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Perception of Barriers to and Factors Associated with HPV Vaccination Among Parents of American Indian Adolescents in the Cherokee Nation

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Abstract

The purpose of this study was to understand the perceptions of HPV vaccination barriers and factors among parents or guardians of American Indian adolescents in the Cherokee Nation. Fifty-four parents of American Indian adolescents in the Cherokee Nation participated in one of eleven focus group discussions from June to August 2019. Discussions were recorded, transcribed, coded, and analyzed for themes. Protection against cancer was the primary parent-reported reason for vaccinating their children against HPV. The lack of information and safety concerns about the HPV vaccine were the main reasons for non-vaccination. To increase HPV vaccine uptake, parents strongly supported offering vaccinations in school. Furthermore, increased healthcare provider–initiated discussion can ease parental concerns about HPV vaccine safety and improve coverage.

Keywords American Indians · Cancer prevention · Cherokee Nation · Focus groups · HPV vaccination

Introduction

Human papillomavirus (HPV), the most common sexually transmitted infection (STI) in the USA (US) [1], causes cervical cancer and is associated with certain genital and head and neck cancers [2]. The burden of cervical cancer is higher among American Indian and Alaska Native persons [3, 4]. In Oklahoma, which had the third-highest incidence rate for cervical cancer in the nation [5], American Indian and Alaska Native women had the highest incidence (14.8 per 100,000 women) and mortality (4.5 per 100,000 women) rates for cervical cancer [6].

To prevent cervical and other HPV-associated cancers, vaccination against HPV is routinely recommended at age 11 or 12 years, with catch-up recommended through age 26 years, and shared clinical decision-making recommended for adults aged 27 to 45 years [7, 8]. In 2019, the national ≥ 1 dose-HPV vaccination coverage was lower among American Indian and Alaska Native adolescents (71.1%) compared to Hispanic (76.8%), Asian (74.8%), multiracial (73.0%), and Black (72.0%) adolescents [9]. To improve HPV vaccination rates among American Indian and Alaska Native persons, it is important to identify, understand, and address vaccination barriers specific to this community.

Few qualitative studies have investigated the barriers and factors associated with American Indian and Alaska Native persons at the individual [10, 11] and provider levels [12, 13]. At the individual level, the most common barriers to HPV vaccination among American Indian and Alaska Native parents were concerns about HPV vaccine safety, vaccine mistrust, and lack of knowledge about the vaccine [10, 11]. At the provider level, a lack of recommendation was the most prominent reason for non-vaccination [12, 13]. Although these studies were integral in advancing the science focussing on American Indian and Alaska Native persons, most were limited in scope, tribal communities covered, and were conducted before 2010. Also, as American Indian and Alaska Native communities are diverse in policies and patterns for vaccination, it is important to gather and understand perspectives from different American

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Indian tribes. Furthermore, perceptions of cultural aspects of health can be better explored and explained using qualitative research methods, which can facilitate the collection of rich and authentic data. Additionally, qualitative approaches can provide in-depth insights to inform the community that is engaged in the process.

The purpose of this study was to better understand the perceptions towards HPV vaccination barriers and factors among parents or guardians of American Indian adolescents in the Cherokee Nation. The results from this study will inform public health and clinical interventions targeted to increase the coverage of HPV vaccination among vaccine-eligible American Indian adolescents within the Cherokee Nation reservation.

Methods

We followed the CONSolIDated critERtia for strengthening the reporting of health research involving Indigenous Peoples (CONSIDER) guidelines [14]. We also used the consolidated criteria for reporting qualitative research (COREQ) checklist items [15], wherever applicable, and presented them as supplementary material.

Study team

Personal Characteristics

All focus group discussions were facilitated by the principal investigators from Cherokee Nation (AC and MB). The team included investigators with formal training and experience in conducting qualitative health research.

Relationship with Participants

Before the study, the team did not know the participants. Therefore, the principal investigators from Cherokee Nation introduced themselves at the start of the focus group discussion and then explained the study purpose, importance, and process to the participants.

Study Design

For this study, we used thematic analysis to conduct focus groups using a semi-structured discussion guide.

