ORIGINAL ARTICLE

Alaska Native adolescent views on cervical cancer, the human papillomavirus (HPV), genital warts and the quadrivalent HPV vaccine

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ABSTRACT

Objectives. To understand the knowledge levels, attitudes and perceptions of Alaska Native adolescent girls about cervical cancer, HPV, genital warts and the HPV vaccine.

Study design. A qualitative study.

Methods. Seventy-nine in-depth interviews were conducted with adolescent females aged 11 through 18 years in 4 communities in Alaska. The convenience sample was recruited through word of mouth, posters and flyers distributed in community schools, medical clinics and stores.

Results. Many of those surveyed didn’t know the purpose of a vaccine and were not familiar with basic knowledge about HPV, genital warts and cervical cancer. After learning about cervical cancer and HPV, most teens felt that someone their age had an average likelihood of contracting the diseases and that having the disease would be quite bad. Most teens said they were interested in vaccination. When asked if they would get a vaccine, older teens most commonly cited concerns about side effects or doubts about vaccine efficacy, while younger teens were afraid the shot would hurt. Most teens stated that they preferred to learn about health topics such as these through television programming, followed by the Internet, brochures and posters.

Conclusions. The findings provide valuable information on how to inform adolescents about the vaccine and alleviate their concerns. The design of an educational campaign should vary depending on the age of the adolescents. For younger teens, distribution of information should be at school using a brochure or curriculum, while for older teens a web page may be more appropriate.

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Keywords: Alaska Natives, adolescents, cervical cancer, genital warts, HPV, quadrivalent HPV vaccine
INTRODUCTION

This paper will present the results of a qualitative study involving female Alaska Native youth with the purpose of understanding their knowledge levels, attitudes and perceptions about the human papillomavirus (HPV), genital warts, cervical cancer and the HPV vaccine. In 2007, the same researchers conducted an Alaska Native parent focus group study in 4 different locations within Alaska. The first study found that while many parents had heard of HPV they were not aware of its link with cervical cancer. The majority of parents interviewed wanted to have their daughters vaccinated. Those who were hesitant feared side effects and desired more testing of the vaccine before their daughters received it. Some parents also stated that they were influenced by their daughters’ attitudes about getting vaccinated (1). These findings precipitated the second study in an effort to understand the attitudes and knowledge levels of adolescent females on this topic. In addition to influencing their parents, if these adolescents do not get vaccinated before adulthood, they will then be responsible for making a decision on whether to get vaccinated as a young adult.

Both studies were the product of a unique, multi-organization collaboration which began in Anchorage, Alaska, in 2006. At this time the Statewide HPV-Vaccine Alaska Native Project Evaluations (SHAPE) committee was created to assist with the introduction of the HPV vaccine within the Alaska Native population. This committee is composed of representatives from the Alaska Native Tribal Health Consortium (ANTHC); Centers for Disease Control and Prevention’s Arctic Investigations Program (CDC AIP); State of Alaska Division of Public Health; and Southcentral Foundation, a tribal health organization. One of the tasks proposed by this workgroup was to conduct qualitative research to examine factors which would influence vaccine acceptance within the Alaska Native population. There have been no previously published studies examining knowledge and attitudes about cervical cancer, HPV and the HPV vaccine among American Indians or Alaska Natives.

In the same year that the SHAPE committee was formed, Merck launched an intense marketing campaign to introduce the first HPV vaccine to the general public. Prior to that year, researchers found very low levels of HPV knowledge among adolescents and young adults in the United States (2). In 2007, the U.S. Food and Drug Administration Advisory Panel approved the use of Gardasil® in girls and women 9–26 years of age to prevent 4 strains (Types 6, 11, 16, 18) of HPV responsible for 70% of cervical cancer cases. Later that year in July, the Advisory Committee on Immunization Practices voted to recommend that Gardasil® be administered routinely to young females 11–12 years old with catch-up for teens up to age 18.

