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Modifiable and Non-Modifiable Factors Associated with HPV Vaccine Decision-Making among American Indian Women College Students

Christine Samuel-Nakamura and Felicia Schanche Hodge

Although cervical cancer is preventable, it is highly prevalent among American Indian (AI) women, resulting in significantly higher mortality rates compared to the general population. The AI age-adjusted cervical cancer mortality rate in the Southwest in 2007–2009 was 4.1/100,000¹ higher than the national AI rate of 3.6² and the national rate for all races of 2.7.³ Both insufficient cervical cancer screening (16.5 for AIs compared to 10.8 for whites)⁴ and a disproportionate prevalence of highrisk human papillomavirus (HPV) types (25% for AIs compared to 15% for the US population)⁵ contribute to cervical cancer mortality among AI women.

There are about forty types of HPV that can infect the genital areas. Some types can cause cervical cancer in women and other less common cancers such as cancer of the anus, vagina, vulva, and oral cavity (base of the tongue, the tonsils, soft palate, and walls of the pharynx). HPV genotypes 18 and 16 are estimated to cause 70 percent of cervical cancers. The mean time to clear human papillomavirus is eight to nine months, with most infections clearing by twenty-four months. Considered one of the

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most common sexually transmitted infections (STIs) in the United States, HPV has a prevalence rate of upwards of 50 percent among all sexually active people, with an estimated 80 percent of sexually active women becoming infected during their lifetimes. HPV infections are most common among those in their late teens and early twenties.

Since 2006 and 2009 two vaccines have been available for primary protection against the HPV virus, Gardasil® and Cervarix®.¹¹⁰ HPV vaccines were initially recommended for women between the ages of twelve to twenty-six who were not yet sexually active.¹¹ Completing the Cevarix® vaccine series is 93 percent effective against Cervical Intraepithelial Neoplasia 2+ (CIN2+) associated with HPV 16/18 and is 54 percent effective for non-vaccine oncogenic HPV types,¹² potentially reducing the global cervical cancer mortality rate by 67 percent. For Gardasil® the efficacy was 96 percent for CIN1, 100 percent for CIN2, 97 percent for CIN3, and 100 percent for adenocarcinoma in situ, respectively, for HPV6/11/16/18.¹³

Despite its proven efficacy, additional efforts are needed to improve HPV awareness among AI women. Only 64.8 percent of AI women received at least one initiating vaccine dose and 40.5 percent completed the vaccine series. Here is no HPV-vaccine coverage data for AI men. Our project was designed to assess HPV-vaccine readiness among AI college students, and identify factors that influence their decision-making. Identifying modifiable risk factors is critical so that those factors can be targeted for health behavior education and intervention. Further, identified risk factors can be tailored for designing effective interventions in high-risk communities.

METHODS

Sample and Recruitment

American Indians attending two West Coast colleges (a, b) and two Southwestern colleges (c, d) were recruited to participate in focus groups exploring their HPV perceptions, experiences, and vaccination decision-making strategies. Thirty-four female and twenty-three male AI college students consented to participate in the survey and focus groups. Each of the four schools held two focus groups on site. Trained AI graduate students recruited participants via flyers and through word of mouth. The flyers were posted at American Indian studies departments, student unions, and news boards across each of these schools. Potential participants were screened using the following eligibility criteria: (1) self-identified as American Indian; (2) between the ages of eighteen and twenty-six; and (3) currently enrolled as a college student. The focus groups were held at the thirty-four community rooms in the student unions or in conference rooms in the American Indian studies departments. Institutional Review Board (IRB) review and approval was obtained at one of the partnering colleges; the other colleges deferred to their IRB oversight.

Focus groups were led by a trained AI facilitator and each lasted approximately one hour. The facilitator obtained consent from each student prior to each focus group, with copies of the signed consent form provided to each student. Students were told that their participation was voluntary and that they did not have to answer any question that they did not want to. Students were also told if desired they could

request that audio recording of the session be shut off during the discussion. A \$25 Target® gift card was offered to each student for participating.

