



Published in final edited form as:

J Community Health. 2017 April ; 42(2): 400–412. doi:10.1007/s10900-016-0269-4.

Diverse Families' Experiences with HPV Vaccine Information Sources: A Community-Based Participatory Approach¹

Djin Lai, BSN, RN^{1,2}, Julia Bodson, BS¹, France A. Davis, MMC, MMin^{3,4}, Doriena Lee^{3,5}, Fahina Tavake-Pasi, MS^{3,6}, Edwin Napia^{3,7}, Jeannette Villalta^{3,8}, Valentine Mukundente, BA^{3,9}, Ryan Mooney, BS¹, Heather Coulter, MEd¹⁰, Louisa A. Stark, PhD^{11,12}, Ana C. Sanchez-Birkhead, PhD, WHNP-BC, APRN^{3,13,14}, and Deanna Kepka, PhD, MPH^{15,16}

¹Research Assistant, Cancer Control and Population Sciences, Huntsman Cancer Institute, Salt Lake City, UT

²PhD Student, College of Nursing, University of Utah, Salt Lake City, UT

³Community Leader, Community Faces of Utah, Salt Lake City, UT

⁴Pastor, Calvary Baptist Church, Salt Lake City, UT

⁵Member, Calvary Baptist Church, Salt Lake City, UT

⁶Executive Director, National Tongan American Society, Salt Lake City, UT

⁷Youth Programs and Special Project Manager, Urban Indian Center, Salt Lake City, UT

⁸Wellness Coach, Hispanic Healthcare Task Force, Salt Lake City, USA

⁹Executive Director, Best of Africa, West Valley, UT

¹⁰Community Liaison, Community Outreach and Collaboration Core, Center for Clinical and Translational Science, School of Medicine, University of Utah, Salt Lake City, UT

¹¹Co-Director, Community Outreach and Collaboration Core, Center for Clinical and Translation Science, School of Medicine, University of Utah, Salt Lake City, UT

¹²Research Professor, Department of Human Genetics, School of Medicine, University of Utah, Salt Lake City, UT

¹³Associate Professor, College of Nursing, University of Utah, Salt Lake City, UT

¹⁴President, Hispanic Health Care Task Force, Salt Lake City, UT

¹⁵Assistant Professor, College of Nursing, University of Utah, Salt Lake City, UT

¹**Acknowledgements:** The authors wish to acknowledge Guadalupe Tovar, Echo Warner, Ivoni Nash, & Maria Borrerero who helped with the facilitation and organization of the focus groups, Alfonse, Esperance, Paul and Cecilia from Best of Africa who assisted with the translations, and the families who participated in this research. The authors also wish to acknowledge the late Sylvia Rickard, former executive director of the Hispanic Health Care Task Force and a key contributor in the early phases of this study; and Grant Sunada from the University of Utah and Brenda Ralls from the Utah Department of Health who also provided valuable feedback during the research process. The last author was funded by a grant from the Primary Children's Hospital Foundation and an award from the National Center for Advancing Translational Sciences from the National Institutes of Health under Award Number KL2TR001065. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Address correspondence to: Djin Lai, Cancer Control and Population Sciences, Huntsman Cancer Institute, 2000 Circle of Hope, Room 4127, Salt Lake City, UT 84112, USA., Office: 801-213-5691, fax: 801-585-7477, Djin.Lai@hci.utah.edu.

¹⁶Investigator, Huntsman Cancer Institute, Salt Lake City, UT

Abstract

Current sources of publicly available human papillomavirus (HPV) information may not adequately meet the needs of diverse families. This study sought to describe associations between sociodemographic and acculturation factors, and sources of HPV information among diverse parents and caregivers. Community organizations purposively recruited participants from African American, African refugee, Hispanic/Latino, American Indian, and Native Hawaiian and Pacific Islander communities for a 21-item survey ($N=228$). 93 of these participants also participated in 10 focus groups conducted in three languages. Descriptive statistics and Fishers' Exact Test for Count Data were produced and triangulated with focus group data to provide additional context. Overall, HPV vaccine awareness and knowledge in the five communities was low. This study found that a greater proportion of lower-acculturated participants had heard of HPV through personal networks (foreign-born=50% vs US-born=30%, $p<0.05$; medium acculturation=60% vs high acculturation=26%, $p=0.01$), while greater proportions of US-born participants reported media sources (49% vs foreign-born=29%, $p<0.05$). Across communities, healthcare system sources were described as important and preferred sources of HPV information. Hearing about the HPV vaccine from healthcare settings was significantly associated with increased accuracy in HPV vaccine knowledge ($p<0.05$). Communities described a need for more in-depth information about the HPV vaccine, and culturally and linguistically appropriate educational materials. Culturally-competent delivery of HPV information through the healthcare system sources may be important in improving knowledge and acceptability of the HPV vaccine among diverse families.

Keywords

Papillomavirus vaccines; adolescent health; culturally competent care; community-based participatory research; consumer health information

Human papillomavirus (HPV)-associated cancers affect 33,200 individuals annually [1]. Analyses of population level data have found that rates of HPV-associated cancers such as anal, vulvar, vaginal, and oropharyngeal cancers are on the rise and are higher in the African American population [2]. In addition, cervical cancer, which is disproportionately higher in the Hispanic/Latino population, has decreased for all racial/ethnic groups except for the American Indian/Alaskan Native (AI/AN) population [2].

Public knowledge and awareness about infections is generally low [3]. Racial and ethnic communities may be at greater risk for lower knowledge and awareness of HPV and HPV-associated cancers and conditions [4–8]. Despite the availability of an efficacious and safe vaccine [9–11], lower knowledge about the HPV vaccine remains a barrier to vaccination uptake in the AI/AN, African American, Native Hawaiian and Pacific Islander (NHPI), and Hispanic/Latino communities [4, 6, 12–15].

