

HPV VACCINE READINESS AMONG AMERICAN INDIAN COLLEGE STUDENTS

Introduction: Young adults experience high rates of human papillomavirus (HPV) infection. This article reports on American Indian (AI) university students' HPV vaccine readiness and female vaccine decision-making.

Methods: Eight focus groups were held with AI students attending four universities. A questionnaire was also administered. Fifty-seven students, 23 males and 34 females, aged 19 to 26 participated. Audio-recorded sessions were transcribed. Common themes were coded and categorized following grounded theory procedures. Statistical tests included chi-square and two sample independent t tests.

Results: A significant difference was observed between sexes and HPV risk status ($P=.008$). Females perceived a higher risk and were more knowledgeable about HPV and the vaccine than males, however, they did not know where to seek information and were less likely to recommend the vaccine to friends. Fifty-two percent of males reported perceived low risk of contracting HPV. Six explanatory factors were identified: low knowledge, access barriers, fear of side effects, culture, adverse historical events, and poor risk perception.

Discussion: American Indian female college students are not at a stage of readiness to comply with HPV vaccine recommendations, and need improved access to the HPV vaccine. (*Ethn Dis.* 2011;21(4):415-420)

Key Words: American Indians, Human Papillomavirus, HPV, Vaccines, Readiness, Barriers

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INTRODUCTION

Cervical cancer is a preventable disease, yet cervical cancer mortality is significantly higher among American Indians (AI) as compared to the general population. In 1999 to 2003, the AI age-adjusted mortality rate for cervical cancer was 3.7/100,000 among the entire Indian Health Service population. Among Southwest AIs, the rate was even higher at 4.1, significantly higher than for US all races (2.7).¹

Cervical cancer is caused by persistent infection with the human papillomavirus (HPV).² While HPVs are a group of over 100 viruses, only four types cause cervical cancer.² The virus is considered one of the most common sexually transmitted infections (STIs) in the United States with infection rates of 50% among all sexually active people and an estimated 80% of sexually active females becoming infected during their lifetimes.^{3,4}

Two major vaccines have been available since 2006 for protection against HPV. Initially, vaccines targeted females aged 12 to 26 years. Currently, males are included in vaccine protocols for protection against genital warts, transmission of the virus, and cancers of the penis and anus.⁵ Completing the vaccine series (3 injections) has been shown to be 99% effective for protecting against cervical cancer and potentially reduces the global cervical cancer mortality rate by 67%.⁵

Our study identifies disparities in HPV knowledge and perceived risk and explores the factors influencing HPV vaccine decision-making among AI college females. Studies have reported high incidence of HPV infection in college females.^{6,7} Egendorf reports that a college woman can have greater than 85% probability of leaving college with

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an HPV infection.⁸ Our study targeted AI college students because cervical cancer is more common in AI women than in White women,⁹ and because of high HPV infection rates among college students.⁷

METHODS

The study sample consisted of AIs attending universities in California and Arizona who were recruited in 2009 to participate in focus groups exploring their HPV experiences and vaccination decision-making influences. A total of 57 college students participated from the University of California, Los Angeles, University of California, Berkeley, Arizona State University and the University of Arizona. Each college held two focus groups. Trained AI facilitators recruited students via flyers. Eligibility criteria included: 1) self-identified as AI; 2) aged 18-26; and 3) currently enrolled college student. Institutional Review Board approval was obtained from UCLA. Following consent, survey administration and one-hour focus groups took place in college community rooms. A \$25 gift card incentive was offered.

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MEASURES

Questionnaire

The survey instrument was a 15-minute questionnaire measuring: demographics - students were asked their sex, tribal affiliation, age and college; knowledge - overall knowledge of criteria for HPV vaccine was based on eight questions; attitude - overall HPV attitude was based on three questions; perception - an overall score for positive perception about HPV was created based on seven questions; and barriers - scores for high HPV barrier to vaccine were created based on four questions.

Data Analysis

Significant differences between classifiers based on chi-square or two-sample independent *t* tests were conducted. Sex differences under the broad classes of HPV knowledge, attitude, perception, and barriers to HPV vaccines were measured.

Focus Groups

All participants self-administered a brief questionnaire measuring HPV knowledge and experience. Focus groups were guided by a research protocol assessing knowledge, attitudes, perceived risks, barriers and decision-making experiences regarding HPV and the HPV vaccination. Prompts probed participants about ever being asked to be vaccinated against HPV, their decision-making reasoning, and if they decided to receive the vaccination. Additional probes examined cultural influences that might affect attitudes/knowledge and decision-making towards HPV vaccination.