Survey Measures

A self-administered questionnaire was given to students measuring their HPV knowledge and experience prior to entering the focus group. The following information was collected via the questionnaire:

Socio-demographics: Students were asked to report their gender, tribal affiliation, age and college of attendance.

Knowledge about the HPV vaccine: Knowledge about the HPV vaccine was determined using a composite measure based on eight questions. Each correct response received a score of 1. Knowledge scores had a possible range of 0–8.

Attitude toward the HPV vaccine: Attitude toward the HPV vaccine was based on three questions. For each question, a score of 1 was assigned if the response indicated "positive attitude" with regard to that question, strong or slight. Individuals' scores of 0 or 1 were added to obtain the total perception score, which ranged from 0–3.

Perception of HPV: Perception of HPV was based on seven questions. For each question, a score of 1 was assigned if the response indicated "positive perception" with regard to that question, strong or slight. Individuals' scores of 0 or 1 were added to obtain the total perception score, which ranges from 0–7.

Barriers to HPV vaccination: Barriers to HPV vaccination was based on four questions. For each question, a score of 1 was assigned if the response indicated "high barrier" with regard to that question, strong or slight. Individuals' scores of 0 or 1 were added to obtain the total perception score, which ranges from 0–4.

Focus Groups

All but four of the students who completed the questionnaire participated in a focus group. The discussions were designed to elicit more information about students' decision-making experiences regarding HPV and the vaccine. Focus group scripts included broad questions and prompts to guide the discussion and probe participants' HPV experiences. Students were asked if they had ever been asked to be vaccinated against HPV and if they had obtained the vaccination. Information on their age, parental involvement, and barriers to this particular vaccination were also addressed. Participants were asked about their decision-making reasoning and about past experiences that resulted in their having been asked or actually being vaccinated against HPV. Additional questions examined cultural influences that might affect their knowledge or attitudes, and decision-making toward HPV vaccination.

Data Analysis

Data from the survey were coded and analyzed using SAS software.¹⁵ Chi-square analysis and two-sample independent *t*-tests were conducted to detect differences between genders and groups. Differences between gender categories were identified under the

following broad classes: HPV experience(s), knowledge of HPV virus and vaccines, attitude about HPV, perception about HPV, and barriers to HPV vaccines. All statistical analyses were performed with a Statistical Analysis Program (SAS/STAT).

Established qualitative research methods were used to analyze data derived from the focus groups. The eight audiotaped focus group transcriptions were coded line-by-line using Grounded Theory methods. Resulting codes were used to form themes based on the topics and significant codes for each of the focus groups. These themes were then augmented with additional notes and explanatory memos from the audiotapes of the focus group discussions. Themes were then formed into categories to explain the decision-making strategy of the focus group participants. Additional categories were employed to supplement the questionnaire findings on knowledge, attitude, perceived risks, and barriers. Three researchers reviewed the findings and came to consensus regarding common groupings, uncommon responses, and differing themes. In the case of a disagreement, the researchers listened to the audiotapes and re-reviewed the transcripts to reach consensus on response categories.

SURVEY RESULTS

Demographic characteristics: A total of fifty-seven AI students (34 females and 23 males) participated in the study. The average age of students was twenty-two years with an age range of eighteen to forty-five years. Seventy percent (n=40) were members of a Southwest tribe; others reported membership in tribes from California, Oklahoma, or other states. Nearly one quarter (23.5%; n=8) of participating women reported having had at least one of three HPV vaccinations (p=.0004).

Knowledge about the HPV vaccine: On average, female students reported very low levels of knowledge about the HPV vaccine. Eighty-five percent of females answered only one HPV knowledge question, "Who can get HPV?" (out of a possible 8 questions) correctly.

Attitude toward the HPV vaccine: Females held a more positive attitude toward the HPV vaccine than males did (scoring 1.5 times higher on the HPV attitude scale). More females than males (67.6% vs. 60.9% respectively) reported that they "do everything to prevent contracting HPV," although females were less likely than males to recommend the HPV vaccine to a friend (50.0% vs. 65.2% respectively). Additionally, all participating females (100%) reported that they were comfortable talking about HPV, compared to only 45.4% of males.

