



## Acceptance of the HPV vaccine among women, parents, community leaders, and healthcare providers in Ohio Appalachia

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### ABSTRACT

To assess HPV vaccine acceptability, focus groups of women (18–26 years), parents, community leaders, and healthcare providers were conducted throughout Ohio Appalachia. Themes that emerged among the 23 focus groups ( $n = 114$ ) about the HPV vaccine were: barriers (general health and vaccine specific), lack of knowledge (cervical cancer and HPV), cultural attitudes, and suggestions for educational materials and programs. Important Appalachian attitudes included strong family ties, privacy, conservative views, and lack of trust of outsiders to the region. There are differences in HPV vaccine acceptability among different types of community members highlighting the need for a range of HPV vaccine educational materials/programs to be developed that are inclusive of the Appalachian culture.

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### 1. Introduction

Women living in Ohio Appalachia have increased cervical cancer incidence and mortality rates compared to women living in non-Appalachian regions of Ohio and in other geographic regions of the United States (U.S.) [1–4]. Many social factors contribute to the cervical cancer disparities among women living in this geographic region, including values, beliefs, and attitudes about cervical cancer, the social environment (limited healthcare access and public transportation, low socioeconomic status), pathophysiological changes (prevalence of HPV), provider–patient communication issues (including lack of recommendation for screening), psychosocial factors (fear of cancer, stress), as well as behavioral factors (tobacco use, risky sexual activity) [5–9].

Approximately 70% of cervical cancers are caused by high-risk human papillomavirus (HPV) types 16 and 18 [10,11] and low-risk HPV types 6 and 11 cause genital warts and low-grade cervical lesions, but do not lead to cervical cancer [12]. HPV infection is a common sexually transmitted infection in the U.S., with an estimated 20 million individuals infected with HPV; another 6.2 million become newly infected each year; and approximately half of all sexually active men and women will become infected during their lifetime [13,14].

In June 2006, the U.S. Food and Drug Administration (FDA) approved a quadrivalent vaccine (Gardasil®), given in three doses, for females to protect against infection with HPV types 6, 11, 16, and 18 [15]. The Advisory Committee on Immunization Practices recommends HPV vaccination for females 11–12 years of age, but the vaccine may be administered as early as 9 years of age, with catch-up vaccinations for females 13–26 years old [16]. In September 2008, the FDA extended the vaccine for the prevention of vaginal and vulvar cancer caused by HPV types 16 and 18 [17].

Young women living in the Appalachian region may have the greatest potential to benefit from widespread diffusion and uptake of the HPV vaccine because of the persistence of the increased cervical cancer rates in this geographic region [1–4]. Reasons why Appalachian residents may or may not accept the HPV vaccine to prevent cervical cancer include many factors such as material circumstances (income, education), the social environment (poor access to healthcare), health behaviors (risky sexual activity), life experiences (family or friends with bad experiences with vaccines or those with a history of cervical cancer or HPV), and culture (beliefs, attitudes, values) [18–32]. Information is limited about the acceptance and barriers to HPV vaccine uptake among rural residents [18–22], and specifically among residents of Appalachia [18,19]. In one study conducted in Appalachia, college-aged women were more likely to indicate acceptance of the HPV vaccine if they were sexually active, had a history of a sexually transmitted infection, or had a history of an abnormal Pap test [18]. In the second study, two important findings were documented among women living in Appalachia. Women (85.2%) indicated an interest in the HPV

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vaccine for themselves, however, vaccine acceptability was lower among older women, and women (67.6%) were less accepting of vaccinating young girls [19].

Since the unique features of the Appalachian culture may play a role in the acceptance of the HPV vaccine, we thought it was important to gain insight into the factors that might affect acceptance at the individual and community level in Ohio Appalachia. Focus groups were conducted of women eligible for the vaccine (18–26 years), parents of young girls, community leaders, and healthcare providers to explore beliefs and attitudes about the HPV vaccine at the individual and community level. We thought it was important to include different types of residents living in Ohio Appalachia in order to develop effective educational materials and programs.

