



## 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<sup>®</sup>), 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

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