Non-healthcare system sources of HPV vaccine information such as health-related websites and print and television advertisements may have greater visibility and accessibility compared to healthcare system sources of information. Exposure to media advertisements

have been reported as the most common format of HPV vaccine information associated with vaccine awareness among parents [13]. Engagement in researching HPV vaccine information online has been associated with greater parental knowledge, intention to vaccinate female adolescents, and acceptability of the vaccine [16]. Moreover, use of multiple sources for HPV vaccine information may improve perceptions of the vaccine and encourage parents to vaccinate their adolescents [17]. However, the majority of publicly available HPV vaccine information is in English. Those with limited English proficiency may have difficulty obtaining accurate, in-depth information about the HPV vaccine [18, 19].

Few studies have examined how diverse communities receive and seek HPV information. No studies have done this in Utah, a state with low HPV vaccination rates [20]. The purpose of this study was 1) to describe the associations between sociodemographic and acculturation characteristics and exposure to sources of HPV information among diverse parents and caregivers, and 2) to examine the association between these sources and HPV vaccination knowledge.

Methods

This community-based participatory research (CBPR) study was reviewed and approved by the University's Institutional Review Board (IRB). In this study, researchers, community members, and organizational partners were active collaborators in all stages of research, and were jointly responsible for the conduct and products of the research process in accordance with CPBR principles [21].

This research was conducted in collaboration with the Community Faces of Utah (CFU), an organizational partnership consisting of five diverse community groups, the state Department of Health, and the Collaboration and Engagement Team of the Center for Clinical and Translational Science at the University of Utah. The ethnic groups represented were the African American, African refugee, AI/AN, Hispanic/Latino, and NHPI communities.

CFU community leaders provided vital feedback and actively participated in the development of the survey instrument and focus group questions. They also recruited all participants for the focus groups and surveys, planned and co-facilitated the focus groups, provided cultural interpretation for the findings, and participated in presenting findings at conferences.

Research design

This descriptive cross-sectional study utilized a quantitative-dominant, concurrent triangulation mixed method design in which quantitative and qualitative data were collected simultaneously in the first phase of the study [22], and additional quantitative data were collected in a second phase of the study. Data consisted of self-reported measures in a survey and audio-recorded semi-structured focus groups.

Survey

A 21-item survey instrument was developed based on an internal review of the literature and community leaders' input. The survey collected basic demographic data, acculturation indicators such as place of birth, and language-based acculturation characteristics based on an adapted five-item language subscale of the Marin's Short Acculturation Scale for Hispanics (SASH) [23]. The language subscale has demonstrated higher correlation with other acculturation indicators compared to the overall scale [24]. While the SASH has not been validated in the four other racial groups in this study, the SASH demonstrated reliability and validity when adapted for Korean [25] and Filipino immigrants in the US [26]. Data on participants' knowledge, awareness, perceptions, and usage of the HPV vaccine and sources of HPV vaccine information were also collected.

Spanish versions of the study documents were developed for the Hispanic/Latino community. As the majority of the African refugees did not read their native language, Kirundi, an English version of the survey was read aloud to participants by community translators. Responses were color-coded to facilitate the selection of appropriate answers.

Participants and Settings

After obtaining IRB approval, the five CFU leaders and their associates purposively recruited participants within their communities from May 2014 to October 2014 for ten 60–90 minute long focus groups; two focus groups were held by each of the five communities. Recruiters then conducted rolling purposive recruitment for additional surveys in their communities from October 2014 to February 2015.

Parents, legal guardians, or caregivers (18 years or older) who were vaccination decision-makers for children aged between 11 and 17 years and members of the five CFU communities were eligible to participate. Individuals who participated in the focus groups received a \$25 gift card for their time. Participants who completed the survey but did not participate in the focus groups received a \$15 gift card.

Ninety-three participants attended 10 focus groups and completed surveys within a focus group session in Phase 1. An additional 135 participants completed only surveys in a second phase of data collection. $N=228$ surveys were administered over the course of the study.

First Phase of Data Collection- Focus groups with Surveys

At the beginning of each focus group session, facilitators and community translators verbally translated surveys for participants who were unable to read English or Spanish (i.e. some Tongan and most African refugee participants). AI/AN, African American, most NHPI, and Hispanic/Latino participants filled out the surveys independently. After completion of the survey, participants were invited to participate in the subsequent focus group.

A cancer patient navigator with experience in facilitating focus groups about the HPV vaccine in diverse communities led focus groups. This facilitator was assisted by either a community leader or a trusted community member, who helped build trust and rapport

between the research team and the participants, facilitated understanding of the questions within a cultural context, and provided translation where necessary.

Focus group questions asked participants where or from whom participants received cervical, HPV, or HPV vaccine information, how they sought answers about health questions, and what their preferences were for health information pertaining to these topics. Each focus group was digitally audio-recorded, and research team members took notes of focus group interactions. Audio files were transcribed by external transcription agencies, which also provided Spanish and Kirundi translations. Quotes from focus groups were discussed with community leaders for appropriateness and authenticity of cultural interpretation.

Second phase of data collection- Surveys only

Community recruiters continued to collect survey data in a second phase of data collection. With the exception of the African refugee group, which was administered similarly to phase 1 methods, all surveys were self-administered. Community translators clarified questions from participants throughout the group-administered survey process.

Analytic strategy

Survey data, together with free text responses, were condensed into three categories of HPV vaccine information sources, 1) *Personal Network*, 2) *Media*, and 3) *Healthcare System* sources, and analyzed with Fisher's Exact Test for Count Data to compare distributions between caregivers who had and had not heard of the HPV vaccine through each information source. To avoid overfitting, multivariable regression analysis was not conducted. For all analyses, p -values of < 0.05 were considered significant. All statistical analyses were performed using R-2.15.1. Caregivers' perceptions and experiences with information sources regarding the HPV vaccine were analyzed using an interpretive description approach [27]. The transcripts of the focus groups were read by the research team recursively in order to become sensitized to the data, guided by the research question, "What are participants' experiences and perceptions of each of the three types of sources of HPV vaccine information?" The focus group data were then triangulated with the survey data.

Results

Participant characteristics

A total of 228 participants completed surveys, the majority of whom were 35–50 years old ($n = 148$, 64.9%), female ($n = 162$, 71.1%), and married or living as married ($n = 174$, 76.3%). Almost two-thirds were immigrants; however, there was a fairly even distribution across English-usage levels (18.9% "low," 31.6% "medium," 26.8% "high"). Just over half of the participants had health insurance ($n = 127$, 55.7%). Slightly under half of participants reported being aware of the HPV vaccine ($n = 106$, 46.5%). Participants' sociodemographic characteristics are reported in Table 1.