## 2. Methods

This qualitative study was conducted with the support of the Community Awareness, Resources and Education (CARE) Project, one of eight NIH-funded Centers for Population Health and Health Disparities [33]. Focus groups of Ohio Appalachia residents were conducted concentrating on knowledge, barriers, beliefs, and attitudes about the HPV vaccine at the individual and community level. The Institutional Review Board of The Ohio State University approved the protocol for this study.

### 2.1. Focus group guides

Focus group guides were developed based on the Social Determinants of Health Framework (SDH) by Marmot and Wilkinson [34]. According to the SDH, inequalities of the social environment (neighborhood disadvantage, social networks, etc.) are important to consider when focusing on health disparities. With this in mind, understanding features of the local Appalachian culture, as well as individual health behavior choices, becomes important to understand HPV vaccine acceptance.

Focus group questions that guided the discussion about the HPV vaccine included major constructs from the SDH framework. For example, questions focused on material factors (cost of the vaccine), knowledge (cervical cancer, Pap smears, HPV-related diseases), health behaviors (risky sexual activity, tobacco use), general health status, healthcare access, and issues associated with the Appalachian culture (privacy) (Table 1). Additionally, at the end of each focus group, ideas were sought about what information should be included in future educational materials and programs designed to promote the HPV vaccine. Focus group participants were provided with various publicly available brochures to get input about what they liked or disliked about the brochures. The focus group guide was developed by the principal investigator (MLK) and refined by members of the research team (DP, MR, EDP).

### 2.2. Participant recruitment

Participants were recruited from different Ohio Appalachia counties by members of local community-based Appalachian cancer coalitions associated with the Ohio Appalachian Community Cancer Network (ACCN). ACCN cancer coalition members have a history of working with the investigators on research projects, including CARE. Members posted flyers at various sites in the different counties (e.g. health departments, libraries) and also contacted local community-based agencies. Participants were recruited for focus groups with four types of community constituents: healthcare providers, community leaders, parents of young girls, and women (18–26 years old). Interested and eligible individuals were asked to participate in a 1-h focus group discussion about the HPV vaccine. When participants arrived and prior the start of the focus group, they completed a consent form and a short survey focusing

on demographic information (age, gender, education, occupation) and a 14-item knowledge quiz (true–false format) focusing on cervical cancer risk factors and symptoms, and HPV.

### 2.3. Focus groups

The focus groups were led by an experienced female moderator (MLK), and field notes of salient points and group dynamics were recorded by a staff member. We conducted focus groups until attaining information saturation. The focus groups were conducted during the Summer of 2007 and all focus groups lasted approximately 1 h and were audio recorded. All focus groups' discourse was transcribed verbatim, and the transcripts were reviewed for accuracy. The participants received a \$25 gift card to Walmart for appreciation of their time and a \$5 gift card to a local gasoline station to cover travel expenses.

### 2.4. Data analysis

Research team members (MLK, PR, SH) read all transcripts of the focus groups. A coding tree was developed and all three members of the research team coded the same focus group transcript, reviewed differences, and reached a consensus [35]. A revised coding tree was used to code all transcripts using NVivo qualitative software (QSR International Pty. Ltd.) to aid in classifying, sorting, and categorizing data. Focus group transcripts were examined for themes within each type of focus group and across the different types of focus group. Quotations were selected to illustrate the various issues that emerged from each major theme. For each participant, the total number of correct answers was summed on the knowledge quiz. Comparisons across group means were conducted using an ANOVA test (SPSS, Version 16).

