

ORIGINAL ARTICLE

ALASKA NATIVE PARENTAL ATTITUDES ON CERVICAL CANCER, HPV AND THE HPV VACCINE

Melissa Toffolon-Weiss ¹, Kyla Hagan ¹, Jessica Leston ²,
Lynn Peterson ¹, Ellen Provost ¹, Tom Hennessy ³

¹Alaska Native Tribal Health Consortium, Alaska Native Epidemiology Center,
4000 Ambassador Drive, C-DHS, Anchorage, Alaska 99508, USA

²Alaska Native Tribal Health Consortium, Office of Alaska Native Health Research,
4000 Ambassador Drive, C-DHS, Anchorage, Alaska 99508, USA

³Arctic Investigations Program, National Center for Infectious Diseases,
Centers for Disease Control and Prevention, 4055 Tudor Centre Road, Anchorage, Alaska, 99508, USA

mmtoffolonweiss@anmc.org

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ABSTRACT

Objectives. To describe Alaska Native parents' knowledge of and attitudes towards cervical cancer, the human papillomavirus (HPV) and the HPV vaccine.

Study Design. This was a qualitative study composed of 11 focus groups (n=80) that were held in 1 small village, 2 towns and 1 large urban centre in Alaska.

Methods. A convenience sample of Alaska Native parents/guardians was recruited in each community to participate in focus groups and to fill out a quantitative survey.

Results. While many parents had heard about HPV, most were unaware of its link with cervical cancer. The majority wanted to vaccinate their daughters because they had health and safety concerns; believed that vaccines work; had personal experiences with cancer; or believed that their daughters were susceptible to HPV. Reasons for refusal included general concerns about vaccines; a need for more information; a fear of side effects; wanting more vaccine research; and a fear of being in an experimental trial.

Conclusions. The majority of parents were interested in having their daughters vaccinated. Acceptance of the vaccine was primarily based on a parent's desire to protect her/his child from cancer; while reasons for refusal revolved around trust issues and fear of unknown negative consequences of the vaccine. (*Int J Circumpolar Health* 2008; 67(4):363-373)

Keywords: human papillomavirus, vaccines, acceptance, cervical cancer, Alaska Native, parents

INTRODUCTION

The Centers for Disease Control and Prevention (CDC) estimates there are 6.2 million new genital human papillomavirus (HPV) infections in the U.S. each year. HPVs are now recognized as the major cause of cervical cancer (1). In June 2006, the U.S. Food and Drug Administration's Advisory Panel approved Merck's HPV vaccine (GARDASIL®) against 4 strains of HPV for girls 9–26 years old. These 4 strains are responsible for 70% of cervical cancer cases and 90% of genital warts. The Advisory Commission on Immunization Practices voted to recommend that the HPV vaccine be given routinely to girls aged 11–12 years old.

Knowledge levels about cervical cancer and HPV among women and girls have been changing in the last 7 years with the advent of the new HPV vaccine. A survey conducted in 2000 found that HPV was mentioned as a sexually transmitted disease by only 2% of a national sample (2). In 2005, however, a National Association of Reproductive Health Professionals survey found that 49% of women had heard of HPV and 23% correctly identified it as the primary cause of cervical cancer (3). In the same year, the Health Information National Trends Survey found that 40% of women had heard of HPV and, of those who were familiar with HPV, 47% knew that it was a cause of cervical cancer (4,5). Knowledge levels have continued to increase. In June 2007, a nationwide survey of 1,421 women revealed that 90% had heard of HPV and 8 in 10 named it as a cause of cervical cancer (6).

This increase in knowledge about HPV may be attributable to a Merck-sponsored national mass-media campaign designed to increase awareness of HPV and the link between HPV

and cervical cancer. This campaign began in April 2006 and included national TV and magazine ads targeted at moms and young adult females (18–26 years old), a website and materials for doctors' offices for patients to read. Another national media campaign by Merck began in November 2006 and mentioned GARDASIL® as a way to protect against HPV and cervical cancer (personal communication, Babak Bazmi, January 2008).