Perception of HPV: On a scale of 0–7, female and male students reported mid-range scores (3.0 and 3.7 respectively) for questions assessing perceptions about the HPV vaccine. More females reported that they felt at risk for acquiring HPV, compared to men (23.5% vs. 13.0% respectively). More females than males thought that HPV was easy to contract (44.1%, vs. 43.5%) and not easily treated (50.0% vs. 43.5% respectively).

Female students were twice as likely as males (70.6% vs. 34.8%) to report that they were worried about getting HPV as much as other types of STIs (p=0.008). Females were also more likely to believe that HPV information is important (76% females

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vs. 65% males), and that HPV is a serious occurrence among AIs (50.0% females vs. 43.5% males).

Barriers to HPV vaccination: On a scale of 0–4, both female and male students scored very low (1.00 and .83 respectively) on questions assessing barriers to vaccination. Women reported more barriers than men (35.3% vs. 21.7% respectively) when shown a list of possible barriers, including: "don't know where to seek HPV information" (32.4% vs. 26.1% respectively), "don't feel comfortable seeking HPV information" (6.06% vs. 4.35% respectively), and "health insurance is an impediment" (32.35% vs. 30.43% respectively).

QUALITATIVE RESULTS

Themes identified from the focus groups help elucidate HPV vaccine decision-making by AI college women, including modifiable factors: low levels of knowledge, access barriers, fear of side effects, poor risk perception; and non-modifiable factors, including cultural influences and adverse historical events.

Modifiable Factors

Low levels of knowledge: In each of the eight focus groups, most women reported that they had scant knowledge about the HPV vaccine. Women reported that knowing more about HPV and the HPV vaccine would facilitate their decision to be vaccinated. One student noted that "I would not recommend anything unless I knew a lot about it." Misconceptions about the vaccine were common, and when directly asked, an average of one to two students per group reported ever hearing about the HPV vaccine. One student shared, "I've learned most of [what I know about HPV] through classes here at the university—I had a public health class." Several expressed misunderstandings about the purpose of the vaccine. One shared, "I heard that the vaccine can lead to getting cancer." Participants admitted they did not know much, if anything, about the vaccine, but provided suggestions explaining why a low level of HPV knowledge occurs among AIs. One participant noted "you don't know what to ask about." Another explained, "I think that ... it's [other American Indians not knowing about HPV] because of a lack of education on the reservation." Students did not know where to seek HPV information and were less likely to recommend the vaccine to friends.

Access barriers: Several women noted that "residing in rural areas results in having less of a chance for early detection or any detection of HPV." A combination of lack of insurance and poor financial resources can limit access to health-care services. Without health insurance, "you know it's really going to be expensive," one student stated. It was a common sentiment that not all AIs might have access to Indian Health Service (IHS) clinics or providers because rural distance and isolated locations create barriers to services: "I lived an hour away (from the IHS health clinic) so just going back the three times, that whole series, I couldn't do it."

Adverse effects: The fear of potential adverse effects (short- or long-term side effects) was reported by a student to have influenced her decision to refuse the HPV vaccine.

Short-term adverse effects that induced fears included nausea, pain, and some discomfort at the injection site: "One of my friends said it hurt so badly." Following the shot "she just felt kind of sick . . . she vomited off her head and then she did not feel the greatest after . . . she said [after] she got it—that there was something wrong with her."

Other side effects that students identified included threats to life or some possible unknown injury: "This [vaccine] might end up killing you at the end," said one young woman, while another wondered, "don't know how American Indians react to the vaccine [as it may be bad]." Distrust of physicians and pharmaceutical companies who recommend the HPV vaccinations were discussed: "Why are American Indian women just being targeted? Is it to decrease the population or what are the side effects?" Several women wondered about the unknown long-term effects of the HPV vaccine. One student commented, "If you are going to get vaccinated . . . you have to look at it over ten or twenty years. You can't rely on something that small data. Maybe it works for now, but what about ten or fifteen years from now?" Toward the end of the focus group, one young woman warned that "being careful about vaccines" was her strategy for vaccine decision-making.