Healthcare system sources (HSS) of HPV vaccine information

Summary data on the types of HPV information sources are reported in Table 1. HSS identified in the survey included physicians, nurses, and school health providers, as well as brochures or posters located in the clinical setting; this was the most common source of HPV vaccine information. In focus groups, participants most commonly reported receiving HPV vaccine information from a healthcare provider when they took their child to a well-child check-up. While a majority of participants who had heard of the HPV vaccine had heard of it through HSS ($n = 72$, 67.9%), Fisher's Test for Count Data found no significant differences in socioeconomic, healthcare, or acculturation characteristics among these participants (see Table 2). When asked about sources from which they would prefer receiving information about the HPV vaccine, the majority of participants mentioned healthcare providers, "I would say if it's coming from your physician, you're definitely going to trust it."

Having a positive encounter with a healthcare provider enabled some of the participants with limited English proficiency to access HPV information, as described by an African refugee mother, "So he [doctor] takes his time to explain to me and gave me a book about it or something to read about it... [and] he did tell me he recommend that for her."

Associations between HPV information from HSS and knowledge of HPV, HPV vaccine, and cervical cancer—

HSS was significantly associated with higher proportions of correct HPV vaccine administration knowledge. Higher proportions of participants who correctly answered that the HPV vaccine was not given in a single dose (55.7%, vs. 29.4%, $p = 0.01$), or that the ideal age for girls (77.5% vs. 47.1%, $p < 0.01$) and boys (68.1% vs. 32.4%, $p < 0.01$) to receive the HPV vaccine was between 11 and 12, reported receiving HPV information from HSS compared to non-HSS (Table 3). However, knowledge about cervical cancer and HPV, such as knowing that HPV can cause cervical cancer, or that HPV infections are often asymptomatic, was not associated with receiving HPV information from HSS.

Focus group data also found that while some participants reported receiving basic knowledge of the HPV vaccine through their healthcare provider, few had in-depth knowledge about the vaccine. For example, some of participants were not aware that the vaccine was recommended for boys as well. Additionally, several limitations of HSS-delivered HPV information were identified in the focus groups. An African American mother commented, "Doctors have such limited time with you as is, so you're not going to get that in-depth information that you're looking for." The perceived inadequacy of face-to-face communication with providers led some to seek information through other channels. A participant in the African American community expressed: "I'd rather have it [HPV vaccine information] in brochures...I want it sitting in front of me so when I sit down, I can check the facts and then make an educated decision on what I'm going to do."

Non-healthcare system sources of HPV vaccine information

Other sources of HPV information exposure identified in the survey included personal networks (PNS; $n = 43$, 40.6%) and media sources (MS; $n = 41$, 38.7%; Table 1). PNS of

HPV information included friends, families, and community organizations such as churches; while MS included the internet, television, radio, magazines and newspapers, and billboards.

Personal Networks and HPV information—Bivariate analyses found that acculturation characteristics such as place of birth, years spent in the US (for immigrants only), parents' place of birth, and language acculturation were significantly associated with HPV information received from PNS. Among those who had heard of the HPV vaccine, lower proportions of participants born in the US (29.8%) reported hearing about the HPV vaccine through PNS compared to those born in other countries (50.0%, $p < 0.05$; Table 2). Similarly, lower proportions of participants whose parents were born in the US (23.3%) reported receiving HPV information from PNS compared to participants whose parents were born in other countries (45.2%, $p < 0.05$; Table 2). Among immigrants, higher proportions of participants who had lived in the US for 20 or more years (72.7%) had received HPV information from PNS compared to 37.5% of participants who lived in the U.S. for less than 20 years ($p = 0.01$; Table 2). In addition, lower proportions of participants with higher self-reported English use (26.2%) also reported receiving HPV vaccine information from PNS compared with those with medium (59.4%) and lower English use (50.0%, $p = 0.01$; Table 2).

Focus group data suggested that PNS information exposure was linked to anecdotal reports of side effects experienced by relatives' and friends' children. A participant reflected:

I had a neighbor [whose] son became sick after he had been vaccinated. But it wasn't just a regular cold- he became disabled. They attributed it to the vaccine. So I always was apprehensive to do the vaccinations. I still did them, but with a lot of hesitation and I asked a lot of questions when I went in. – *NHPI mother*

Some participants started looking for HPV information after knowing someone with cervical cancer. A Hispanic/Latino mother stated, "I heard from my family in Mexico that one of my relatives had that disease and they told me, 'she doesn't want to go to the doctor, she doesn't want anything.' And I just thought, 'what is this? What is this virus?'" This knowledge sometimes led to negative perceptions regarding cervical cancer. A mother from the AI/AN community stated,

I believe three people in my world- friends and family- have actually had cervical cancer. I'm wondering if there is some shame about that, then. It has been caused by the HPV...when I got a little bit more information, I thought that's maybe what it is. It's shameful. – *AI/AN mother*

Media Sources and HPV information—In quantitative analyses, place of birth was the only characteristic associated with receiving HPV vaccine information from MS, with higher proportions of US-born participants reporting receipt of HPV information from MS (48.9%) compared to foreign-born participants (29.3%, $p < 0.05$). Several participants in the AI/AN, NHPI, and a few from Hispanic/Latino communities reported receiving HPV vaccine information from billboards, radio and television commercials. Focus group data provided additional context. Many who reported seeing information about the HPV vaccine through billboards and advertisements commented that these sources provided less information

value, or failed to hold their attention, “[I know] only what I’ve seen on the commercials, that we should really consider having our teenagers vaccinated, [but] it’s kind of vague.”

Participants with higher English proficiency such as African American, NHPI and AI/AN parents and caregivers reported using the internet frequently for health information in the focus groups,

Yeah. I’m a huge internet Googler. So I’ll get on the internet, and I’ll check several different websites just to make sure that the information is consistent. So like Web MD and all those, and I’ll do blogs and research stuff because, if you get the medical opinion as well as other people’s opinions, it helps a lot. – *African American mother*

Due to the limitations in accessing in-depth information from healthcare providers, the internet was often seen as a valid, accessible, and convenient source of HPV information to complement information from a healthcare provider.