Analysis

The questionnaire was coded for analysis in a SAS computer statistical analysis program. Summary statistics, chi-square analysis, and two-sample independent *t* tests were conducted to assess any differences between sexes and groups.

Qualitative analysis involved grounded theory methods to analyze the data derived from the focus groups.¹⁰ Audiotaped focus groups transcriptions were coded line-by-line.¹¹ Codes were used to form themes based on most frequent topics and significant initial codes for each of the focus groups. Groupings were then augmented with additional notes and explanatory memos from the audiotapes of the focus group discussions as needed. Themes were formed into categories to explain the decision-making strategy of the female focus group participants.

RESULTS

Demographics

The sample consisted of 57 AI students attending a college in the Southwest; 59.6% female and 40.4% male, with an average age of 22 years. The majority (70%) were members of a Southwest tribe. In addition, 23.5% (*n*=8) of females had received the HPV vaccine (*P*=.0004). Table 1 reports on the HPV vaccine readiness of AI students by sex.

Knowledge of HPV Vaccine

Although females were slightly more knowledgeable than their male counterparts, overall, their HPV vaccine knowledge scores were low (2 on a 0-8 scale). Both males and females scored below average on all 8 items in the knowledge scale. The one item related to HPV knowledge that was answered correctly by the majority was "Who can get HPV." Seventy-three percent of males and 85.3% of females answered this question correctly.

HPV Attitude

Females scored 1.5 times higher than males on the overall HPV attitude scale. Although the majority of males and females reported that they "do everything to prevent contracting HPV" (60.8% males vs 67.6% females), more males reported that they would

recommend the HPV vaccine to a friend (71.4% vs 58.6% respectively). Females (100%) reported that they were somewhat comfortable talking about HPV (compared to 45.4% males). However, 52% of males noted that they do not worry about HPV, stating that males are less likely to be at risk.

HPV Perception

Males and females reported similar midrange scores (3.0 and 3.7 respectively) on the overall positive perception about HPV (scale range of 0-5). More females reported that they were likely to get HPV than males (23.5% vs 13.0% respectively), thought that HPV was easy to get (44.1% vs 43.5%), and felt that HPV was not easily treated (50.0% vs 43.5%). However, more males felt that getting the vaccine was a "natural" occurrence (60.8% males vs 52.9% females).

Females were twice as likely to report they were worried about (getting) HPV as much as other STIs (70.6% females vs 34.8% males), which was statistically significant (*P*=.008). More females also believed that HPV information is important (76% vs 65%), and that HPV is a serious occurrence among AIs (50.0% vs 43.5%).

Barrier to HPV Vaccine

Scores for "high HPV barrier to vaccine" were relatively low for both males (.83) and females (1.00) on a scale of 0-4. Female students consistently reported higher barriers than males in areas of specific barriers (35.3% vs 21.7%, respectively), where to seek HPV information (32.4% vs 26.1%), "don't feel comfortable seeking HPV information" (6.06% vs 4.35%), and "health insurance is an impediment" (32.35% vs 30.43%).

Factors Influencing HPV Vaccine Decision-making Identified from the Focus Groups

Six explanatory factors associated with HPV vaccine decision-making by

Table 1: Characteristics of American Indian young adults by sex for HPV knowledge, attitude and perceptions