Regardless of whether a study took place before or after the initiation of the Merck campaign, over half of parents surveyed were accepting of HPV vaccination. Vaccine acceptability ranged from 55% among White and African-American parents in Georgia to 75% among parents in California (7–9). Researchers found that parents who were accepting of the vaccine cited the following reasons: to protect their daughters' health and to prevent illness; to prevent the need for future medical intervention; a belief in a susceptibility to HPV; a fear of severe consequences of HPV; and a belief in the efficacy of vaccines (9–12). Parents who were not accepting of the vaccine generally considered HPV not to be a problem; needed more information; thought that a vaccination would encourage sexual activity; considered their daughters too young to receive a sexually transmitted infection (STI) vaccination; feared negative side effects; and were averse to the cost of the vaccine (8,10–13). A randomized intervention study of written information about HPV demonstrated that while providing parents with information about HPV raised their knowledge levels, it had little effect on influencing the parents to accept the vaccine (12).

Studies that examined the influence of demographics on vaccine acceptance yielded

conflicting results. All but 2 of these studies were conducted prior to the 2006 marketing campaign (8,9). Two studies examined the effect of urban versus suburban status on vaccine acceptability; Olshen et al. found that urban parents were generally more positive about all vaccines, while suburban parents favoured “serious” disease vaccines (13). In contrast, Zimet et al. found no association between STD vaccine acceptability and an urban/suburban setting (15). Researchers in Cuernavaca, Mexico, found no association between HPV immunization acceptance and age, education, socio-economic status, age at first intercourse or history of Pap tests (16). Conversely, a study in Georgia demonstrated that acceptance of the HPV vaccine was related to lower income, having more sons, having received all required vaccines and having a family history of an abnormal Pap test (7). Two studies found that there was no association between a parent’s acceptance of a sexually transmitted disease vaccine and the parent’s age, gender, child’s age, child’s gender, insurance status or parent education (8,13). Conversely, a study of women in two Appalachian Kentucky counties found that women who were younger, of lower-income, and who smoked were more likely to support HPV vaccination (14).

Several studies have examined the relationship between HPV vaccine acceptance and race/ethnicity. A quantitative study of 1,350 respondents from across Canada conducted in 2006 revealed that cultural background (White or Aboriginal) was not associated with a parent’s intention to vaccinate (9). Prior to the Merck campaign, researchers in California found that Hispanic parents were more likely to accept vaccination for their

daughter(s) than non-Hispanic parents, while African-American and Asian-American parents were less likely (8). A more recent study conducted in 2006 with separate focus groups for African Americans and Hispanics found differences between the two groups. Although both groups overall were accepting of the vaccine, African Americans expressed skepticism about the vaccine’s effectiveness, concerns about side effects and whether men and women might be more promiscuous and have unprotected sex after getting the vaccine. Others mentioned being embarrassed about admitting they were sexually active by getting the vaccine. Latino women were overwhelmingly in favour of the new vaccine and any reservations they held focused on cost. While Latina women appeared to trust the vaccine, African-American women mentioned reservations about trusting something new and a few participants cited the Tuskegee Syphilis Study as a reason for distrust (17).

There have been no studies that examine knowledge of and attitudes towards the HPV vaccine among American Indian and Alaska Native (AI/AN) parents. This article presents findings from a qualitative study conducted in Alaska to assess Alaska Native parents’ knowledge of and attitudes towards cervical cancer, HPV and the new HPV vaccine. Findings from this study were used to design a tailored educational campaign focused on promoting the HPV vaccine.

MATERIAL AND METHODS

We recruited a convenience sample of Alaska Native parents from 3 different size communities in Alaska (urban, hub and village). In rural

Alaska, a hub community serves as a commercial, medical, educational and transportation hub for numerous surrounding villages. The majority of parents were Alaska Native as opposed to American Indian; therefore, for the purposes of this article, participants will be referred to as "Alaska Natives." Inclusion criteria were being Alaska Native/American Indian, English speaking and having a 9-to-18-year-old daughter or ward. For the purposes of this description, all participants (guardians and parents) will be referred to as "parents."