Associations between HPV information from non-HSS sources and knowledge of HPV, HPV vaccine, and cervical cancer—Quantitative analyses of the survey data found that non-HSS information were not significantly associated with any items related to correct knowledge about HPV and the HPV vaccine; results are described in Table 3. Focus group data supported these results, as reflected by the many questions about HPV and the HPV vaccine generated in the focus groups, and the need to clarify misunderstandings about both the virus and the vaccine in question-and-answer sessions that followed the focus groups, particularly among those who had not yet vaccinated their children against HPV.

Discussion

Less than half of the participants in this study had heard of the HPV vaccine, suggesting low baseline HPV vaccine knowledge in these communities. This finding is in line with studies that found greater needs for HPV vaccine education among young Hispanic/Latino and African American women [28], native populations [12], and other low-income and racially diverse populations compared to the majority population [5, 29].

Although the HPV vaccine is projected to significantly reduce the risk of death from HPV-associated cancers, disparities in these cancers will continue if underlying issues such as access to the vaccine persist [30]. A vital first step to improving access to the HPV vaccine in diverse populations is to improve understanding of this important and widely available vaccine.

This study also found that among those who had heard about the HPV vaccine, greater proportions of foreign-born participants with lower to moderate English language use or who lived in the US for 20 years or more had been exposed to this information through PNS, indicating that personal networks may be influential in HPV information brokering in these communities. Family and friends may be important influencers of healthcare decision-making [31]. Minority women were found to be more likely to perceive the HPV vaccine as effective when they report PNS as their source of information compared to other types of

sources [32]. Immigrant communities with lower acculturation such as Hispanic/Latino, African refugee and recently immigrated NHPIs, may benefit from greater involvement of community health workers who are able to provide health promotion through personal and community relationships.

In focus groups, some participants expressed seeking others' personal stories and experiences with the HPV vaccine to support their decision-making when searching for information online; hearing about personal accounts about the HPV vaccine served to consolidate perceptions about the vaccine and influence decision-making among participants. These personal narratives may be a useful tool for communicating cancer information [33]. Previous interventions utilizing narrative-based educational tools, such as a *radionovela*, or short story broadcasted on the radio have been found to be successful at increasing knowledge and HPV vaccine acceptability among rural Latino parents [34]. Future research could evaluate narrative-based approaches against traditional HPV educational material with other non-English speaking populations.

This study also found that higher proportions of US-born participants reported receiving HPV information from MS. This may suggest that media formats of HPV vaccine information may be less used by non-US born participants from the five communities. Given that more inaccurate HPV vaccine information has been associated with MS [35], this finding also raises concerns. A content analysis of news magazine coverage in the US about the HPV vaccine found much coverage of the vaccine centered on the adverse effects in 2006 to 2007 [36], while analysis of news-related blog posts about the HPV vaccine in 2011 showed greater negative media coverage about the vaccine compared to healthcare sources of information [37]. Repeated exposure to controversial news about the HPV vaccine can eventually diminish public support for the vaccine [38]; thus, the accessibility and availability of authoritative and accurate online information is important for HPV vaccine promotional efforts.

Perceptions of the HPV vaccine were influenced by multiple sources of information; while public media campaigns raised awareness, they sometimes triggered information-seeking behaviors that prompted some participants to seek information online or through healthcare providers. This dynamic and interactive behavior in information-seeking is reflected in studies examining multiple sources of HPV vaccination information in minority populations. A study conducted by Almeida, Tiro, Rodriguez, and Diamant [39] found that knowledge retention about the HPV vaccine was greatest when individuals were exposed to advertisements in conjunction with other sources of information. However, our study found that the non-exclusive use of PNS and MS for HPV information was not associated with positive HPV vaccine knowledge outcomes. Rather, it was the receipt of HPV information from healthcare system sources that were associated with these outcomes.

The experience of a firm provider recommendation was associated with participants' acceptance of the vaccine and decisions to vaccinate. For those who did not receive consistent or firm recommendations, this led to the perception that the vaccine was optional or less important compared to the other adolescent vaccines. Multiple studies with racial and

ethnic minorities have identified a provider recommendation as an important facilitator of decisions to vaccinate youth of diverse backgrounds [8, 29, 40, 41].

This study found that significant differences in HPV knowledge were associated with HPV information obtained through HSS, suggesting that healthcare providers are an important channel of HPV vaccine information for diverse communities. The community that faced the greatest challenges in accessing HPV vaccine information was the refugee community. Many parents in these communities had never been to school and were illiterate. Due to limited English proficiency, participants from this community were only able to access HPV and other health information through word-of-mouth, often through their health workers; thus, they were systematically excluded from many sources of valuable information. The few who had heard of the HPV vaccine had heard about it through a healthcare provider. However, a study of healthcare providers found that about two-thirds of physicians did not recommend the HPV vaccine to lower income and immigrant patients, citing limited clinical time and underuse of preventive health visits in this population as the main barriers to HPV vaccine education [42]. As such, there may be a need for increased provider and community interventions to improve patient education about the HPV vaccine among the most vulnerable of families from diverse communities.

Limitations

This study was conducted in one geographical area with a diverse sample of participants; thus, the findings may not be generalizable to other populations. However, the wide range of racial and ethnic groups included in this study is a strength for transferability of the findings since the sample represents a heterogeneous representation of minority groups in the U.S. by language use and acculturation characteristics. This study was also limited by the self-reported nature of the data; nevertheless, triangulation of qualitative and quantitative data provided additional richness and context to findings. Nevertheless, this is one of the first mixed-method studies to examine HPV vaccine information sources among five diverse and underrepresented communities. To date, no studies have been conducted with these five communities in this geographical area, a region with low HPV vaccination rates [43]. In addition, by examining acculturation indicators in addition to racial and ethnic categories, our findings provide greater insight into cultural differences in accessing HPV vaccine information.