Participant Selection

Convenience sampling was used to select participants. To inform potential participants about the focus group, an e-mail was sent to all Cherokee Nation employees. In addition, flyers about the study were posted within Cherokee Nation clinics, social media platforms, and the Cherokee Nation Public Health website. In total, 11 focus groups with 54 participants, a majority of whom were female (89.0%), were conducted without any dropouts. Eligible participants included parents or guardians of American Indian adolescents aged 9 to 17 years who (or their children) are currently patients of Cherokee Nation Health Services. On average, each focus group had approximately five participants, with a range of two to ten participants.

Study Setting

All focus groups, except one, were undertaken at Cherokee Nation Health Services clinics. These facilities were selected to ensure that participants could communicate their opinions in private and controlled spaces. Furthermore, no one besides the participants and study team was present during the focus groups.

Data Collection

Given a lack of research and data on HPV vaccination barriers and factors in this population, a semi-structured interview guide was developed to cover the main topic areas (Supplementary File 2). The guide included topic areas related to knowledge of HPV and HPV vaccine, beliefs on HPV vaccination, personal experience with HPV vaccination, trusted sources for HPV vaccination information, and attitudes related to interventions to increase HPV vaccination coverage. In addition, verbal and non-verbal probing techniques were used. Each focus group was audio-recorded and took between 30 and 60 min to complete.

Coding and Analysis

Focus group recordings were transcribed verbatim, checked for accuracy, and loaded into qualitative computer software MAXQDA 2018 (VERBI Software, Berlin, Germany) for analysis. The study team (SG, SM, AA) read through all transcripts independently and created codes based on the purpose of the focus groups and the focus group discussion guide as well as data that emerged from the focus groups. Thereafter, detailed definitions and instructions were developed for each code. The team iteratively refined the codebook by coding one interview together, updating the codebook, coding a second interview together, and finalizing the codebook as a team. The study team then independently coded a transcript to check inter-rater reliability, which was above 90%. For the final coding, the study team divided the transcripts, and each served as a primary coder and a secondary coder for a third of the

transcripts. The study team reviewed codes and resolved any conflicts. The coded focus groups were then analyzed for themes. Team members first independently identified themes within and across codes, and then the team met to discuss and finalize themes.

Ethics

The study was approved by the Cherokee Nation Institutional Review Board. Before each focus group, a written informed consent was obtained from all participants. Participants were provided $30 gift cards as compensation for participation.

Results

The themes associated with knowledge and sources of knowledge about HPV and HPV vaccine are provided in Table 1 and described below.

Parents Had Some Knowledge of HPV and the HPV Vaccine, But Details Were Limited

Some participants in all focus groups had heard of HPV and knew it could cause cancer. Most groups discussed that HPV is an STI that can be prevented by a vaccine. Only a few focus groups discussed the high prevalence of HPV and that it can spread when an individual is

Table 1 Knowledge and sources of knowledge about HPV and HPV vaccine — Cherokee Nation, 2019

Themes		No. of focus groups ($n=11$)	Representative quotes
Parents have some knowledge of HPV and the HPV vaccine, but details are limited			
HPV knowledge	1. HPV causes cancer	11	"That's—to think it was…that pronounced, like, easy to spread."
	2. HPV is sexually transmitted	7	"I think if more people knew that, they would all—they would jump at those vaccinations."
	3. Do not have enough knowledge about HPV	5	"Is it potentially reoccurring? 'Cause this is the most description I've ever heard on HPV"
HPV vaccine knowledge	1. HPV is prevented through vaccination	11	"I didn't know about the vaccination. Well, I knew about HPV, but I didn't know about the vaccination until I took my daughter to get her on birth control. And then they told me, and she was vaccinated then."
	2. The vaccine is a series of shots	6	"You just get the two shots and then you're done for the rest of your life. There's no boosters."
	3. Aware of the age range of vaccine eligibility	6	"Mine just explained like what she said, like it could cause whatever in boys and then girls and she recommended that we start giving it at age—I think it was 9? Was it 9?"
Healthcare providers are the primary source of knowledge about HPV			
Source(s) of information about HPV and HPV vaccine	1. Television	11	"I'd rather someone just kind of tell me instead of giving me something to read. I don't have time to sit down and read this, you know? I can do a commercial, but I don't watch TV so I'm, you know."
	2. Healthcare provider	9	"I know like nothing about it. So, the commercials didn't do anything for me and the pediatrician didn't do anything for me. That big old sign in women's clinic, that didn't do anything for me. I just did it because it was a vaccination and it was something that I would rather my kid—child not have."
	3. Most information seen is online is anti-vaccination information	6	"Anything that's anti-vaccine is—is obviously, I mean, it's not helpful. And there—there are times I go there just to look and see what they're saying, even though, you know, I've already chosen to vaccinate."