Staff recruited parents by posting flyers in the community, sending email messages to tribal health organizations and other tribal authorities, making announcements on the local VHF radio, and contacting local public health providers. In all, 80 parents participated in 11 single gender focus groups. Prior to the onset of the study, the Alaska Area Institutional Review Board and each region's tribal health corporation reviewed and approved the study protocol. The focus groups, each lasting approximately 60 minutes, were carried out between January and March 2007. At this time the Merck educational campaign was underway in Alaska; however, the vaccine was not widely available in the Alaska Native Tribal Health System. A professional moderator and a trained assistant who were employed within the Alaska Native Tribal Health System conducted each group. The authors developed the focus group guide and tested it with a pilot focus group of Alaska Native parents in Anchorage, Alaska. Participants received a \$25 incentive payment for their participation.

Prior to each group, the moderator provided each parent with a study consent form in order to obtain his/her verbal consent. Then, each parent filled out a quantitative survey that

collected demographic information and asked knowledge-based questions on cervical cancer, HPV and the HPV vaccine. The moderator, using a guide that consisted of 12 open-ended questions, asked about the parents' perceptions of cervical cancer, HPV, vaccines in general and the new HPV vaccine. During the course of the focus group, topics were introduced and, after the parents answered questions pertaining to the topic (i.e., cervical cancer), a brief explanatory statement about each topic was read by the moderator and the questions that the participants had were answered. Each session was digitally recorded and an assistant moderator took notes on non-verbal behaviour. The digital audiofiles were professionally transcribed and the resulting transcriptions were analysed using Atlas TI qualitative data analysis software. The quantitative survey data were analysed using SPSS statistical software.

RESULTS

Focus group sample demographics

All of the participants were Alaska Native parents or guardians of girls between the ages of 9 and 18 yrs. Over eighty percent of those involved in the focus groups were mothers. Approximately 31% of parents were between the ages of 31 and 40 years and 38% were between 41 and 50. Thirty-five percent of participants had experience working in a medical setting or had a relative who worked in a medical setting (see Table I). Seventy-three percent of the fathers who were interviewed lived in a village setting as compared to only 33% of mothers. The participants in the hub communities tended to be slightly younger than those in the village and urban communities. There

were more participants in the urban (67%) and hub communities (43%) who were linked to a medical setting as compared to those living in villages (6%).

Quantitative survey findings – knowledge about cervical cancer, vaccines, HPV and the HPV vaccine

The majority of parents (70%) knew that the Pap test is used to screen for cervical cancer. This knowledge was more prevalent among the participants in the hub communities (96%) as compared to the urban (79%) and village communities (46%). Parents were asked what came to mind when they heard the word “vaccine.” Common themes that emerged in all focus groups were a shot, prevention, protection and a requirement for school. The majority of participants (65%) knew that a vaccine prevents disease and can stop the spread of a disease. The same percentage of parents in the hub and urban communities (83%) knew this informa-

tion; however, only 39% of village-based parents knew the purpose of a vaccine. Overall, only 56% of parents knew that there was a vaccine for HPV and far fewer (20%) associated the vaccine with the prevention of cervical cancer. More parents in the hub communities (83%) knew there was an HPV vaccine as compared to urban (58%) and village (36%) parents.

Although many of the parents had heard about HPV before, many were unaware that there was a link between HPV and cervical cancer. Those who had heard about it said they had seen a commercial or heard a news report or had learned about it from working in a medical setting or from a visit to a clinic. Few village-based parents knew how HPV is transmitted (36%) as compared to those from the urban (63%) and hub communities (74%). In both the urban and hub communities, a similar percentage of parents (38%) knew there was an association between HPV and genital warts, while only 6% of village-based parents were aware of this association.

Table 1. Demographic characteristics of the sample.