Conclusion

The lack of understanding of the HPV vaccine is well documented [3]. Diverse families face additional challenges to accessing, receiving, and accepting the HPV vaccine [5, 28, 29]. This study found that existing sources of HPV vaccination information do not adequately meet the needs of diverse families with various levels of acculturation. Individuals with lower English proficiency may face greater challenges in accessing information about the HPV vaccine. This study highlights the importance of healthcare system-delivered HPV information in supporting diverse families' vaccine knowledge.

Participants in this study described their need for accessible and in-depth information about the HPV vaccine. Information obtained through healthcare providers and other healthcare

system sources is important for improving knowledge, awareness, and acceptance of the HPV vaccine. Other information channels may also potentially increase the reach of HPV vaccine messaging in diverse communities. Culturally and linguistically appropriate HPV vaccine messaging may enhance provider-delivered messages.

References

- Centers for Disease Control and Prevention. HPV-associated cancer statistics. 2016. Retrieved from <http://www.cdc.gov/cancer/hpv/statistics/>
- Jemal A, Simard EP, Dorell C, et al. Annual report to the nation on the status of cancer, 1975–2009, featuring the burden and trends in human papillomavirus (HPV)–associated cancers and HPV vaccination coverage levels. *Journal of the National Cancer Institute*. 2013:djs491.
- Klug SJ, Hukelmann M, Blettner M. Knowledge about infection with human papillomavirus: A systematic review. *Preventive Medicine*. 2008; 46(2):87–98. [PubMed: 17942147]
- Lee HY, Kown M, Vang S, et al. Disparities in human papillomavirus vaccine literacy and vaccine completion among Asian American Pacific Islander undergraduates: Implications for cancer health equity. *Journal of American College Health*. 2015; 63(5):316–23. [PubMed: 25836058]
- Bastani R, Glenn BA, Tsui J, et al. Understanding suboptimal human papillomavirus vaccine uptake among ethnic minority girls. *Cancer Epidemiology, Biomarkers and Prevention*. 2011; 20(7):1463–72.
- Buchwald D, Muller C, Bell M, Schmidt-Grimminger D. Attitudes toward HPV vaccination among rural American Indian women and urban White women in the Northern Plains. *Health Education & Behavior*. 2013; 40(6):704–11. [PubMed: 23460671]
- Fowler B, Bodson J, Warner EL, Dyer J, Kepka D. Poor HPV vaccine-related awareness and knowledge among Utah Latinas overdue for recommended cancer screenings. *Journal of Community Health*. 41(4):825–837.
- Galbraith KV, Lechuga J, Jenerette CM, Moore LA, Palmer MH, Bodson JB. Parental acceptance and uptake of the HPV vaccine among African-Americans and Latinos in the United States: A literature review. *Social Science & Medicine*. 2016; 159:116–26. [PubMed: 27180256]
- Baandrup L, Bloomberg M, Dehlendorff C, Sand C, Anderson KK, Kjaer SK. Significant decrease in the incidence of genital warts in young Danish women after implementation of a national human papillomavirus vaccination program. *Sexually Transmitted Diseases*. 2013; 40(2):130–135.
- Brotherton JM, Fridman M, May CL, Chappell G, Saville AM, Gertig DM. Early effect of the HPV vaccination programme on cervical abnormalities in Victoria, Australia: An ecological study. *Lancet*. 2011; 377(9783):2085–2092. [PubMed: 21684381]
- Macartney KK, Chiu C, Georgousakis M, Brotherton JM. Safety of human papillomavirus vaccines: A review. *Drug Safety*. 2013; 36(6):393–412. [PubMed: 23637071]
- Duvall J, Buchwald D. Human papillomavirus vaccine policies among American Indian tribes in Washington State. *Journal of Pediatric & Adolescent Gynecology*. 2012; 25(2):131–135. [PubMed: 22260893]
- Hughes J, Cates JR, Liddon N, Smith JS, Goettlieb SL, Brewer NT. Disparities in how parents are learning about the human papillomavirus vaccine. *Cancer Epidemiology, Biomarkers & Prevention*. 2009; 18(2):363–372.
- Glenn BA, Tsui J, Coronado GD, et al. Understanding HPV vaccination among Latino adolescent girls in three U.S. regions. *Journal of Immigrant & Minority Health*. 2015; 17(1):96–103. [PubMed: 24557745]
- Kepka DL, Ulrich AK, Coronado GD. Low knowledge of the three-dose HPV vaccine series among mothers of rural Hispanic adolescents. *Journal of Health Care for the Poor and Underserved*. 23(2):626–635.
- McRee AL, Reiter PL, Brewer NT. Parents' internet use for information about HPV vaccine. *Vaccine*. 2012; 30(25):3757–3762. [PubMed: 22172505]