asymptomatic. Participants in approximately half of the focus groups indicated they did not know much about HPV or that the focus group had provided more information on HPV than they had ever heard of before.

All groups knew about a vaccine to prevent HPV, but very few groups named the brand of vaccine (GARDASIL®9). Over half of the focus groups described the vaccine as a series of shots, with some debate about whether the series includes two or three doses or which children were recommended to get two vs. three doses. The groups often described the target age range for the vaccine but were unsure exactly how young children could be to receive vaccination and if there was a maximum age for vaccination. The timing of the vaccination was often discussed around the context of an adolescent becoming sexually active, with questions on whether it was still beneficial to get the vaccination after becoming sexually active or whether parents wished their child had received the vaccination before becoming sexually active. Participants in two focus groups discussed knowing some individuals who had experienced reactions to the vaccine or not knowing about the effectiveness or safety of the HPV vaccine.

Healthcare Providers Were the Primary Source of Knowledge About HPV

Most groups described the clinic and its providers as the primary source of information. While most groups had talked to their doctor or nurse about the vaccine, some expressed a desire for more information to come from their provider or more details to be provided. All focus groups described seeing TV commercials that provided information about the HPV vaccine. Participants had mixed feelings about the effectiveness of the commercials, stating that the commercials were confusing or often just scary, especially when describing the side effects. While participants in all focus groups were aware of the TV ads, some stated that they rarely watched TV and it was not an effective way to distribute information. Only a few groups mentioned seeing vaccine ads or information on social media sites, such as Facebook or Twitter, but many groups had seen discussions on social media sites referencing the side effects of vaccines, anti-vaccination support, or misinformation. A couple of groups mentioned getting their information about the HPV vaccine from friends, school, or training as part of their health profession. A few groups discussed using online sources from government or medical websites to get information on the HPV vaccine.

The themes about HPV vaccination facilitators and barriers are presented in Table 2.

Healthcare Providers Did Not Adequately Discuss HPV Vaccination

Most of the groups indicated that their healthcare provider did not provide adequate information about the HPV vaccine but did recommend receipt of the vaccine. Most of the focus groups also stated their healthcare provider-initiated conversations about the HPV vaccine, and some participants noted that their provider strongly recommended the HPV vaccine. In contrast, other participants stated that their provider indicated that the HPV vaccine was optional or not required by the school. In some focus groups, participants mentioned that information about the HPV vaccine was provided when the vaccine was recommended, but not before the appointment. About half of the focus groups also had at least one participant who was unaware of the HPV vaccine until the provider recommended it during an appointment.

Preventing Cancer Was the Main Reason for HPV Vaccination

Most focus groups reported getting their children vaccinated against HPV to prevent cancer and to protect against infection. Participants also stated that a recommendation from a healthcare provider and trust in healthcare professionals were reasons for getting the HPV vaccine for their children. Other reasons for vaccination that emerged during the focus group discussions included parents being pro-vaccine, their child being sexually active, HPV vaccine being available, preventing their child from sickness, and protecting their child's future partners.