## 3. Results

### 3.1. Participant characteristics

Twenty-three focus groups were conducted with 112 participants (Table 2). In addition, we conducted an in-depth interview on two occasions when only one person arrived for the focus group. The focus groups and interviews were conducted in 9 of the 29 Ohio Appalachia counties and participants ( $n = 114$ ) were residents of 14 different Appalachian counties. Participants included 37 healthcare providers (nurses, pediatricians, pharmacists, and a gynecologic surgeon) in 6 groups and one in-depth interview, 31 community leaders (church leaders, health agencies) in 6 focus groups, 19 parents in 6 focus groups, and 27 women in 5 focus groups and one in-depth interview. Most participants ( $n = 106$ ) were white and non-Hispanic ( $n = 111$ ). Approximately one-third of the parents and women who participated in the focus groups had not completed high school.

The healthcare providers mean score on the short knowledge quiz (14 items) was 11.2, which was significantly higher than the community leaders (8.9;  $p = 0.018$ ), women (7.2;  $p < 0.001$ ), and parents (6.6;  $p < 0.001$ ).

### 3.2. Themes

Major themes emerged from the data collected from the different focus groups: barriers (Table 3), knowledge (Table 4), attitudes and beliefs (Table 5), and suggestions for educational materials and programs.

#### 3.2.1. Barriers

Many barriers to acceptability of the HPV vaccine were identified by the different focus groups. General healthcare issues raised

**Table 1**

Components of the Social Determinants of Health (SDH) framework included in the focus group guides.

Section of focus group guide	Component of SDH framework	Examples of questions
Appalachian culture	Social environment/culture	What are the biggest health challenges for young women who live in your community? What types of communication about the HPV vaccine are going on in your county? Are there groups in your community that support or would not support HPV vaccine use?
Risky behaviors and cervical cancer	Health behaviors	How concerned are young women in your community about becoming infected with HPV? Does the fact that the HPV is sexually transmitted affect the decision to get the HPV vaccine? Do you believe that abstinence programs are a way of preventing HPV in your community?
Cancer screening, HPV vaccine acceptance	Culture, psychology	Do doctors in your community provide the HPV vaccine? Has your doctor discussed the HPV vaccine with you? What important issues associated with accepting the HPV vaccine would be important to include in an educational program in your community?
Healthcare access, utilization, and trust	Material factors, social environment	How do you currently receive most of your health information? Are there things about the HPV vaccine that concern young women in your community? (cost, safety, etc.) Do you think the HPV vaccine should be mandatory young girls?

HPV: human papillomavirus.

**Table 2**Characteristics of human papillomavirus (HPV) vaccine focus group participants.<sup>a</sup>

	Healthcare providers (n = 37)	Community leaders (n = 31)	Parents (n = 19)	Women (n = 27)
Age (years)				
Mean (S.D.)	48 (10)	48 (10)	36 (5)	23 (2)
Range	30–72	21–69	26–47	19–26
Race				
White, non-Hispanic	33	22	16	25
White, Hispanic	0	0	1	1
Black, non-Hispanic	0	4	0	0
Marital status				
Single	0	7	4	16
Married	30	21	11	11
Separated/divorced/widowed	6	3	4	0
Education				
<High school	0	0	6	10
High school	3	10	5	10
>High school	33	21	7	7
HPV knowledge score (0–14)				
Mean (S.D.)	11.2 (2.1) <sup>b</sup>	8.9 (2.5)	6.6 (3.9)	7.2 (4.2)
Range	6–14	4–13	0–14	0–14

S.D.: Standard Deviation.

<sup>a</sup> Note: Frequencies may not sum to sample size total due to missing data.<sup>b</sup> Healthcare providers had significantly better HPV knowledge scores than community leaders ( $p = 0.018$ ), parents ( $p < 0.001$ ), and women ( $p < 0.001$ ).**Table 3**

Human papillomavirus (HPV) vaccine barriers by focus group type.