Research is very limited regarding adolescent views on cervical cancer, HPV and the HPV vaccine. Studies involving racial and ethnic populations in the United States after the introduction of the HPV vaccine and its media campaign have demonstrated low levels of knowledge of HPV and cervical cancer among adolescent females. Read et al. found that in 2007–2008, only 55.8% of inner-city Caribbean and African-American adolescents at an adolescent medical clinic knew what HPV was, and this knowledge was significantly associated with awareness of the link between cervical cancer and HPV as well as the desire for HPV vaccination (3). Kahn et al. found that respondents surveyed at a teen health centre
in Cincinnati were able to answer 40% of the study’s HPV knowledge questions correctly (4). In this study, approximately 5% of respondents had already received at least 1 HPV shot. A focus group study with Latinas and African-Americans in the Midwest found that participants fell into 2 groups in terms of knowledge: those who knew very little and those who had some knowledge. The majority of respondents could not answer confidently when asked what they knew about cervical cancer. Very few focus group participants were able to correctly associate cervical cancer or the cervix with the reproductive system. None correctly identified HPV as the cause of cervical cancer (5).

**MATERIALS AND METHODS**

The protocol for this study was approved by the Alaska Area Institutional Review Board, along with 3 Tribal Health Organization review committees. In 2008, interviews were conducted with 79 adolescent females in 4 different communities in Alaska. These communities were of different sizes (1 urban, 2 hub and 1 village). In rural Alaska, a hub community serves as a commercial, medical, educational and transportation centre for surrounding villages. The initial sample design specified that the same amount of young women should be interviewed from each type of community in order to be able to compare these subsamples. However, due to difficulties recruiting respondents in the urban and village environments, the sizes of 2 of the subsamples were not large enough to allow for a comparison.

Inclusion criteria for respondents were: having youth assent and parental consent; being an English-speaking American Indian or Alaska Native or American Indian young woman; and being between 9 and 18 years of age. The respondents were recruited by several means. In a previous research study employing parent focus groups, participating parents were asked by researchers for permission to contact their daughters at a later date for interviews in this study. If the parent gave his or her permission, then the daughter was contacted for her assent. Additional recruitment of young women was conducted through schools and medical clinics in each community. Flyers were posted and handed out in places where young women visit, such as stores and youth group meeting places. Parents and young women were also asked to refer interested friends and relatives for study participation. Both parental consent and youth assent were obtained prior to the interview process. The interviews were held in private meeting spaces at health clinics, schools and a hotel where confidentiality could be maintained. Participants received a $25 gift certificate to a general store in their area in appreciation for their participation.

Interviewers followed a standard open-ended interview guide to conduct interviews that lasted approximately 20–30 minutes. First, the young women were asked if they had heard of cervical cancer, HPV and genital warts and if they knew about how each disease was transmitted, its signs and symptoms and its treatment. After answering the knowledge questions about cervical cancer, HPV and genital warts, each respondent was given a brief educational session on each topic and then asked how likely she thought it would be that a person her age would get the disease and how bad it would be to get it. Additionally, respondents were asked questions regarding whether they would like to be vaccinated, why or why not and how they liked to learn about health issues such as these.
The qualitative data collected in the interviews were analysed using Atlas Ti qualitative data analysis software (6). The data were examined for common themes presented by all of the teens and in subgroups based on their ages (11–14 years and 15–18 years) and whether they had any family members who worked in a health care setting.

RESULTS

Study population
Researchers recruited 79 young females through the ages of 11 to 18 years from 4 Alaskan communities. Ten per cent of participants came from an urban area; 65% came from hub communities; and 25% were from a village. It was much more difficult to recruit respondents in urban areas because Alaska Native youth make up a smaller percentage of the urban population and are more difficult to reach as a group through school and tribal activities. Forty-seven per cent of respondents were 11 to 14 years of age and the remainder was 15 to 18 years old. Slightly over half of respondents (53%) had at least 1 relative who worked in the health care system (see Table I).

Perceptions of vaccines
When asked to state the purpose of a vaccine approximately half of the participants answered accurately. The 15–18-year-old group tended to give answers that demonstrated a more accurate understanding of what a vaccine does. An example of an accurate answer given by a participant was “something that helps you from getting diseases that can kill you or make you sick.” Other accurate responses were “a shot that helps you not to get something,” or “medicine used to prevent illness.” Examples of answers that were not considered medically accurate were “medicine that helps you get better,” or “treatment… something to help you.” It is interesting to note that those participants with relatives working in a health care setting did not give more accurate answers than those participants without a relative in health care. Researchers also asked who decided if the participant was to get a vaccine. For both age groups, the most frequent response was that their mother made the decision. Other commonly reported decision-makers were the young woman’s guardian and the young woman herself in conjunction with a parent. Only 2 of the 15–18-year-olds reported that getting vaccinated was solely their decision.