Concern regarding the safety of the HPV vaccine was identified as being a significant deterrent to receiving the HPV vaccine. A student voiced concern over the potential negative effect on fertility: "No [I would not get the HPV shot], because . . . it's kind of scary and risky and I would like to have children one day." Another shared, "If I had daughters, I wouldn't treat them like piglets, because I wouldn't know the side effects about it." It was clear that women were concerned about their safety and the safety of future offspring. One young woman in the focus group circle stated "risk of autism" as a possible result of vaccination.

Poor risk perception: Each of the eight focus groups discussed perception of risk for HPV to be low, and thus obtaining vaccination was viewed as being of low importance. Several members in each group voiced perceptions of poor HPV-risk. As one woman stated, "Virtually everybody gets the papillomavirus, but you do not [get] cancer ... necessarily." One male expressed a commonly held view that only women experience HPV risk, stating, "Males don't really know about it, because it doesn't affect us at all, it might but they don't know." Another cautioned, "You've got to take into consideration that vaccination is only preventable for certain kinds of HPV," and thus they may not have that particular HPV type of strain so they are not at risk. Other students considered their personal risk and calculated that they were at poor risk of contracting the HPV infection. "I think if I were more . . . in ways of contracting the virus—I think I would take it into better consideration, take it more seriously."

A number of young women had serious misinformation about the HPV vaccination. "Doesn't the vaccine only work for young girls until twenty-one and then it does not work anymore?" one student asked. This student felt that there was no reason to obtain the vaccination since she was older than twenty-one.

Non-modifiable Factors

Cultural influences: Each focus group discussed AI cultural taboos associated with talking about sex. Discussions of a sexual nature were not encouraged in AI families as families "do not talk about it—sexual activity or anything like that." Commenting that rural communities have taboos associated with sex, one participant stated, "So if you are talking about ... anything to do with protecting someone when it comes to sex," families are not going to talk about it. The focus group participants reported that they did not expect their parents to talk to them about the HPV vaccination, and thus were not encouraged to obtain the inoculation: "My parents are really traditional like that." Participants noted that most parents would feel that the "vaccine is advocating having sex"; thus, fears about condoning sex might overrule the decision to obtain the HPV vaccine.

Women participants also discussed traditional approaches to health with regard to HPV infection. For example, one participant commented, "there probably is something [that can be done] based on traditional medicine." Reliance on traditional medicine for healing was commented on by several participants, who noted these beliefs remain strong among young and elderly AIs. Several other participants in different focus groups noted a concern that the youth are losing their culture and thus, from their perspective, their ability to heal. "Many of (my) peers don't understand their culture. They don't know their language. They have identity issues. They are ashamed. Many don't practice their traditional ways."

Adverse historical events: Several participants noted fears about and mistrust of the federal government that continue to this day. "For Natives, vaccinations are crazy. The whole history with the IHS, I'm not sure people believe they can trust them." Another student voiced distrust of vaccines supported by the federal government, stating, "The federal government will find a way to scare you."

DISCUSSION AND STUDY LIMITATIONS

The decision to obtain the HPV vaccination among the project's sample of women college students is influenced by several factors that are either (1) amenable to change through education and overcoming access barriers, or (2) less amenable to change due to deeply ingrained cultural beliefs and adverse historical events. Lack of knowledge and misunderstandings regarding the purpose, risks and benefits of the HPV vaccination was evident among both women and men in our project. These findings are similar to other published findings among young students; Ingledue and colleagues found that most college students knew very little about HPV despite its high prevalence and the complications associated with HPV infection. Furthermore, although Lambert reports that college students tend to be more knowledgeable and informed on many subjects, the project nonetheless found a great need for HPV-prevention education among college women as their understanding of HPV is poor and many were unaware of the availability of a vaccine. The project of the availability of a vaccine.

Providing clear information on why the vaccine is effective and the protocol for the inoculation will help alleviate some of the common misunderstandings and gaps in knowledge. However, tailoring the information to disseminate it in a manner that is culturally appropriate and acceptable to AI youth and parents presents challenges that require support and resources from AI community leadership, clinicians, researchers and funders. The use of traditional approaches to respond to HPV infections and acceptance of the vaccine remains elusive. Working with the families, communities, and school and clinic personnel should provide the first steps needed for planning and implementation of educational and immunization programs.