17. Underwood NL, Gargano LM, Jacobs S, et al. Influence of sources of information and parental attitudes on human papillomavirus vaccine uptake among adolescents [Advanced online publication]. *Journal of Pediatric & Adolescent Gynecology*. 2016
18. Hunter JL. Cervical cancer educational pamphlets: Do they miss the mark for Mexican immigrant women's needs? *Cancer Control*. 2005; 12(Suppl 2):42–50. [PubMed: 16327750]
19. Kobetz E, Menard J, Hazan G, et al. Perceptions of HPV and cervical cancer among Haitian immigrant women: Implications for vaccine acceptability. *Education for Health*. 2011; 24(3):479. [PubMed: 22267344]
20. U.S Department of Health and Human Services. The 2014 National Immunization Survey – Teen [Dataset] National Center for Health Statistics. Centers for Disease Control and Prevention; Hyattsville, MD: 2014.
21. Israel BA, Schultz AJ, Parker EA, Becker AB. Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health*. 1998; 19:173–202.
22. Plano-Clark VL, Huddleston-Casas CA, Churchill S, Green DO, Garrett AL. Mixed methods approaches in family science research. *Journal of Family Issues*. 2008; 29(11):1543–1566.
23. Marin G, Sabogal F, Marin BV, Otero-Sabogal R, Perez-Stable EJ. Development of a short acculturation scale for Hispanics. *Hispanic Journal of Behavioral Sciences*. 1987; 9(2):183–205.
24. Ellison J, Jandorf L, Duhamel K. Assessment of the Short Acculturation Scale for Hispanics (SASH) among low-income, immigrant Hispanics. *Journal of Cancer Education*. 26(3):478–83.
25. Choi SE, Reed PL. Psychometric validation of a short acculturation scale for Korean immigrants. *Nursing Research*. 2011; 60(4):240–246. [PubMed: 21677595]
26. dela Cruz FA, Padilla GV, Butts E. Validating a short acculturation scale for Filipino-Americans. *Journal of the American Academy Nurse Practitioners*. 1998; 10(10):453–460.
27. Thorne S, Kirkham SR, MacDonald-Emes J. Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing & Health*. 1997; 20(2):169–177. [PubMed: 9100747]
28. Gelman A, Nikolajski C, Schwarz EB, Borrero S. Racial disparities in human papillomavirus vaccination: Does access matter? *Journal of Adolescent Health*. 2013; 53(6):756–762. [PubMed: 23992645]
29. Greenfield LS, Page LC, Kay M, Li-Vollmer M, Breuner CC, Duchin JS. Strategies for increasing adolescent immunizations in diverse ethnic communities. *Journal of Adolescent Health*. 2015; 56(5 Suppl):S47–53. [PubMed: 25863555]
30. Burger EA, Lee K, Saraiya M, et al. Racial and ethnic disparities in human papillomavirus-associated cancer burden with first-generation and second-generation human papillomavirus vaccines. *Cancer*. 2016; 122(13):2057–2066. [PubMed: 27124396]
31. Fox, S. The social life of health information. 2014. Retrieved from <http://www.pewresearch.org/fact-tank/2014/01/15/the-social-life-of-health-information/>
32. Casillas A, Singhal R, Tsui J, Glenn BA, Bastani R, Mangione CM. The impact of social communication on perceived HPV vaccine effectiveness in a low-income, minority population. *Ethnicity & Disease*. 2011; 21(4):495–501. [PubMed: 22428357]
33. Green MC. Narratives and cancer communication. *Journal of Communication*. 2006; 56(1):S163–S183.
34. Kepka D, Coronado GD, Rodriguez HP, Thompson B. Evaluation of a radionovela to promote HPV vaccine awareness and knowledge among Hispanic parents. *Journal of Community Health*. 2011; 36(6):957–965. [PubMed: 21452030]
35. Bodemer N, Muller SM, Okan Y, Garcia-Retamero R, Neumeyer-Gromen A. Do the media provide transparent health information? A cross-cultural comparison of public information about the HPV vaccine. *Vaccine*. 2012; 30(25):3747–3756. [PubMed: 22421558]
36. Abdelmutti N, Hoffman-Goetz L. Risk Messages about HPV, cervical cancer, and the HPV vaccine Gardasil in North American news magazines. *Journal of Cancer Education*. 2010; 25(3):451–456. [PubMed: 20232189]

37. Daily KM, Nan X, Briones R. Analysis of HPV vaccine information on influential blog sites: A snapshot amid the 2011 Republican presidential primary debates. *Atlantic Journal of Communication*. 2015; 23(3):159–177.
38. Gollust SE, Dempsey AF, Lantz PM, Ubel PA, Fowler EF. Controversy undermines support for state mandates on the human papillomavirus vaccine. *Health Affairs*. 2010; 29(11):2041–2046. [PubMed: 21041746]
39. Almeida CM, Tiro JA, Rodriguez MA, Diamant AL. Evaluating associations between sources of information, knowledge of the human papillomavirus, and human papillomavirus vaccine uptake for adult women in California. *Vaccine*. 2012; 30(19):3003–3008. [PubMed: 22326776]
40. Warner EL, Lai D, Carbajal-Salisbury S, et al. Latino parents' perceptions of the HPV vaccine for sons and daughters. *Journal of Community Health*. 2015; 40(3):387–394. [PubMed: 25269400]
41. Schmidt-Grimminger D, Frerichs L, Black Bird AE, Workman K, Dobberpuhl M, Watanabe-Galloway S. HPV knowledge, attitudes, and beliefs among Northern Plains American Indian adolescents, parents, young adults, and health professionals. *Journal of Cancer Education*. 2013; 28(2):357–366. [PubMed: 23564429]
42. Bruno DM, Wilson TE, Gany F, Aragonés A. Identifying human papillomavirus vaccination practices among primary care providers of minority, low-income and immigrant patient populations. *Vaccine*. 2014; 32(33):4149–4154. [PubMed: 24886959]
43. Lai D, Ding Q, Bodson J, Warner EL, Kepka D. Factors associated with increased HPV vaccine use in rural-frontier U.S. states. *Public Health Nursing*. 2016; 33(4):283–294. [PubMed: 26331614]

Table 1Demographic Characteristics of Participants from Focus groups and Surveys ($N = 228$)

Demographic Characteristic	<i>N</i>	% ³
Age Group (Range = 18–74; $M = 43.09$; $SD = 10.19$)		
< 35 years old	42	18.4
35 – 50 years old	148	64.9
> 50 years old	35	15.4
Missing	3	1.3
Gender		
Male	64	28.1
Female	162	71.1
Missing	2	.9
Race/Ethnicity		
African American	17	7.5
African Immigrant	39	17.1
American Indian/Alaskan Native	23	10.1
Hispanic/Latino	64	28.1
Native Hawaiian/Pacific Islander	70	30.7
Other (includes multiracial)	7	3.1
Missing	8	3.5
Marital status		
Married or living as married	174	76.3
Other	49	21.5
Missing	5	2.2
Number of children age 11–17 (Range = 1–14; $M = 2.39$; $SD = 1.67$)		
1 – 2 children	118	51.8
3 children	63	27.6
Missing	47	20.6
Educational attainment		
< High School	29	12.7
High School/GED	85	37.3
AD Diploma or Certificate	52	22.8
Bachelor's degree	42	18.4
Missing	20	18.8
Annual household income		
<\$20,000	86	37.7
\$20,000 – \$40,000	69	30.3
> \$40,000	60	26.3
Missing	13	5.7
Place of birth		
U.S.	72	31.6
Other	154	67.5

Demographic Characteristic	N	% ³
Missing	2	.9
Years in the U.S. for foreign-born participants¹ (Range = 2–55; <i>M</i> = 25.62; <i>SD</i> = 17.25)		
< 20 years	68	44.2
20 years	74	48.1
Missing	12	7.8
English Usage²		
Low (< 2.5)	43	18.9
Medium (2.5 – 4)	72	31.6
High (> 4)	61	26.8
Missing	52	22.8
Health insurance coverage		
Yes	127	55.7
No	94	41.2
Missing	7	3.1
Type of health insurance³		
Private	82	64.6
Public	40	31.5
Missing	12	3.9
Heard about HPV vaccine through (<i>N</i>=106)⁴:		(%) ³
Personal Network sources (PNS) ⁵	43	40.6
Media Sources (MS) ⁶	41	38.7
Healthcare System sources (HSS) ⁷	72	67.9
Only PNS	19	17.9
Only MS	10	9.4
Only HSS	39	36.8
PNS and MS	5	4.7
PNS and HSS	7	6.6
MS and HSS	14	13.2
All three types of sources	12	11.3

Note. Data included survey responses for focus group participants and participants who completed only surveys.