Lack of Information and Safety Concerns Were the Main Reasons for Non-vaccination

The lack of information about the HPV vaccine and concerns about vaccine safety were the most common reasons reported by focus group participants for non-vaccination. Despite the HPV vaccine being available since 2006, focus group participants felt that the HPV vaccine was too new. Participants shared that they were not well informed on the long-term effects of the HPV vaccine. Closely related to the lack of information about the HPV vaccine, participants also stated that their healthcare provider had not discussed or recommended the HPV vaccine. Condoning sex was another reason for non-vaccination that emerged in focus group discussions in which participants felt that getting the HPV vaccine may be perceived by their children as permission to initiate sexual activity.

The themes about attitudes and perceptions surrounding are presented in Table 3.

Table 2 Experience with HPV vaccination facilitators and barriers — Cherokee Nation, 2019

Themes		No. of focus groups ($n = 11$)	Examples or quotes
Healthcare providers did not adequately discuss HPV vaccination			
Healthcare provider HPV vaccine discussion/recommendation	1. Healthcare provider-initiated conversation about HPV vaccine	10	"I heard about it when I went to the health clinic when ***** like when she got her immunizations, when the Gardasil came out."
	2. Provider did not provide adequate information about vaccine, just recommended uptake	10	"I went in and they said, hey he needs his HPV and I was like, what is that? And they told me and I said, then no. If you didn't even tell me what it was, you're not gonna stick him with it. [laugh] There wasn't ever—they didn't really—they don't really educate you on it before you even get—they just in here and say, hey you need this, and they give you a handout, but the handout is right when it's time for your shots, so you don't even have time to read it."
	3. Provider strongly recommended HPV vaccine	7	"Yeah. Yeah. She [provider] was very adamant."
Preventing cancer was the main reason for HPV vaccination			
HPV vaccination reasons	1. To prevent cancer	7	"I mean you wanna protect your kid. You love them. You don't want something bad to happen to them, so you try to do what you can to prevent things that you got [the] power to do, you know? If it's in your power to prevent something like that [cancer] from happening to your kid, then why wouldn't you?"
	2. To protect against warts or infection	4	–
	3. Recommendation from, or discussion with, healthcare provider	2	"I asked him [doctor] if it—if it were you, would you give it to your kids? And he said absolutely I would. Okay well"
Lack of information and safety concerns were the main reasons for non-vaccination			
Non-vaccination reasons/HPV vaccination barriers	1. Lack of information about the HPV vaccine	5	"I didn't feel like I was informed well enough on exactly what this was gonna be–if there were any side-effects, you know, the long-term uh causes or conditions that come with it"
	2. Fear of side effects	5	–
	3. HPV vaccine has not been out for long (too new)	3	"I did not get my son vaccinated. Because it [HPV vaccine] has only been out for 10 years. That's not long enough to see what kind of risk and what kind of a thing that they are putting into my kid"
	3. Condoning sex	3	"You may feel like you're kinda giving them permission to go start having sex"

Table 2 (continued)

Themes		No. of focus groups ($n = 11$)	Examples or quotes
HPV vaccination series completion barriers	1. Forgot/lack of a reminder	4	"The only suggestion I have is…[a] reminder. You know how like paying bills and stuff, they'll [Cherokee Nation] send you an automated text message like each time when it's due" "Any reminder is a good reminder"
	2. Taking time off from work	2	"I think for a lot of parents, you know, having to take off work, take their kids to the doctor, you know, not getting paid"
	3. Transportation issues	2	–

Participants Believed That the HPV Vaccine Is Necessary

Most focus groups stated they believed the HPV vaccine was necessary for both boys and girls. Several focus groups had at least one participant indicate that the necessity of the HPV vaccine is attributed to their child's sexual activity. Some groups believed the HPV vaccine is necessary because of the risk of cancer if one does not receive the vaccine and some groups had at least one participant state that the HPV vaccine was necessary to prevent others from contracting HPV. One focus group had at least one participant feel as if the media mislead them to believe the HPV vaccine was unnecessary.

Concerns for Potential Side Effects from the Vaccine Were Present

Several focus groups stated their concern with HPV vaccine safety was because of potential long-term side effects. Participants in approximately half of the focus groups indicated that the lack of time that the HPV vaccines have been available contributed to their concerns about vaccine safety. A few focus groups had at least one participant who had safety concerns about immunizations in general, not specifically the HPV vaccine. Concern about the ingredients of the HPV vaccine was also mentioned in one focus group.