Characteristics	Overall (n=57)	Male (n=23)	Female (n=34)	P
HPV-related outcomes	%	%	%	
Received vaccine, yes	14.04	.00	23.53	.0004*
Recommend vaccine to friends, yes	64.00	71.43	58.62	0.51
Knowledge	mean (SE)	mean (SE)	mean (SE)	
Knowledge of criteria for HPV vaccine (0–9: higher numbers indicate higher knowledge)	2.56 (.24)	2.22 (.34)	2.79 (.33)	0.24
	%	%	%	
Correctly answered: who can get HPV?	80.36	72.73	85.29	0.24
Perception	mean (SE)	mean (SE)	mean (SE)	
Overall strong positive perception about HPV (0–5: higher numbers indicate positive perception)	3.42 (.23)	3.04 (.37)	3.68 (.30)	0.18
<i>Specific perceptions (strongly or slightly) agree that:</i>	%	%	%	
I am likely to get HPV	19.30	13.04	23.53	0.33
HPV is easy to get	43.86	43.48	44.12	0.96
HPV is not easily treated	52.63	43.48	50.00	0.63
Worried about HPV as much as other STI	56.14	34.78	70.59	.008*
HPV is serious among AIs	47.37	43.48	50.00	0.63
Getting vaccine is natural	56.14	60.87	52.94	0.55
Information about HPV is important	71.93	65.22	76.47	0.35
Barriers	mean (SE)	mean (SE)	mean (SE)	
Overall high barrier (0–4: higher numbers indicate high barriers)	.93 (.13)	.83 (.18)	1.00 (.18)	0.52
<i>Specific barriers</i>	%	%	%	%
(strongly or slightly) agree that:				
Don't know where to seek info about HPV	29.82	21.74	35.29	0.27
Don't know where to seek info about vaccine	29.82	26.09	32.35	0.61
Don't feel comfortable seeking info about STIs	5.36	4.35	6.06	0.78
Health insurance is an impediment	31.58	30.43	32.35	0.88
Attitudes	mean (SE)	mean (SE)	mean (SE)	
Overall High Attitude about HPV (0–3: higher numbers indicate positive attitude)	1.76 (.22)	1.59 (.22)	3.00 .00 *(n=3)	X
<i>Specific attitudes</i>	%	%	%	
(Strongly or slightly) agree that:				
Do everything to prevent HPV	67.86	60.87	67.65	0.28
comfortable talking about HPV	52.00	45.45 (n=22)	100.00 (n=3)	.08

Don't worry because I am male (asked only of male participants)	X	52.00	X	X

* Significant difference between classifiers based on chi-square (categorical/binary variables) or two-sample independent t tests (continuous variables) at alpha=.05.

AI college females were identified in focus groups: low knowledge, access barriers, fear of side effects, cultural, adverse events, and poor risk perception.

Low Knowledge

A majority of female students reported little knowledge about the HPV vaccine. It was reported that gaining more knowledge about HPV and the HPV vaccine facilitated making a decision to be vaccinated. One University of Arizona (UA) student noted, “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. A UA female student stated, “I’ve learned most of (what I heard about HPV) through... a public health class.” Another UA student stated, “I remember reading an article where the vaccine led to increasing your chances of getting cancer.” Others provided suggestions explaining why a low level of HPV knowledge occurs among AIs. One University of California, Berkeley

(UCB) participant noted, “How do you educate yourself about something when you don’t know what to ask about it?” Another UCB student explained, “I think that other AIs don’t know (about HPV) ... it’s because of a lack of education on the reservation.”

Access Barriers

Several University of California at Los Angeles (UCLA) female participants noted that “residing in rural areas results in having less of a chance for early detection or any detection of HPV.” No insurance and poor financial

resources limited access to health care services. "I don't have health insurance so you know it's really going to be expensive" stated one student (UCB). It was a common sentiment that not all AIs may have access to Indian Health Service clinics or providers, thus distance and isolated rural locations created barriers to services. According to one UA student, "When they suggested that I get the vaccine, it was harder for me to actually get it because I lived an hour away...so just going back three times...I couldn't do it because I was in high school."

Fear of Side Effects

The fear of short- or long-term side effects was reported by females to have negatively influenced their decision to be vaccinated for HPV. Short term side effects discussed included pain at the injection site and nausea. Reported one UA student, "One of my friends - she actually got the vaccine. She said it hurt so badly and she was telling me all about it." She added, "...she just felt kind of sick...(after) she got it - that there was something wrong with her."

Fear of long-term side effects included threats to life or some possible unknown injury. "Watch - this [vaccine] might end up killing you at the end," cautioned one UCLA female. Another from UCLA wondered, "Don't know how American Indians react to the vaccine." Fear of nefarious reasons for physicians and pharmaceutical companies recommending HPV vaccinations were evident. Said one Arizona State University student (ASU), "Why are American Indian women just being targeted? Is it to decrease the population or what are the side effects?" Several females wondered about the unknown long-term effects of the HPV vaccine, with one ASU student commenting, "If you are going to get vaccinated...you can't rely on something (with) small data. Maybe it works for now, but what about 10 or 15 years from now?" Students voiced concern over the po-

tential 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," said one ASU student. It was clear that female participants were concerned about their safety and the safety of future offspring. UCLA students commented that "risk of autism" was also considered as a possible result of vaccination and that "being careful about vaccines" was the predominant strategy for vaccine decision-making.