Barriers	Healthcare providers <sup>a</sup>	Community leaders <sup>a</sup>	Parents	Women
Healthcare				
Healthcare access, adequate number of providers	+/-	+	+	+
Health insurance	+	+	+	+
Provider–patient communication	+/-	+/-	+/-	+/-
General social and cultural				
Teenage pregnancy rates are high, smoking is common and accepted, poverty rates are high	+	+	+	+
Poor parent–child communication	+/-	+/-	+/-	+/-
Financial issues				
Cost of vaccine, transportation	+	+	+/-	+
Child care				+
Concerns				
Lack of information about long-term effectiveness, side effects (short-term and long-term), recommendation is for young girls	+	+	+	+
Harm future reproductive capability	+	+	+	

(+: mentioned as a barrier; (-): mentioned as not being a barrier; (+/-): mentioned as being and not being a barrier; blank: not mentioned.

<sup>a</sup> Healthcare providers gave answers regarding their patients' barriers and community leaders' gave answers about community members' barriers.

**Table 4**  
Human papillomavirus (HPV) vaccine knowledge by focus group type.

Knowledge	Healthcare providers <sup>a</sup>	Community leaders <sup>a</sup>	Parents	Women
<b>Cervical cancer</b>				
Cancer rates are increased in Ohio Appalachia	+	+	+	+
Cervical cancer rates are increased in Ohio Appalachia	–	+/-	–	+/-
Risky sexual activity associated with cervical cancer	+/-	–	+/-	+/-
Tobacco associated with cervical cancer	+/-	+/-	–	+/-
Pap tests (what test is for, how often it should be done)	–	+/-	+/-	+/-
<b>HPV</b>				
HPV transmission, HPV and cervical cancer	–	+/-	+/-	+/-
HPV and genital warts	+/-	–	–	+
HPV taught in schools	+/-	+/-	–	–
<b>HPV vaccine</b>				
How vaccines work and logistics (who, when, where, costs, insurance coverage)	–	–	–	–
HPV vaccine if already HPV (+)			–	–
<b>Source of HPV vaccine information</b>				
TV commercial, Internet, family and friends	+	+	+	+
Brochures	+	+	+	+/-

(+): has knowledge; (–): does not have knowledge; (+/-): mentioned as having and not having knowledge; blank: not mentioned.

<sup>a</sup> Healthcare providers gave answers regarding their patients' knowledge and community leaders' gave answers about community members.

by the participants included lack of healthcare access, lack of health insurance, poor provider–patient communication, and not having time. These general healthcare barriers were identified by one participant who said *“I would say that in our community, a lot of people don't have access to health care. I mean, we have plenty of people in our community who don't go to a doctor. They don't have health insurance, and they don't take their kids. If they take their kids, they take them to urgent care.”*

All groups mentioned the importance of provider–patient communication, and depending on the participants' relationship with their healthcare provider, communication was identified as positive or negative. In addition, women reported being busy working and/or having family issues that caused them not to have the time to go for medical visits. Although participants in all focus groups mentioned that Appalachian residents had difficult life circumstances,

only healthcare providers and young women mentioned increased “stress” among residents.

Specific barriers to the HPV vaccine identified were the cost of the vaccine, the short and long-term side effects, and many social and cultural issues including the poor attitude toward preventive health, lack of privacy, and strong feelings of resisting government intrusion in their personal life. One participant who knew the cost of the HPV vaccine recalled *“My gynecologist offers the HPV vaccine but you have to pay \$135 up front and it is three shots, so you pay \$135 a piece for each shot and insurance does not reimburse you or cover it.”*

One issue that resonated with most participants was the concern about the lack of long-term research about the new vaccine and the concern that it may harm future reproductive capabilities of the young women. This concern was expressed by participants *“I*