Interventions to Increase HPV Vaccine Uptake at the Community and Clinic Levels

At the community level, almost all focus groups supported the idea of offering the HPV vaccine in school. According to participants, it would make the vaccine more accessible and alleviate major inconveniences for parents, such as taking time off from work. At the clinic level, several focus groups discussed that text message reminders about the HPV vaccination would help increase HPV vaccine uptake. Also, participants discussed the need to receive more information from their healthcare provider. Participants shared that healthcare providers need to discuss and provide information about the HPV vaccine.

Discussion

In this study of perceptions towards HPV vaccination factors and barriers, the main reason reported by American Indian parents in Cherokee Nation for vaccinating their children was to protect them from cancer. Our results also indicate that a lack of information about the HPV vaccine coupled with concerns about vaccine safety were the main reasons for non-vaccination.

The main reason described by parents for HPV vaccination was preventing cancer in their children. This finding of cancer prevention being the most compelling

Table 3 Attitudes and perceptions surrounding HPV vaccination — Cherokee Nation, 2019

Themes		No. of focus groups ($n=11$)	Examples or quotes
Trust in HPV vaccine and/or healthcare provider	1. Trust in HPV vaccine because they trust healthcare provider who recommended the vaccine	10	"She said that, I recommend it. She highly recommended it, so. Glad she did, I trusted her."
	2. Lack of trust due to limited time HPV vaccine has been available	4	I honestly um I don't know, I didn't… I opted out. I did not get my son vaccinated. Because it's only been out for 10 years. That's not long enough to see what kind of risk and what kind of a thing that they are—were putting into my—my kid."
	3. Lack of trust in vaccine due to limited amount of information about vaccine and/or its effectiveness	3	"It's kinda like they said, oh you need to think about doing this and if they want it. Like it's up to you to go do research and you figure out if that's right for you or your child. And when you come back, say oh give her the shot, then they give her the shot. But nobody says, this is what it's for, this is how long we think it lasts, or these are the side effects—no one says anything like that."
Participants believed that the HPV vaccine is necessary			
Is HPV vaccine necessary?	1. HPV vaccine necessary for boys and girls	9	"I don't think it matters whether they're girls or boys"
	2. Necessity of HPV vaccine is attributed to child's sexual activity	7	"I mean, like, you don't know like when they're older how promiscuous they're going to be or who they're going to be with, so, I mean, better to protect them beforehand."
	3. HPV vaccine necessary due to cancer risk	4	"Cancer prevention is my number one reason. If there is something I can do, anything I can do to keep my child from contracting a type of cancer, I'm gonna do it."
Concerns for potential side effects from the vaccine were present			
Vaccine safety	1. Concern for potential side effects of HPV vaccine	7	"I'm uhm at odds on exact information or long term study or whatever you make. I mean waiting around could definitely uh, cause problems for his future life, like that commercial says [laugh]. And I don't want to be responsible for that but, I'm also kinda wondering what the overall—the overall side effects—or is there any side effects?"
	2. Safety concerns attributed to lack of time HPV vaccine has been available	5	"… I opted out. I did not get my son vaccinated. Because it's only been out for 10 years. That's not long enough to see what kind of risk and what kind of a thing that they are—were putting into my—my kid."
	3. HPV vaccine perceived as being safe/not harmful	5	"Oh yeah. I think it's safe, yeah. I mean same thing, I think it's a precaution for something they're gonna do."
Interventions to increase HPV vaccine uptake at the community and clinic levels			

Table 3 (continued)