	Urban (n=24)	Hub (n=23)	Village (n=32)
Population size	260,283	3,500–5000	800
Number of groups	3	5	3
Gender of participants			
Female	20	23	21
Male	4		11
Age			
21–30	2	3	0
31–40	9	10	6
41–50	10	5	15
51–60	3	4	4
61 or higher	0	1	1
Missing data		0	6
Experience in a medical setting?			
Yes	16	10	2
No	8	13	29
Missing data			1

Qualitative focus group findings – attitudes and perceptions about cervical cancer, vaccines, HPV and the HPV vaccine

During the focus groups, participants were asked to name their 3 top health concerns for their daughters. The most commonly named concerns were cancer, STDs and general well-ness. Other concerns mentioned were obesity, diabetes, sexual assault, substance abuse and accidents. When asked what came to mind when they heard the words “cervical cancer,” the comments from participants centred around the following themes: death; personal experiences with cancer; fear; Pap smears; hysterectomy; ability to reproduce; and older women. Parents had many questions related to cervical cancer. Table II lists the main themes from participants’ questions. The parents’ questions about HPV and cervical cancer were very similar to questions that arose in focus groups with Caucasians, Hispanics and African Americans in the lower 48 states conducted by Friedman et al. (11). A similar reaction exhibited by participants in both focus group studies was one of surprise that they had not previously heard of this virus and its consequences.

Decision-making and acceptance of the vaccine

The majority of mothers in the Alaskan focus groups said that they alone made the decision to vaccinate their children against a disease. Some said that they made the decision in conjunction with their spouses and a few said that they involved their daughters and spouses in the decision-making. Many of those who said that they involved their daughters had older teenage daughters. For example, one urban mother stated, *“My daughter is 17, and she’s the one who went out, did her research on the shot, and she’s been patiently waiting for it.”* The majority of the fathers said that the decision is a joint decision between them and their spouses.

When asked in a “round-robin” fashion at the end of the focus group whether they would get their children vaccinated, the majority of parents answered affirmatively. Table III lists factors associated with vaccine acceptance or rejection mentioned by participants. One reason for acceptance was to protect their daughters and prevent future disease (both HPV and cancer). One hub-community mother described it this way, *“I see it as just part of being a mom and wanting to protect your child against cancer.”* Another hub parent stated,

Table II. Themes on cervical cancer and HPV from parents’ questions.

Common questions/themes	Cervical Cancer	HPV
What is it and what are symptoms?	X	X
How do you test for it?	X	X
How do you get it?	X	X
Are there different types?		X
What happens when you get it?	X	X
Who is most at risk to get it?	X	X
At what age do people get it?	X	
Do men get it and can they be tested?		X
How is it treated?	X	X
How can you prevent getting it?	X	X

“For me, having a strong history of all kinds of cancers in my family, one less cancer – the vaccine could protect my daughter from at least that.” Other parents believed strongly in vaccines. One village parent said, *“I didn’t have all that privilege of getting all of those kinds of vaccines. Now that they are coming up with good kinds of things I would give my kids the privilege to get them.”* Another theme that was mentioned by at least one parent in each community was that often sexual exposure was not under the control of the young woman, as in the case of rape, and this vaccine would offer the young woman protection from HPV.

None of the accepting or non-accepting parents were worried about the vaccine encouraging sexual activity in their children. This issue was only brought up when they were asked why other people may not want to vaccinate their daughters – but not in relation to their decision to not vaccinate. The parents appeared to view the vaccine strictly from a health-related perspective and to accept that their daughters would eventually be sexually active as they grew older and would become susceptible to HPV. One urban father stated directly, *“I don’t think it’ll encourage my daughter to go out and have sex. I don’t want her to have sex now. She’s 14. I hope she has sex in the future and has kids and lives a normal life, but I don’t think it will encourage her to go act irrationally.”*