¹ Percentages calculated out of 154 (number of participants reported born out of the U.S.).

² Five questions were used to create the composite English Use score- “What language do you: 1) know, 2) speak at home, 3) speak with friends, 4) speak at work, and 5) think in?” Responses were measured with a 5-point Likert scale, ranging from 1 = Only native language, to 5 = Only English. A mean English Use score was calculated.

³ Percentages calculated out of 127 (number of participants reported having health insurance).

⁴ Analysis only performed on people who reported having heard of the HPV vaccine.

⁵ Responses were coded as *Personal Network* sources when participants indicated hearing about the HPV vaccine from one or more of the following sources: friends, family, community organizations, and other types of personal relationships.

⁶ *Media* sources included television, radio, newspapers, billboards, or websites.

⁷*Health Care System* sources included healthcare providers, clinic visits, or brochures obtained in a healthcare setting.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Sources of HPV Vaccine Information Exposure

Sociodemographic Characteristic	PNS Yes (n=43) n (%) ²	PNS No (n=63) n (%) ²	p-value ³	MS Yes (n=41) n (%) ²	MS No (n=65) n (%) ²	p-value ³	HSS Yes (n=72) n (%) ²	HSS No (n=34) n (%) ²	p-value ³
Age Group¹									
< 35 years old	8 (38.1)	13 (61.9)	0.64	5 (23.8)	16 (76.2)	0.08	16 (76.2)	5 (23.8)	0.45
35 – 50 years old	29 (39.2)	45 (60.8)		29 (39.2)	45 (60.8)		47 (63.5)	27 (36.5)	
> 50 years old	5 (55.6)	4 (44.4)		6 (66.7)	3 (33.3)		7 (77.8)	2 (22.2)	
Gender¹									
Male	12 (54.6)	10 (45.5)	0.14	8 (36.4)	14 (63.6)	1.00	11 (50.0)	11 (50.0)	0.07
Female	30 (36.1)	53 (63.9)		32 (38.6)	51 (61.5)		60 (72.3)	23 (27.7)	
Race/Ethnicity¹									
African American	4 (30.8)	9 (69.2)	0.23	9 (69.2)	4 (30.8)	0.25	10 (76.9)	3 (23.1)	0.73
African Immigrant	2 (25.0)	6 (75.0)		2 (25.0)	6 (75.0)		7 (87.5)	1 (12.5)	
American Indian/Alaskan Native	5 (35.7)	9 (64.3)		5 (35.7)	9 (64.3)		9 (64.3)	5 (35.7)	
Hispanic/Latino	19 (52.8)	17 (47.2)		11 (30.6)	25 (69.4)		22 (61.1)	14 (38.9)	
Native Hawaiian or Pacific Islander	12 (42.9)	16 (57.1)		11 (39.3)	17 (60.7)		20 (71.4)	8 (28.6)	
Other (includes multiracial)	0 (0.0)	5 (100.0)	1.00	2 (40.0)	3 (60.0)	0.33	4 (80.0)	1 (20.0)	0.80
Marital status¹									
Married or living as married	34 (41.0)	49 (59.0)		30 (36.1)	53 (63.9)		57 (68.7)	26 (31.3)	
Other	9 (40.9)	13 (59.1)		11 (50.0)	11 (50.0)		14 (63.6)	8 (36.4)	
Number of children age 11–17¹									
1 – 2 children	17 (32.1)	36 (67.9)	0.81	26 (49.1)	27 (50.9)	0.16	34 (64.2)	19 (35.9)	0.21
3 children	10 (35.7)	18 (64.3)		9 (32.1)	19 (67.9)		22 (78.6)	6 (21.4)	
Educational attainment¹									
< High School	3 (50.0)	3 (50.0)	0.82	1 (16.7)	5 (83.3)	0.11	4 (66.7)	2 (33.3)	0.96
High School/GED	12 (37.5)	20 (62.5)		8 (25.0)	24 (75.0)		22 (68.8)	10 (31.3)	
AD Diploma or Certificate	15 (44.1)	19 (55.9)		17 (50.0)	17 (50.0)		24 (70.6)	10 (29.4)	
Bachelor's degree	11 (35.5)	20 (64.5)		14 (45.2)	17 (54.8)		20 (64.5)	11 (35.5)	