**Table 5**  
Human papillomavirus (HPV) vaccine attitudes and beliefs by focus group type.

Attitudes and beliefs	Healthcare providers <sup>a</sup>	Community leaders <sup>a</sup>	Parents	Women
<b>Attitudes</b>				
Appalachians are proud, patriotic, religious, conservative, and have close knit family and communities	+	+	+	+
Do not value prevention, ignorant about health, encourage abstinence, HPV is a female stigma	+	+	+	+
Trust of medical community and “outsiders”	+	+/-	+	+
Many foreign-born doctors do not recommend/offer vaccines	+	+		
Healthcare providers are disrespectful	+/-		+	+
Suspicion of pharmaceutical companies		+	+	
Government intrusion (vaccine mandate)	+	+	+/-	+
Embarrassment associated with having cervical cancer, privacy is important, do not trust “outsiders”	+	+	+	
HPV vaccine promotes promiscuity	+	+	+	–
Women put themselves last on the list, use home remedies	+	+		
Stress	+			+
<b>Beliefs</b>				
Cervical cancer is hereditary, vaccines in general are accepted, HPV vaccine implies being sexually active, sex should be associated with marriage, do not like being told what to do	+	+	+	+
Not going to happen to my daughters/myself, medical problems linked to vaccines (autism), abstinent women do not benefit from vaccine	+	+	+	
Fear of cancer/fatalism	+	+		+
Sexually active women should not get the vaccine	+	+		+/-
Cervical cancer is caused by an environmental issue (water, air)	+		+	+
Cervical cancer is a “dirty” disease		+		
Vaccine if previous STI (HPV or other), abnormal Pap test			+	+

Pap: Papanicolaou. (+): mentioned as an attitude or belief; (–): mentioned as not having an attitude or belief; (+/-): mixed messages about attitudes or beliefs; blank: not mentioned.

<sup>a</sup> Healthcare providers gave answers regarding their patients' attitudes and beliefs and community leaders' gave answers about community members' attitudes and beliefs.

would want to make sure that there have been enough studies done on this vaccine that she would be not be having other health issues in the future if she decided to have children or later on her life” and “. . . that’s what I’m saying; is it going to have effects on her child rearing years if she does this now at this young age?” Another issue that was raised often by the different groups was that the vaccine was being recommended for very young girls. One participant stated “I’ll say the one thing and I consider myself pretty open-minded and liberal, and I would have a hard time having my nine-year-old vaccinated. That just seems to me. . . I mean, I know. . . that seems so young. I know why you’re doing it and how important is at that age to get them protected that early but nine just seems so young for me. And so whenever I see nine I’m like aw! That’s just, you know, my reaction to it.”

### 3.2.2. Knowledge

Most groups discussed the general lack of knowledge about cervical cancer, HPV, and the HPV vaccine among the Appalachian population. Although individuals living in Ohio Appalachia are aware of the high cancer rates that exist in their communities, members of the focus groups discussed the high rates of lung, breast, and colon cancer as being a problem in their communities. As one participant stated “. . . I think they focus on other types of cancer and not this in particular, but breast cancer is so high everywhere.” Several participants attributed the limited educational materials and programs about cervical cancer prevention to the fact that it addresses the part of a women’s body that is not discussed in public. One participant discussed this issue and said “I think they perceive it as a dirty disease to be honest with you.”

Most groups reported becoming aware of HPV and the fact that it is a STI because of discussion about the HPV vaccine. Focus groups of women and providers, however, also mentioned the association between HPV and genital warts. Most groups discussed that the population did not know how vaccines work, the logistics about the HPV vaccine, and if the HPV vaccine should be obtained if a woman has a history of HPV or another STI. The most common source of information about the HPV vaccine mentioned was a TV commercial and by word of mouth (family and friends). One participant became aware of the HPV vaccine because “My little girl goes around and does that ‘One less I want to be one less.’ I think because she thinks it is a cheer on TV because it’s just a catchy little phrase that she walks around when it’s on.” Another participant thought that the TV commercial for the vaccine started conversation about cervical cancer “Before they wouldn’t know, but then you start to see that commercials on TV all the time then you start thinking.”