Themes		No. of focus groups ($n=11$)	Examples or quotes
Interventions	1. Vaccine clinics in schools	10	"I think for a lot of parents, you know, having to take off work, take their kids to the doctor, you know, not getting paid, you know, having to reschedule. I think that [vaccine clinics] would be more beneficial"
	2. Text message reminders	10	"That's why I thought it would be cool to send automated text messages like that because a lot of people won't even answer their phone"
	3. Need more information from doctor/doctor needs to discuss HPV vaccine	7	"I think the doctors need to sit down and tell you about it [HPV vaccine]"
Using the term "cancer vaccine"	1. Misleading	5	"I think they would open a whole different can of worms too, because, you know, you run into the risk of, I'm immune from all cancer now"
	2. Agree	4	"I think people would pay attention, a little more attention" "I think more parents would [be] open to get it"
	3. –	–	–

reason for HPV vaccination was also reported in a survey of Cherokee Nation parents [16] and in a national study of over 1000 parents [17]. Our finding that parental concerns about safety being a major barrier to HPV vaccination is also consistent with the findings from a systematic review among American Indian and Alaska Native persons [18] and reviews among other US populations [19–21]. Also, data from the National Immunization Survey-Teen show that concerns about safety are among the most common reasons for the lack of HPV vaccine initiation among adolescents. Another barrier to vaccination that emerged from the focus group discussions was the lack of information about the HPV vaccine. Although parents were aware of and had some knowledge of the HPV and HPV vaccine, they lacked information about vaccination safety, series, and eligible age groups, among others. To address this issue, focus group participants indicated a need for their healthcare provider to discuss and provide adequate information about the HPV vaccine. Discussing the HPV vaccine, addressing safety concerns, and answering questions can ease parental concerns and potentially improve the HPV vaccine uptake.

To make the HPV vaccine more accessible, alleviate inconveniences, and increase vaccine uptake, parents strongly supported offering HPV vaccinations in school. Previous studies have found that providing HPV vaccination outside traditional healthcare settings, such as schools [22], can improve HPV vaccination coverage. In a study conducted in Texas, the initiation and completion of HPV vaccination doubled at intervention schools that provided onsite vaccination and community-based education when compared to schools without any intervention. Parents also suggested the importance of text message reminders about the HPV vaccination. Reminder systems are cost-effective in notifying parents when their children are due for their HPV vaccination. The Community Preventive Services Task Force has provided strong evidence to recommend reminder and recall interventions to increase vaccination rates in adolescents [23].

Our study is subject to several limitations. First, individual responses in the focus groups may have been influenced by the group discussion or the members who dominated the conversation. Second, although multiple sources of recruitment methods were employed, some focus group participants were healthcare providers. As a result, their participation may have influenced the discussion, especially about knowledge and experience with HPV vaccination. Most focus group participants were females; however, this reflects that mothers are primarily responsible for decisions surrounding vaccinations [24]. Finally, this study was conducted before the SARS-CoV-2 pandemic. Although our study results are not influenced by the widespread misinformation about vaccines during the pandemic [25], it may differ from the current perceptions of vaccinations in general.

Despite these limitations, the study had several strengths. Most importantly, the study was designed by the Cherokee

Nation to address questions important to the tribal community. The facilitators were American Indian, worked and lived in the same community as the participants, and therefore, had better connections to the participants to draw out details and context. Another strength of the study was the variation in focus group locations across multiple clinics throughout Cherokee Nation. Lastly, there were no dropouts in the study.

The reduction of cancer health disparities for HPV-related cancer is a significant priority for Cherokee Nation and American Indian communities. The findings from this study have identified some of the potential factors associated with HPV vaccination and barriers to vaccination as described through focus groups of parents with HPV vaccine–eligible American Indian adolescents in the Cherokee Nation reservation. The participants discussed potential ways of improving vaccination coverage by increasing the information provided by the healthcare system, text reminders, and school-based interventions. More work is needed to gather perspectives from additional partners, which include healthcare providers, hospital administrators, and schools to design a multilevel intervention to improve HPV vaccine uptake in this population.

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Author Contribution AC and MB designed the study and conducted the focus group interviews. SM, AA, and SG coded and analyzed. The first draft of the manuscript was prepared by SG, and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health Cherokee Nation.

Data Availability The focus group data are not publicly available. The data belong to the Cherokee Nation.

Declarations

Ethical Statement The study was approved by the Cherokee Nation Institutional Review Board.

Consent to Participate Before each focus group, written informed consent was obtained from all participants.

Conflict of Interest The authors declare no competing interests.

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