The youths were asked why they would want to get a vaccine. The 2 most common reasons for a person to get vaccinated were “to not get sick” and “to get better.” Other reasons were “because someone recommends it” and “to be healthy.” Both the 15–18 year olds and those young women with relatives in health care tended to answer “to not get sick.” Reasons that were mentioned for not getting vaccinated included that shots were frightening or might hurt, that the vaccine might not work and that there might be adverse side effects. Others said they would not get vaccinated because they or their partners would never get a sexually transmitted disease. Older teens most commonly cited concerns about side effects or doubts about vaccine efficacy, while younger teens were afraid the shot would hurt. Some study participants answered that they did not mind getting shots or that nothing would prevent them from being vaccinated.

Perceptions of cancer
Early on, interviewers discovered that study participants knew very little about cervical cancer. In response to this lack of knowledge, the questions about cervical cancer were broadened to
include cancer in general. When asked, “What do you know about cancer?” study participants were evenly divided between giving medically accurate answers and replying “I don’t know.” There were many accurate answers pertaining to lung cancer, which suggests that young women had heard more about this type of cancer than they had heard about cervical cancer.

When asked what causes of cancer, the most common responses were “I don’t know” and “using drugs, alcohol and tobacco.” Other common responses included sexual intercourse, sexually transmitted diseases (STDs), HPV, environmental conditions (such as pesticides or radiation) and poor health in general. Older teens were more likely to reference sexual activity, STDs and HPV as the cause of cancer than were younger teens. Young women with relatives working in a health care setting more frequently answered that drug, alcohol and tobacco use was the cause of cancer.

When asked about how to prevent cancer some participants did not think it was preventable, while other respondents proposed the following means of prevention: vaccine; medicine; a healthy lifestyle; safer sex practices; and abstention from sexual activity, drugs, alcohol and tobacco. More study participants answered that there is a cure for cancer than answered “I don’t know,” or that “there is no cure.”

After a short explanation of cervical cancer, study participants rated on 10-point Likert scales the likelihood that a young woman their age would get cervical cancer, as well as how bad having this type of cancer would be. In terms of the likelihood that young women would get cervical cancer, the respondents’ mean was 5 and there were 2 modes: 5 and 7. The mean for younger teens was 4.8 (mode 7). The mean for older teens was 5.5 (modes 5 and 7). When asked how bad it would be to contract cervical cancer on a scale of 1–10, the most common answer was “very bad” at 10 and the mean was 8. The mean for younger teens was 7.9 (modes 8 and 10). The mean for older teens was 8.3 (modes 9 and 10). It is important to interpret these results very cautiously due to the use of a non-random sampling technique in this study. This information is provided to give the reader an idea of the range of responses that were given; however, this information cannot be generalized to a larger Alaska Native population.

### Table I. Sample demographics of participants.

|                          | Urban    | Hub 3,505–4,922 | Village 811 | Total |
|--------------------------|----------|-----------------|-------------|-------|
| Sample size              | 8        | 51              | 20          | 79    |
| Ages                     |          |                 |             |       |
| 11–14 years              | 6        | 20              | 11          | 37    |
| 15–18 years              | 2        | 31              | 9           | 42    |
| Relative in health care  |          |                 |             |       |
| Yes                      | 2        | 27              | 13          | 42    |
| No                       | 5        | 22              | 7           | 34    |
| Don’t know               | 1        | 2               | 0           | 3     |

### Table II. Reasons for vaccine acceptance or rejection.

| Reasons for vaccine acceptance       | Reasons for vaccine rejection                |
|--------------------------------------|----------------------------------------------|
| • To not get sick                    | • Afraid of shots                            |
| • To get better                      | • Shots will hurt                            |
| • Because someone recommends it      | • Vaccine might not work                     |
| • To be healthy                      | • Self or partner will not get an STD        |
|                                      | • Adverse side effects                       |
**Perceptions of HPV**