After hearing about the HPV vaccine, many people reported finding additional information about the vaccine by using the Internet. One healthcare provider stated “Our age group is, well, we do get some 17-year-olds, but I would say 18 to 23; and yes, they go to the internet.” Another important point about the Internet was raised by one participant who thought that many young women and their parents have poor communication about certain health topics stated, “I think maybe because they can read it again, if their parents make a big deal, in privacy then they can really read that.”

### 3.2.3. Attitudes and beliefs

Many of the attitudes and beliefs about the HPV vaccine mentioned by the various focus groups centered on the fact that individuals living in Appalachia are proud, religious, and come from a very conservative community. This cultural issue was captured by one community leader who stated “Most churches in our community are teaching abstinence. So there would be no reason for them to feel it necessary to vaccinate girls against HPV.” Focus groups of parents and community members mentioned belief that the HPV vaccine would increase sexual promiscuity, and healthcare providers mentioned that this belief is often raised by parents of young girls.

Many of the barriers associated with the HPV vaccine addressed the above mentioned social and cultural issues. Many participants shared their attitudes and beliefs about these topics and additional cultural issues raised during the discussions included: (1) the family and community are close-knit and central, “Multigenerational, everyone raises the family: aunts, you know, grandma, uncles, the person down the street that’s known them all their lives, and they call me up and they’re no relation. I mean honestly, it’s a different culture.” The need to have multi-generational input for medical decisions takes more time and often makes it more complicated because of differences of opinions among the many family members. Another participant suggested that the best way to promote the HPV vaccine among the Appalachian community would be to “Go educate grandma,” (2) the importance of privacy, “So I remember my mom being upset because she thought. . . she’s a nurse too and this is when the HPV vaccine was just coming out. She thought that it was just given to the girls who are sexually active. And my sister is not. . . so my sister was upset because she thought, oh my gosh, everybody would think she is sleeping around. And you know my mom was upset because she thought my daughter’s not sleeping around,” (3) lack of preventive health behaviors as voiced by one healthcare provider “Trying to get that message of prevention and screening. It’s still a slow, slow process,” and (4) the HPV vaccine promotes promiscuity. “That’s kind of what I am hearing from the people who are asking me generally. You know, do you think I should promote this with my daughter and then if she gets it is that going to be telling her that she can have as many partners as she wants because she is not going to get cancer?”

A few other interesting topics emerged from several of the focus groups. Several focus group participants mentioned that many Appalachian residents believe that cervical cancer is hereditary or caused by environmental carcinogens in the air and water. Another theme that emerged was the lack of trust of the medical system, including healthcare providers from outside the community, and suspicion of the pharmaceutical companies using young women as guinea pigs for the HPV vaccine. One community leader summed this feeling up as “I do think it’s also true that a lot of people and within good reason are suspicious of the drug companies right now. And so whatever the drug companies come out with, whether it’s true or not true, we are all going to be questioning it a lot.” Another topic that emerged was that only girls were being blamed for HPV by targeting the vaccine only towards young girls. One participant stated “And also the vaccine is for girls. Again, it’s always the women. It is more of a stigma for women or for young girls.”

## 3.3. Educational materials and programs

### 3.3.1. Format

Suggestions for educational materials included using a low reading level, large print, and using a limited amount of text. Suggestions for HPV vaccine educational programs included having a female healthcare provider, preferably a nurse, facilitate the educational programs. In addition, having someone from the community and not an “outsider” was also mentioned as being important for the program’s success.

### 3.3.2. Content

Focus groups strongly suggested that educational materials and programs provide: (1) factual information about HPV and the HPV vaccine including the transmission process, local cervical incidence and mortality rates, and how the vaccine works, and (2) logistical information about the vaccine including who should get the vaccine, where in the county someone could get the vaccine, how much it costs, and insurance coverage, etc. One participant stated “I don’t think that I would not include anything because I think the people that are less educated and poor, I think they get offended when you keep things from them and treat them like they are. . . you know, just because



they are less educated and poor doesn't mean that they don't care as much about their children."