Cultural Influences

American Indian cultural taboos associated with talking about sex were discussed. "In my family we really do not talk about it - sexual activity or anything like that," said a UA student. Commenting that AI communities have taboos associated with sex, one UCLA participant stated, "so if you are talking about a vaccine that has anything to do with protecting someone when it comes to sex, they are going to say it is sinful and bad so we are not going to talk about it." A few students expected parents to talk to them out of the HPV vaccination, and thus they were not encouraged to obtain the inoculation. "My parents are really traditional like that and to have them talk to me about it is kind of weird," reported one UA student. UCLA participants noted that most parents would feel that the "vaccine is advocating having sex or supporting it in some way." Thus fears about condoning sex overruled the decision to obtain the HPV vaccine.

Students also discussed traditional approaches to HPV prevention aside from vaccination. "There probably is a cure, I mean from a traditional perspective, not White man's medicine," opined one ASU student. Reliance on traditional medicine for healing was commented upon by several participants who noted these beliefs remain strong among AIs. Several other participants noted a concern that youth are losing their culture and their ability to heal.

According to one ASU student, "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 that fears about, and mistrust of, the federal government continue to this day. One ASU student commented, "For Natives, vaccinations are crazy. The whole history with the IHS (Indian Health Service), I'm not sure people believe they can trust them." Another ASU student voiced distrust of vaccines supported by the federal government stating, "The federal government will find a way to scare you."

Poor Risk Perception

The importance of obtaining the vaccination against HPV was not seen as high. Several members in each group voiced poor HPV risk perceptions. One UCLA student stated, "Virtually everybody gets the papillomavirus, but you do not (get) cancer...necessarily." Another UA student cautioned, "You've got to take into consideration that vaccination is only preventative for certain kinds of HPV." Other UA students considered that their personal risk of contracting the HPV infection was low. "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."

Several female students had significant misinformation about the HPV vaccination. "Doesn't the vaccine only work for young girls until 21 and then it does not work anymore?" one UCLA student asked. Another UCLA student reasoned that "Cervical cancer is treatable if caught early, so there would be no need to get a vaccine if you are doing an annual Pap smear." Poor personal risk perceptions played a role in their decision not to obtain the HPV vac-

nation. One UA student stated, "I think that something has to happen for me to actually recommend or actually take it myself. I know it is kind of bad." Thus, significant personal risks would have to be present to decide to get the HPV vaccine.

DISCUSSION

Lack of knowledge and misunderstandings regarding the purpose and need for the HPV vaccination was evident among both female and male participants. These findings build upon other study findings among college students.⁶ Further, while college students tend to be more informed on many subjects, we concur with Lambert,⁷ and there remains a need for HPV prevention education among college women, as their understanding of HPV is poor and many are unaware of the availability of a vaccine.

Our study found that the decision to obtain the HPV vaccination is influenced by several factors that are either amenable to change through education and access or not amenable to change due to cultural and adverse historical events. Providing clear, in-

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depth information on vaccine need (to prevent cancer and genital warts) and inoculation protocol may help to alleviate misunderstandings. However, tailoring HPV information and delivering it in a manner that is culturally-appropriate can pose a challenge in light of the fears and barriers reported in our study. The avenue in which the HPV education is delivered is as important as the message itself. Students shared that there is a cultural taboo of talking about sexual issues with family members ("we don't talk about it"). Students voiced a concern that to bring up the topic of a HPV vaccine may lead family and friends to assume that they are sexually active and concerned about a STI (thus creating a stigma). Working with families, communities, and school and clinic personnel should provide first steps needed for the planning and implementation of educational and immunization programs. Further, efforts to address barriers of insurance, rural isolation and few or no resources (eg, for transportation) are necessary for HPV vaccination programs to succeed.

The literatures reports that frequently reported side effects of HPV vaccinations are dizziness, nausea, headache, partial or complete loss of consciousness and injection site reactions. More serious side effects reported in other studies include high fever, allergic reaction, deep vein thrombosis, inflammation of the pancreas and death. These serious reactions are reported by a small percentage (6%) of the population and require immediate medical attention.¹² Concerns regarding vaccine safety and unknown long-term side effects were a major part of the focus groups discussion. Threat of side effects, real or imagined, played a significant role for students not to obtain the HPV vaccination. It was the potential unknown long-term side effects to fertility, offspring, and personal health that held the greatest influence. Fears of unknown side effects were laced with the influence

of historical events of genocide, disease epidemics and conflict with the federal government that significantly reduced tribal populations.¹³ An uncomfortable history of medical tests and studies,¹⁴ female sterilizations (without consent),¹⁵ and environmental contamination¹⁶ experienced by AI populations has left a legacy of distrust. Additionally, misinformation and contemplating governmental attempts to "do away with us" led into a discussion regarding the trustworthiness of the HPV vaccine and whether it was a means to encourage sexual activity, or as a means of genocide. The impact of adverse historical events, coupled with cultural taboos limiting discussions regarding sexuality, place a difficult barrier around the opportunities and acceptance of the HPV vaccines.