Sources of HPV Vaccine Information Exposure									
Sociodemographic Characteristic	PNS Yes (n=43) n (%) ²	PNS No (n=63) n (%) ²	p-value ³	MS Yes (n=41) n (%) ²	MS No (n=65) n (%) ²	p-value ³	HSS Yes (n=72) n (%) ²	HSS No (n=34) n (%) ²	p-value ³
Annual household income ¹			0.85			0.39			0.48
<\$20,000	9 (36.0)	16 (64.0)		9 (36.0)	16 (64.0)		15 (60.0)	10 (40.0)	
\$20,000 – \$40,000	16 (43.2)	21 (56.8)		12 (32.4)	25 (67.6)		24 (64.9)	13 (35.1)	
> \$40,000	16 (38.1)	26 (61.9)		20 (47.6)	22 (52.4)		31 (73.8)	11 (26.2)	
Place of birth ¹			<0.05			<0.05			0.21
US	14 (29.8)	33 (70.2)		23 (48.9)	24 (51.1)		35 (74.5)	12 (25.5)	
Other	29 (50.0)	29 (50.0)		17 (29.3)	41 (70.7)		36 (62.1)	22 (37.9)	
Years in the US ¹			0.01			0.35			1.00
< 20 years	12 (37.5)	20 (62.5)		7 (21.9)	25 (78.1)		20 (62.5)	12 (37.5)	
20 years	16 (72.7)	6 (27.3)		8 (36.4)	14 (63.6)		13 (59.1)	9 (40.9)	
Parents' place of birth ¹			<0.05			0.18			0.49
US	7 (23.3)	23 (76.7)		15 (50.0)	15 (50.0)		22 (73.3)	8 (26.7)	
Other	33 (45.2)	40 (54.8)		25 (34.3)	48 (65.8)		47 (64.4)	26 (35.6)	
Generation of immigrant ¹			0.41			0.25			0.27
First	27 (48.2)	29 (51.8)		17 (30.4)	39 (69.6)		34 (60.7)	22 (39.3)	
Second	6 (35.3)	11 (64.7)		8 (47.1)	9 (52.9)		13 (76.5)	4 (23.5)	
Acculturation/English Usage ^{1,4}			0.01			0.32			0.18
Low (2.5)	9 (50.0)	9 (50.0)		5 (27.8)	13 (72.2)		10 (55.6)	8 (44.4)	
Medium (2.5 – 4)	19 (59.4)	13 (40.6)		11 (34.4)	11 (65.6)		19 (59.4)	13 (40.6)	
High (4)	11 (26.2)	31 (73.8)		20 (47.6)	22 (52.4)		32 (76.2)	10 (23.8)	
Health insurance coverage ¹			0.67			0.53			0.13
Yes	26 (37.7)	43 (62.3)		29 (42.0)	40 (58.0)		50 (72.5)	19 (27.5)	
No	15 (42.9)	20 (57.1)		12 (34.3)	23 (65.7)		20 (57.1)	15 (42.9)	
Type of health insurance ¹			0.25			0.25			0.76
Private	24 (43.6)	31 (56.4)		24 (43.6)	31 (56.4)		38 (69.1)	17 (30.9)	
Public	4 (25.0)	12 (75.0)		4 (25.0)	12 (75.0)		12 (75.0)	4 (25.0)	
Primary care provider for child ¹			0.11			0.18			0.26

Sources of HPV Vaccine Information Exposure																	
Sociodemographic Characteristic	PNS (n=43)		PNS (n=63)		p-value ³		MS (n=41)		MS (n=65)		p-value ³		HSS (n=72)		HSS (n=34)		p-value ³
	Yes	n (%) ²	Yes	n (%) ²	No	n (%) ²	Yes	n (%) ²	No	n (%) ²	Yes	n (%) ²	Yes	n (%) ²	No	n (%) ²	
Yes	28	(34.2)	54	(65.9)			34	(41.5)	48	(58.5)			59	(72.0)	23	(28.1)	
No	10	(55.6)	8	(44.4)			4	(22.2)	14	(77.8)			10	(55.6)	8	(44.4)	

Note. Analysis only performed on people who reported having heard of the HPV vaccine.

¹ Missing values for variables are not shown in this table and were excluded from analysis. See Table 1 for counts of missing values for each predictor variable.

² Percentages calculated out of row totals.

³ P-values calculated using Fisher's Exact Test for Count Data (this test chosen due to small cell sizes). Values are considered significant at $p < 0.05$

⁴ See Table 1 for explanation of variable creation.

Table 3

Association between Sources of HPV Vaccine Information on HPV Vaccine-related Knowledge (Survey Responses)^{1, 2}

#	HPV Vaccine Knowledge Questions	Source of exposure to HPV vaccine information					
		Personal Network			Media		
		Yes	No	p-value ⁴	Yes	No	p-value ⁴
1.	HPV is able to cause cervical cancer			0.412			0.68
	Correct	29 (67.4)	37 (58.7)		27 (65.9)	39 (60.0)	
	Incorrect ³	14 (32.6)	26 (41.3)		14 (34.2)	26 (40.0)	
2.	Most people have HPV at some point in their lives			0.84			0.55
	Correct	18 (41.9)	24 (38.7)		18 (43.9)	24 (37.5)	
	Incorrect ³	25 (58.1)	38 (61.3)		23 (56.1)	40 (62.5)	
3	A female can tell if she has HPV			0.08			0.69
	Correct	15 (35.7)	34 (54.0)		20 (50.0)	29 (44.6)	
	Incorrect ³	27 (64.3)	29 (46.0)		20 (50.0)	36 (55.4)	
4	A male can tell if he has HPV			0.23			0.84
	Correct	15 (37.5)	32 (50.8)		19 (47.5)	28 (44.4)	
	Incorrect ³	25 (62.5)	31 (49.2)		21 (52.5)	35 (55.6)	
5	The HPV vaccine is given in one injection			0.55			0.84
	Correct	18 (42.9)	31 (50.0)		18 (45.0)	31 (48.4)	
	Incorrect ³	24 (57.1)	31 (50.0)		22 (55.0)	33 (51.6)	
6	The best time for girls to get the HPV vaccination is between 11 and 12 but girls can also benefit from getting it when they are between the ages of 9–26			0.40			0.67
	Correct	27 (62.8)	44 (71.0)		29 (70.7)	42 (65.6)	
	Incorrect ³	16 (37.2)	18 (29.0)		12 (29.3)	22 (34.4)	
7	The best time for boys to get the HPV vaccination is between 11 and 12 but boys can also benefit from getting it when they are between the ages of 9–21			0.69			0.84
	Correct	23 (53.5)	37 (58.7)		24 (58.5)	36 (55.4)	
	Incorrect ³	20 (46.5)	26 (41.3)		17 (41.5)	29 (44.6)	

Note. Findings are considered significant at p< 0.05.

¹ Missing values are not shown in this table and were excluded from analysis. Analysis only performed on people who reported having heard of the HPV vaccine.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

² Percentages calculated out of row totals.

³ The response „Don't know” was included in the category „Incorrect.”

⁴ *P*-values calculated using Fisher's Exact Test for Count Data (this test chosen due to small cell sizes).