In addition, participants emphasized the importance of educating both parents and children about the HPV vaccine, however, many participants were adamant that parents should be informed about the HPV vaccine before their children were told about the vaccine. One participant expressed *"But I also think that you have to take the parents into consideration too. I am a firm believer that I never want my daughter or granddaughter to be taken into a room and be told things that I did not have any partaking into the conversation with her."*

Other important suggestions were made by participants in different types of focus groups. Young women who were finding it difficult to raise the issue of HPV vaccination with their parents suggested that we provide advice about how to talk to your parents about the HPV vaccine. *"... maybe putting in some how to talk to your parents or how to address this issue to your parents. OK, you could bring it up this way or you could bring it up this way."* Healthcare providers and community leaders mentioned the importance of ongoing cervical cancer prevention so that women should continue to undergo cervical cancer screening according to recommended guidelines. Many focus groups expressed the need to provide stories about women who have HPV or cervical cancer in an educational program, *"I think they would probably be more likely to listen to what a peer would say or somebody their, more their own age,"* and the need for one-to-one sessions may be important because of the importance of privacy (or mother–daughter events).

### 3.4. Focus group differences

Although many of the topics discussed among the focus groups were similar, there were some distinct differences depending on the type of group. One interesting difference among healthcare providers was seen in those who mentioned that in their interactions with patients it appeared that many Appalachian residents were burdened with the feeling of being hopeless, or "stuck in the story." One provider remarked: *"Life in general. I mean, I take care of people who have to choose whether to buy groceries or buy medicine, I mean on a regular basis, and you have to work with them when doing diet teaching because, rice, pasta and potatoes are cheap and vegetables are expensive. . . They're stuck in this rut. That's the way their parents did and their grandparents did."* Healthcare providers also acknowledged that many of their patients are under a lot of "stress" and this was confirmed by several young women. One woman stated: *"There's nothing here, you know what I mean. There's no jobs. Nothing really for your kids to have. I don't like taking my kids to my yard. I refuse to take my kids outside. I don't feel safe."* Healthcare providers and community leaders also mentioned that many residents use home remedies instead of seeking medical care and that some doctors practicing in Ohio Appalachia do not recommend vaccines. In addition, healthcare providers were the only type of group that did not mention the importance of explaining how vaccines work or the pros and cons of HPV vaccination as part of educational programs.

## 4. Discussion

To our knowledge, this is the first study to provide information regarding the HPV vaccine acceptability at the individual and community level by including four groups representing healthcare providers, community members, parents, and women from the same geographic region. Overall, there were many similar issues raised among the women, parents, community leaders, and healthcare providers. HPV vaccine-related issues mentioned by focus group participants were: (1) the general lack of knowledge about

cervical cancer, HPV, and the HPV vaccine, (2) HPV vaccine barriers including limited healthcare access, lack of health insurance and time, the cost of the vaccine, and concern about the short and long-term side effects of the vaccine, (3) cultural attitudes and beliefs that focus on the close knit and conservative nature of the community and the importance of privacy, (4) the attitude that the HPV vaccine promotes promiscuity, (5) belief that cervical cancer is hereditary or caused by environmental factors, and (6) lack of trust of the medical community, individuals from outside the community, and the pharmaceutical companies.

In addition, all groups emphasized the need for educational materials and programs to be developed for both parents and women living in Ohio Appalachia. Although many suggestions focused on the content of the educational materials and programs, a few suggestions were made related to the unique cultural attitudes of individuals living in Appalachia. For example, since privacy and lack of trust of outsiders are significant issues, many groups suggested conducting one-on-one educational sessions by trusted healthcare providers from within the community. Another idea was to include "grandma" in the educational programs to address the multi-generational component of the Appalachian culture. These suggestions address important and distinct cultural factors, but also have significant cost implications for developing cervical cancer prevention campaigns aimed at increasing HPV vaccination rates in this geographic region.