Those parents who did not want to vaccinate their daughters cited the following reasons: not enough research; needed more information; wanted to wait to see if there were any problems with the vaccine; had a general mistrust of vaccines; and did not want the vaccine to be “tested” on them. A typical comment about the newness of the vaccine came from a hub-community mother who stated, *“I don’t like to be the first to use a new vaccine. That makes me uncomfortable that it hasn’t been used by a lot of people yet. Some side effects may turn up that they don’t know about until they vaccinate a whole bunch of kids.”* Another hub-community mother stated, *“I lean towards it, it sounds like a good thing. I just wish there was a lot more information, and I wish there was a lot more information from somebody other than Merck.”* A parent who was mistrustful of vaccines described her view this way, *“Well, just like she was saying, there’s that risk of introducing something into your body that you probably wouldn’t have contracted, but then you introduce it and you get it. That’s my fear.”* The fear that Alaska Native people were going to be used like laboratory test animals was expressed by one hub-community parent, *“Over my lifetime I’ve heard stories about Alaska Natives being used as guinea pigs and being vaccinated without their knowledge. And obviously you guys are trying to inform, but I’ve heard stories.”*

Table III. Factors associated with vaccine acceptance and rejection.

Factors associated with acceptance	Factors associated with non-acceptance
<ul style="list-style-type: none"> • Health and safety concerns • Belief that child is susceptible to HPV • Belief in usefulness of vaccines • Personal experience with the cancer/HPV • In case of sexual assault exposure child will be protected 	<ul style="list-style-type: none"> • General concerns about vaccines • Need more information • Fear of side effects • Not enough research has been done • Will wait to see if problems arise • Don’t want to be used as a “guinea pig”

Recommendations for educational campaign

In all the communities, when parents were asked what information should be included in an educational campaign on the new vaccine, they stressed a focus on prevention. Village-based parents stressed the importance of describing HPV, cervical cancer, and the vaccine and letting people know that the vaccine is safe. Whereas hub parents said to keep it simple and sensitive, and to talk about side effects, the shot schedule, the need for continued Pap smears and how HPV is transmitted. Both urban and hub parents thought that the educational campaign should involve families and more than one generation. When asked "Who should deliver the message about the vaccine?" the same answers came up in all the regions: providers (nurses, doctors, health aides, children services workers, tribal health workers) and teachers. The parents specified that the faces they wanted to see on posters should be Alaska Native, and some suggested having the face of a girl in the target age for the vaccine, a family oriented picture, an elder or a multigenerational picture with a grandmother, mother and daughter. Parents wanted to see TV, radio, Internet, and newspaper ads, community forums and school education programs. Hub and village residents who needed to travel on planes to leave or return to their communities suggested placing posters on the backs of airplane seats, in public bathrooms and at the local post office.

DISCUSSION

The results from this study demonstrate that among participants there was widespread acceptance of the HPV vaccine. While many parents in the study had heard about HPV, most were unaware of the link between HPV and cervical cancer. The majority of participants wanted to vaccinate their daughters because of health and safety concerns; a positive belief that vaccines work; personal experiences with cancer/HPV; or a belief that their daughters were susceptible to HPV. Reasons that participating parents would refuse vaccination included general concerns about vaccines; need for more information; fear of side effects; wanting more research studies done; wanting to wait to see if problems developed; and fear of being in an experimental trial.

The Health Belief Model, which is commonly used when designing health promotion and disease prevention interventions, incorporates the effect of cultural factors on prevention behaviour (18). The model proposes that people will take an action to prevent a disease if they believe that they are susceptible to a disease, that they will suffer serious effects if they get the disease, that the action will reduce their susceptibility to or the impact of the disease, and that the benefit of taking the action outweighs the costs. Factors unique to each race and culture, such as demographic, sociopsychological and structural variables, may all affect how an individual perceives each component of the model, thus affecting their health-related behaviour.

Alaska Native parents who participated in the study believed that their daughters were susceptible to HPV and cancer through their eventual involvement in sexual activity as they grow older or through involuntary involvement via sexual assault. They also perceived the severity of the diseases to be great as reflected in their mention of cancer and STDs as 2 of the top 3 health concerns they have for their daughters. The average annual age-adjusted incidence rate for cervical cancer between 1989 and 2003 was slightly higher for Alaska Natives as compared to Whites in Alaska (5.3/100,000 vs. 4.4/100,000; Odds Ratio 1.2, $p < 0.05$) (19).

