures, standards of care, and additional training of OHP at annual meetings.

Discussion

As public awareness of the link between HPV and OC increases, OHP may play an important role in addressing this issue with their patients. The current study presents the most pressing needs identified by OHP in facilitating effective patient–provider communication regarding the HPV-OC link and the potential uses of the HPV vaccines. Specifically, these areas include: a) increasing knowledge of the HPV-OC link and HPV vaccine; and b) clarifying screening procedures, role, and expectations.

First, while participants reported that they have a clear role in screening for OC, many expressed concerns about appropriate patient–provider communication regarding HPV-related OC. Additionally, though many OHP expressed a baseline awareness of the emerging science regarding HPV-related OC, knowledge of both the link and HPV vaccines varied widely. Although some OHP were quite knowledgeable, others demonstrated either a lack of knowledge generally or confusion about various aspects of the issue. In general, regardless of these inconsistencies, OHP expressed the desire for additional knowledge and training to improve communication with their patients. Many participants discussed how this additional knowledge would improve their comfort level in addressing issues relating to the sexual behavior of patients. As several participants pointed out, OHP have significant experience in communicating about other sensitive topics, such as domestic violence and eating disorders. Presently, high levels of motivation to increase HPV-OC knowledge present a window of opportunity for effective continuing education opportunities specific to the HPV-OC link and the role of vaccines in prevention.

Additionally, study findings point to the possibility that the ability of OHP to effectively screen for OC has been complicated by the shifting standard in OC screening brought about by HPV. According to many of the participants, the introduction of HPV as a risk factor has obscured understanding of the traditional risk factors that they have historically relied upon to assess patients. Accordingly, this new knowledge has impacted their dental practices. Traditional risk factors for oral cancer, such as being male, older, and a smoker, must be revised in the wake of this new relationship, and participants often described this complex amalgam of risk factors as bringing a certain level of uncertainty to their practice, pointing out the absence of guidelines addressing screening for HPV-related OC. Overall, participants were quite vocal when discussing the fundamental importance of professional associations, and their role in leading the development and communication of guidelines dictating the proper standards of care for HPV-related OC.

Limitations

Interpretation of these data must be viewed within the context of this study's limitations. First, the study included a small sample of dental and dental hygiene providers in the state of Florida; findings cannot be generalized to OHP practicing elsewhere. Second, over-representation of females in the sample (among both the dental and dental hygiene focus groups) signals the potential for selection bias. However, the over-representation of women in voluntary focus group samples is common in most fields of inquiry and cannot be interpreted as having any inferential meaning. A stronger probability is that knowledgeable OHP participants self-selected for the study, as demonstrated by some comments in the focus groups. Additionally, over-representation may reflect a common perception of HPV as solely a "women's issue." Finally, because the study was exploratory, a theoretical framework was not applied to interpret findings. In areas of limited knowledge, it is common for researchers to sacrifice the use of existing theoretical frameworks in order to allow themes and concepts to emerge from the data. Despite these existing limitations, this exploratory study provides a foundation on which to build further research.

Implications for practice

As public awareness increases with regard to the association between HPV and OC, the greater the probability that OHP will be looked to as leaders in the primary and secondary prevention of HPV-related OC. Further training of OHP relating to identified issues is critical, and professional associations must take a leading role in determining the most appropriate ways to manage the new screening needs created by the growing HPV-OC connection. Perhaps most importantly, it is essential to facilitate increased communication and interaction between providers across fields, both dental and medical, in light of the interdisciplinary nature of HPV-related OC prevention, detection, and treatment.

Accordingly, three strategies are recommended for potentially increasing knowledge and role clarification. First, it is critical that professional associations provide their OHP members guidance through policy statements. As the leading national organizations representing OHP, the ADA and American Dental Hygienists' Association have the opportunity to develop proactive campaigns highlighting ways to address HPV-related OC nationwide. As scientific research on this connection continues to emerge, professional

organizations must be active in formulating clear guidelines for screening and patient education practices. Second, continuing education venues offered in a variety of preferred formats, reaching a wide range of providers, are critical. Finally, hands-on, skills-building workshops are essential for ensuring a well-trained, confident, and skilled OHP workforce that is effective in HPV-related OC screening and communication techniques.

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