The venues in which HPV education is delivered are as important as the message itself. It is clear from the participants' discussions that there is a cultural taboo against talking about sexual issues with parents or extended family members (the theme of "we don't talk about it"). Students voiced a concern that to bring up questions about or to discuss the HPV vaccine would lead family and friends to assume that they are sexually active and concerned about contracting STIs, thus creating a stigma. Students identified the appropriate venues of discourse to be at schools and with physicians in a health-care setting. Access barriers that impact initiation and completion of the three-shot HPV-vaccine series were also identified, which included lack of insurance, geographic isolation, and lack of transportation.

Concerns regarding vaccine safety and unknown long-term side effects were a major part of the focus groups' discussions. Potential side effects, real or imagined, played a significant role for students not to obtain the HPV vaccination. Several side effects were reported by participants to have been associated with their experience with the HPV vaccine. Although short-term side effects such as pain and nausea were initially identified, unknown, potential long-term side effects to fertility, offspring, and personal health dominated the discussions.

Such fears of unknown side effects were laced with the influence of historical events of genocide, disease epidemics, and conflict with the federal government. American Indians have faced many challenges over the past five hundred years. Tribal wars and conflict with the federal government, coupled with serious medical problems such as measles and influenza epidemics, significantly reduced tribal populations. Smallpoxcontaminated blankets disseminated to reservations infected AI communities and eliminated whole tribes.²¹ AI populations have a tragic history of experience regarding medical tests and studies, sterilizations of women without consent, and environmental contamination which has left a legacy of distrust.²² This history and distrust make it harder to design and implement health-care services, particularly vaccinations. Indeed, sharing that distrust, stories of misinformation and hardship, and contemplating past and future conflicts and governmental attempts to "do away with us" not only led into a discussion of the trustworthiness of the HPV vaccine, but also whether it was a means of genocide or of encouraging sexual activity. The impact of adverse historical events, coupled with cultural taboos limiting discussions regarding sexuality, places a difficult barrier around the opportunities to accept and obtain the HPV vaccine series.

As a whole, the women students reported that they felt little or no risk of contracting HPV infection, and thus perceptions of low personal risk were found to be significant deterrents to accepting the HPV vaccination. Although several students noted the need to obtain the vaccination series, they repeatedly stated that the risk was

low, that cancer risks were not proven, and that their personal risks were not a concern. One student explained that "American Indians are less likely to go to the doctor, so less likely to get the Pap smear, so (perhaps) more likely to contract HPV and get cervical cancer," but this student's revelation did little to change the low risk perception of the group.

Ingledue and colleagues studied college women's perception and knowledge of HPV and cervical cancer among 428 college women ages eighteen to thirty.²³ The findings reported in 2004 were perceived low susceptibility coupled with high-risk sexual behavior. College-age women who participated reported low HPV knowledge and HPV misperceptions, and those uninformed about the risk factors associated with contracting HPV might not practice safe sexual behaviors as a result. These findings might indicate a potential rising group of women who are unprepared and uninformed of the rapidly spread of HPV infection.

Our study similarly indicates that AI women in our sample were not ready to comply with HPV vaccination recommendations and needed better access to culturally relevant HPV information. Understanding and addressing the factors that influence HPV decision-making among AI women will help improve HPV vaccination rates in this population. Recommendations include culturally sensitive education addressing risk perception, misinformation, and common fears. Future interventions should target health-care providers and parent/family communication to further support HPV vaccination among AI young adults.

This study was limited to four university settings and thus generalizability was prohibitive. Our sample was a convenience sample recruited from those students on campus at the time of the study implementation. The small sample size, the multiple tribes represented among the participants, and study location are limitations of the study. Future planned studies should expand the sample size to allow for randomization and generalization. The development and testing of culturally appropriate educational interventions could improve knowledge, acceptance, and perception—and ultimately, vaccine completion rates.

Acknowledgments

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