Researchers found that more than half of the participants were unaware of the existence of HPV. When asked what they knew about it, most answered “I don’t know.” Surprisingly, younger teens were more likely to have heard of HPV as compared to older teens. Those study participants without a relative in health care were more likely to have heard of HPV than those participants with a relative in health care. Examples of accurate statements about HPV were: that it was “sexually transmitted,” “a virus” and “an STD that can be prevented.” An example of an answer that was not accurate was “I heard it on a commercial but I didn’t know what it was. But I knew it was a cancer.” Another answer that indicates a low level of knowledge was “I heard it before but didn’t know what it means.” Three themes emerged in the answers to how HPV is spread. “I don’t know” was the most common answer, followed by “sexually” and lastly “by coughing and/or sneezing.” Many of the young women did not know if there was a cure for HPV.

After a short explanation of HPV, study participants rated on 10-point Likert scales the likelihood that a woman their age would contract HPV, as well as how bad having HPV would be. In terms of the likelihood that young women would contract HPV, the respondents’ answers ranged from 1–10 with a mean of 5.5 (modes 5, 7). The mean for younger teens was 4.9 (modes 1, 5). The mean for older teens was 6 (modes 6, 7). When asked how bad it would be to contract HPV on a scale of 1–10, the most common answer was “very bad” at 10 and the mean was 7.8. The mean for younger teens was 8.0 (modes 9, 10). The mean for older teens was 7.7 (mode 10).

**Perceptions of genital warts**

All of the Alaska Native adolescent females in this study had heard about genital warts, although few could relate accurate information about the condition. Many did not know how warts were transmitted or how to treat them. Examples of medically accurate statements made by respondents regarding genital warts were “an STD that you get warts down there,” “warts you get on your private parts” and “they are down there on males and females [and are] spread from touching.” Study participants did not know if there was a cure for genital warts. Themes that emerged in the answers on how to prevent the spread of genital warts were “I don’t know,” safer sex practices, abstinence and folk remedies.

After receiving a description of genital warts, study participants then rated on Likert scales the likelihood that a young woman their age would contract genital warts, as well as how bad it would be to get genital warts. The responses to the likelihood of getting genital warts ranged from 1–10 with a mean of 5 (modes 5 and 6). Among younger teens the mean was 4.3 (modes 1, 3, 6). Among older teens the mean was 5.6

| Table III. Means of responses on a scale of 1–10 of likelihood to acquire a disease and how bad it would be to have the disease. |
|--------------------------------------------------|
| **Cervical cancer** | **HPV** | **Genital warts** |
| 11–14 yrs | 15–18 yrs | 11–14 yrs | 15–18 yrs | 11–14 yrs | 15–18 yrs |
| Likelihood of getting the disease (mean-scale of 1–10) | 4.8 | 5.5 | 4.9 | 6 | 4.3 | 5.6 |
| How bad would it be to get the disease (mean-scale of 1–10) | 7.9 | 8.3 | 8 | 7.7 | 8 | 8 |
(modes 5, 6). Overwhelmingly, respondents felt that it would be very bad (mode 10) to get genital warts (mean 8). The mean for younger teens was 8 (modes 8, 10). The mean for older teens was 8 (modes 6, 8, 10). Most of the participants said they would get vaccinated against genital warts. Those that would not get vaccinated explained that they would not need to, that they did not like shots or that they did not want a vaccine in their body.

**Health information sources**

Alaska Native teens most commonly reported receiving health information from school, medical staff, family, television and the Internet. Less commonly reported sources were other young people, posters and brochures. More of the younger teens listed school and teachers as a source of health information, whereas older teens more often reported getting information from family. Magazines were also a commonly cited source of information, while newspapers and radio were less frequently chosen as sources. Older teens were more likely to list medical staff, television and the Internet as sources of health information than were younger teens. Only older teens listed other young people as health resources. When asked about their preferred type of media, the most common response was television, followed by the Internet, brochures and posters.