As a whole, the female students reported that they felt little or no risk of contracting HPV, thus perceptions of low personal risks were found to be significant deterrents to accepting the HPV vaccination. Several students noted the need to receive vaccinations, however, they repeatedly stated that the risk of contracting HPV was low, that cancer risks were not proven, and that their personal risks were not of concern. Ingledue et al reported a relationship between low perceived susceptibility with high-risk sexual behavior among college women.⁶ This may indicate a potential expanding group of females who are unprepared for the rapidly spreading HPV infection.

Understanding the factors influencing HPV decision-making behaviors of AI females will help to improve HPV vaccinations among this group. Culturally-sensitive educational programs designed to improve access and knowledge while decreasing misinformation, fears and other barriers to HPV-related services are recommended. Future interventions should target vaccine intent and physician/family communication to increase HPV prevention and vaccination.

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REFERENCES

1. Haverkamp D, Espey D, Paisano R, Cobb N. *Cancer Mortality Among American Indians and Alaska Natives: Regional Differences, 1999–2003*. Indian Health Service: Rockville, MD; 2008.
2. Steinbrook R. The potential of human papillomavirus vaccines. *N Engl J Med*. 2006;354(11):1109–1112.
3. Centers for Disease Control and Prevention. *Genital HPV Infection-Fact Sheet*. <http://www.cdc.gov/STD/HPV/STDFact-HPV.htm>. Accessed April 7, 2011.
4. Dunne EF, Unger ER, Sternberg M, et al. Prevalence of HPV infection among females in the United States. *JAMA*. 2007;297(8):813–819.
5. Centers for Disease Control and Prevention, National Immunization Program, Advisory Committee on Immunization Practices. *ACIP meeting 2006 Record of the Proceedings*. www.cdc.gov/vaccines/recs/acip/downloads/min-archive/min-jun06.txt. Accessed April 5, 2011.
6. Ingledue K, Cottrell R, Bernard A. College women's knowledge, perceptions, and preventive behaviors regarding human papillomavirus infection and cervical cancer. *Am J Health Stud*. 2004;19(1):28–34.
7. Lambert E. College student's knowledge of human papillomavirus and effectiveness of a brief educational intervention. *J Am Board Fam Pract*. 2001;14(3):178–183.
8. Egendorf L. *Sexually Transmitted Diseases (At Issue Series)*. New York: Greenhaven Press; 2007.
9. Centers for Disease Control and Prevention. Genital human papillomavirus. <http://www.cdc.gov/std/hpv/common/ai/ai.pdf>. Accessed April 23, 2011.
10. Morgan DL. Qualitative content analysis: a guide to paths not taken. *Qual Health Res*. 1993;3(1):112–121.
11. Glaser G, Strauss A. *The Discovery of Grounded Theory: Strategies for QR*. Chicago: Aldine; 1967.
12. General Medicine@suite101. *HPV Vaccine Side Effects: Updated Gardasil Safety Analysis*. <http://www.suite101.com/content/hpv-vaccine-side-effects-a157908#ixzz1E53sTGg0>. Accessed August 9, 2011.
13. Patterson KB, Runge T. Smallpox and the Native American, *Am J Med Sci*, 2002;323(4): 216–222.
14. Advisory Committee on Human Radiation Experiments. *Report - DOE Openness: Human Radiation Experiments: Roadmap to the Project. Chapter 12: The Iodine 131 Experiment in Alaska*. http://www.hss.energy.gov/HealthSafety/ohre/roadmap/achre/chap12_4.html. Accessed August 9, 2011.
15. Lawrence J. The Indian Health Service and the sterilization of Native American women, *Am Indian Q*. 2000;24(3)
16. Eichstaedt P. *If You Poison Us: Uranium and Native Americans*. Santa Fe, NM: Red Crane Books; 1994.

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