Many parents mentioned the preventive and protective attributes of the vaccine as a perceived benefit to getting their children vaccinated. The barriers that influenced their taking action were related to the vaccine having possible negative and unknown side effects. A belief that they were not being informed of these side effects stemmed from a general mistrust of the larger medical and pharmaceutical establishments. All of the variables involved in this model are influenced by factors related to the unique circumstances, cultural attitudes and the geographic location of Alaska Native people.

The results from this study suggest that the Alaska Native parents who participated differ from other populations in terms of their reasons for vaccine acceptance and non-acceptance. This is not surprising and is a recognized component of the Health Belief Model. Persons of different cultural backgrounds hold differing beliefs on privacy, sexuality and health that may affect their willingness to accept a vaccine for a sexually transmitted infection. In other studies (7,12), parents appeared to be

more motivated by the recommendations of doctors and by school requirements to vaccinate their children, but these influences were rarely mentioned in this study. Alaska Native parents who participated differed from other parents in stating that a reason to vaccinate was to protect their daughters against a sexually transmitted infection (STI) in case of an event beyond their control, like sexual assault. This comment was not made in any other studies (7-17). These parents also differed in their reasons for declining the vaccination as compared to parents in other studies (7,12,17). Specifically, they did not think that having the vaccine would encourage their daughters to be sexually active and they made no moral association with getting the vaccine. The reasons for not accepting the vaccine all focused on concerns about negative consequences of the vaccine.

An interesting finding from this study is that knowledge levels about vaccines, HPV and cervical cancer were higher among participants in the hub communities, followed by the urban area, and were the lowest in the village communities. Low knowledge levels among participants in the villages may be explained by having more fathers participating in the focus groups and less medical resources in these areas. The difference in knowledge levels among participants in hub and urban settings versus the village may be partially attributed to the inclusion of more parents in the hub and urban focus groups who had a link to a medical setting. These findings should be interpreted cautiously because they are based on a non-random sample; however, this area may warrant further investigation in terms of the levels of knowledge about vaccines and other important health topics in different types of communities in Alaska.

This study has several limitations. The sample was small and selected in a non-random manner. Thus, the results, including the survey data, should not be generalized to the whole Alaska Native population. Rather, the results should be interpreted as an array of possible findings that are present among some Alaska Native parents. Also, since the knowledge level on the topics, especially about HPV, was low, the focus group moderator conducted some education on the topics during the focus group. Although the manner in which the education was conducted was similar for all groups, it may have influenced the attitudes that were expressed. Finally, despite efforts to recruit an Alaska Native moderator, a non-Alaska Native served as the focus group moderator. This was a limitation because some of the parents' concerns regarding their decision to vaccinate their daughters were related to a general mistrust of the medical and pharmaceutical establishment that was promoting the vaccine, which has historically been dominated by Caucasians. The race of the moderator may have affected the responses of the participants.

The findings of this study have been used to design a poster and flyer on the new vaccine oriented towards Alaska Native parents. The pictures on these materials show an Alaska Native teenage girl, her mother and grandmother and the text stresses the safety of the vaccine and the testing that has occurred. The theme of "protection" is present in the headline that reads, "Love her, protect her...with a vaccine against cervical cancer" (20). The findings from this study point to the importance of studying health promotion and disease prevention issues from a racial and ethnic perspective in order to identify the key factors that influence

prevention behaviour. This research is unique in Alaska in that it was undertaken prior to the widespread introduction of the vaccine and was used to guide educational approaches and the development of materials. This approach should be considered for other vaccines or for other populations where vaccine introduction may be controversial or require special attention to cultural or religious sensitivities.

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Melissa Toffolon-Weiss, PhD, MPH
 Alaska Native Tribal Health Consortium
 Alaska Native Epidemiology Center
 4000 Ambassador Drive, C-DHS
 Anchorage, Alaska 99508
 USA
 Email: mmtoffolonweiss@anmc.org