Study participants were asked to rate the likelihood that they would speak to teachers, parents, siblings, grandparents, medical staff and friends about health-related issues such as HPV or cervical cancer. Interestingly, although participants most commonly listed school as a source of health information, when asked to whom they would go with questions about HPV or cervical cancer, teachers ranked lower than medical staff, parents or friends. Medical staff such as physicians, nurses and community health aides were ranked the highest, followed by mothers and then friends. Community health aide practitioners are trained laypeople who work to provide basic health care in rural settings under the supervision of a mid-level provider or physician. Young women were least likely to inquire about health information from their grandfathers, brothers or fathers.

**DISCUSSION**

Although the Merck marketing campaign had begun in Alaska in 2006, prior to the onset of this study, Alaska Native adolescent females knew very little specific information about HPV and cervical cancer. About half of those interviewed had heard about HPV and many had heard about genital warts, although few could relate accurate information about either condition. Younger teens mentioned drugs, alcohol and tobacco as the causes of cancers, while older teens mentioned STDs and HPV. When informed about all of these health conditions, most teens felt that they had a moderate likelihood of contracting the diseases and most imagined that actually having the health problem would be quite bad. Older teens felt that it would be slightly worse to have cervical cancer, genital warts, and HPV as compared to younger teens.

Many of the adolescents surveyed did not know the purpose of a vaccine. Older teens expressed more accurate knowledge as compared to younger teens. The reasons for not wanting to be vaccinated differed depending on age, with younger teens being afraid of shots and older teens concerned about vaccine side effects and efficacy. Although most respondents did not
report that they would make the final decision on whether to receive the HPV vaccine, some said that they would have input into the decision. This is consistent with the results of focus groups with mothers from the first phase of this study. Several mothers said that their daughters had researched the vaccine and asked to be vaccinated.

As part of a healthy life cycle it is important to educate youth so that they become young adults who understand the importance of vaccines for themselves and their future children. Our findings suggest that it is necessary to start at a very basic level by educating teens on what a vaccine does. Some of the teens involved in this study thought that a vaccine helps to treat or cure a disease. This misinformation may affect their vaccine acceptance if they feel that they are not sick with the target disease. For younger teens, this belief coupled with a fear of needles may make them less likely to agree to or pursue vaccination. For older teens, the fear of side effects and lack of knowledge about the purpose of a vaccine may decrease their motivation to get the vaccination. This may be especially important with some older teens because they were the only participants who mentioned that they were the primary decision-maker regarding vaccination.

This study has several limitations. The sample was small and selected in a non-random manner. Thus, the results may not be generalized to the whole Alaska Native community. However, the questions that were asked in the interviews yielded consistently similar themes among Alaska Native youth to the point of theme saturation, indicating that the results may represent a complete range of answers present in this population. Thus, the results should be interpreted as an array of possible findings that are present among Alaska Native adolescent females. In addition, since most participants knew very little about cervical cancer, HPV and genital warts, the interviewer conducted education on these topics during the interview. The manner in which the education was conducted was similar for all groups; however, it may have influenced the attitudes that were expressed afterwards. Finally, another limitation is the fact that 2 out of 3 of the interviewers were not Alaska Natives. In order to put the participants at ease, it would have been optimal to have an interviewer who was of a similar race and cultural background.

Conclusion
This study is unique in that it explores the attitudes, knowledge and beliefs of Alaska Native adolescent females under 18 years of age. Prior to this study, there were no research studies or educational materials on the HPV vaccine focused on this specific population. The findings from this study provide valuable information on how to educate these adolescents on cervical cancer, genital warts, HPV and the HPV vaccine. While it appears that teens fear these diseases, it is important that they realize their need for the vaccine and that this need outweighs the negative consequences of getting vaccinated that they perceive.

This research revealed that the content of an educational campaign along with the method and source for education should be varied depending on the age of the adolescents. For younger teens, it is important to distribute this information at school, since this is the primary source of information on these topics for this age group. A brochure or curriculum for a school health class on cervical cancer, HPV, genital warts and vaccines may be most effective. For older teens, a television commercial or web page may be more appropriate. However, in
some areas of rural Alaska, access to mainstream media and the Internet may be limited.

This research has practicable applications because it was undertaken at the beginning of the HPV vaccine’s introduction and will be used to guide educational approaches and the development of materials. This approach should be considered for other vaccines and for other populations where vaccine introduction may be controversial or require special attention to cultural or religious protocol.

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