There were differences among and between the types of focus groups. Some of the differences cited by the groups were: (1) only young women mentioned child care as a healthcare barrier; (2) all groups except young women mentioned that individuals were concerned that the HPV vaccine may endanger future reproductive capabilities, the lack of privacy, and the embarrassment associated with cervical cancer; (3) young women reported being under a lot of "stress" because of the lack of education, children, and lack of having a job; (4) healthcare providers reported that they thought that many of their patients had "stress" in their life and felt hopeless; and (5) healthcare providers and community leaders reported that women continue to put themselves last on their lists and use home remedies before visiting a healthcare provider.

Differences were also reported for educational materials and programs. For example, young women suggested including strategies to help them talk to their parents about the HPV vaccine. All groups except the healthcare providers suggested including information about how the HPV vaccine works and to list the pros and cons about the vaccine, while all groups except the young women suggested including the importance of ongoing cervical cancer screening. In addition, suggestions for the placement of educational materials and venues for educational programs differed between groups.

Results of this study highlight the complexity of developing educational materials and programs targeting the HPV vaccine for different (women, parents, children, healthcare providers) constituents living in the same geographic region. Previous research focusing on the acceptability of the HPV vaccine usually included only groups of individuals (e.g. providers, parents, or adolescents) [18–32]. Findings from this study corroborate findings from previous studies indicating that there is a lack of knowledge about HPV and its association with cervical cancer, but there is an overall acceptance of the HPV vaccine as a cancer prevention tool; however, at the same time there are concerns about the HPV vaccine's safety and efficacy, the young age for the vaccine recommendation, as well as the element of stigma associated with an STI-related disease.

### 4.1. Limitations

Focus groups by design have certain limitations [36]. The findings cannot be generalized to all women, parents, community

leaders, and healthcare providers living in Ohio Appalachia or other Appalachian states. We tried to minimize this limitation by conducting focus groups throughout the Ohio Appalachia region and by using community-based strategies to recruit participants. Individual responses in the focus groups might have been influenced by the group discussion or by a participant who dominated the conversation. This limitation was minimized by using an experienced focus group moderator.

In several of the focus groups, participants may have had a different perspective because they have treated patients with cervical cancer or abnormal Pap tests, had a friend or family member diagnosed with cervical cancer, or had an abnormal Pap test in the past. Although this personal experience may have influenced the focus group discussion, capturing all perspectives about cervical cancer prevention using the HPV vaccine is important for the development of educational materials and programs.

#### 4.2. Strengths

The strengths of this study included using community cancer coalition members to assist with recruiting community members for the focus groups, thus enabling us to include a large number of residents from throughout Ohio Appalachia. To minimize differences among groups because of technique, one individual facilitated all focus groups and the focus group guide had similar questions that were framed appropriately for each type of focus group. For example, young women were asked about their barriers to receiving the vaccine, parents were asked about barriers to having their children vaccinated, healthcare providers were asked about their barriers to providing the vaccine and about their patients' barriers to receiving the vaccine, and community leaders were asked about the HPV vaccine barriers that were being discussed in the community. This allowed us to document important variations in perspective about the HPV vaccine from different groups even though they live in the same geographic region. In addition, we conducted focus groups until there was information saturation, and several members of the research team assisted with data analysis so that themes identified were not limited to one individual's opinion.

#### 5. Conclusions

Findings from this study suggest that there are significant barriers, lack of knowledge, and cultural attitudes and beliefs that must be considered when developing educational materials and programs to increase HPV vaccination rates among women living in Ohio Appalachia. This study also draws attention to similarities and differences between groups of individuals residing in the same community, highlighting the need for comprehensive and understandable HPV vaccine educational materials and programs about cervical cancer prevention to underserved populations, especially rural populations.

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