

Communication Pathways: HPV Information and Message Barriers Reported among American Indian College Students

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Abstract

Background and Purpose: American Indians (AI) are reported to have high human papillomavirus (HPV) infection rates. This study explores communication pathways among AI college students reporting sources and influences of HPV information. **Methods:** Eight focus groups with 53 AI students were conducted at four Southwest universities. Questions probed HPV knowledge and attitudes, health beliefs, cultural influences, message barriers, and communication pathways. Data was analyzed using Grounded Theory methods. **Results:** Schools and television commercials were common information sources; less frequently mentioned were parents and the tribal community. Preferred communication pathways were siblings, relatives and physicians. Barriers to communication included lack of information sources, stigma, traditional viewpoints limiting discussions related to sexuality, and under-representation of AIs in health media. Sources of HPV information and preferences for communication pathways influences and perceived receptiveness of various channels were identified. **Conclusion:** Education and health messages must take into account AI cultural perspectives, as well as informational and communication preferences. Strategies to reduce information/ communication gaps include improving inter-family communication and facilitating school-based, clinic-based and tribal community health events about protecting sexual and reproductive health. Message barriers must be addressed to reduce HPV-related morbidity and mortality.

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Introduction

It is estimated that nearly all sexually active American men and women will contract the human papillomavirus (HPV) in their lifetime (CDC, 2014). Research indicates that high-risk strains of HPV have been associated with certain cancers, particularly cervical cancer (Bosch, Lorinez, Munoz, Meijer, & Shah, 2002). American Indian/Alaska Native (AI/AN) females experience the third highest rate of death from cervical cancer, followed by Whites and Asians/ Pacific Islanders (CDC, 2010). Studies indicate that infection with HPV is highly prevalent among AI/ANs, and is highest among the Northern Plains tribes, particularly among females age 14 through 24 (Bell, Schmidt-Grimminger, Patrick, Ryschon, Linz, & Chauhan, 2007). High HPV prevalence among this age group is not uncommon in other racial/ethnic groups, but in AI/ANs the infection

appears to be caused by more high-risk oncogenic HPV types (Bell et al. 2007). The spread of high-risk HPV strains in AI groups may be due to isolated populations and poor HPV inoculation rates. Unfortunately, current studies do not address the reason for this disparity.

Communication surrounding HPV may be poor or inadequate in the United States, evidenced by low knowledge and awareness across the general population (Friedman & Sheppard, 2007), and high rates of infection (CDC, 2014). Studies report that White populations were more aware of HPV and HPV vaccines as compared to Black populations (91% vs. 73%) (Ragin, Edwards, Jones, Thurman, Kagan, et al. 2009). Further, despite high prevalence in the adolescent and young adult population, low HPV awareness has been reported among high school and college age females (Marchand, Glenn, & Bastani,

2013). Such information gaps point to problems with both information sources and communication pathways (such as information from parents, school and media as well as communication between friends, healthcare providers and parents). Findings from a CDC study indicate that current popular avenues for communication about HPV among the general public include Internet, interpersonal, print, and broadcast media population (Friedman & Sheppard, 2007); however, as with most national studies, AI/ANs were not sampled. There is a dearth of information regarding communication surrounding HPV among AI/ANs, despite growing numbers of studies on HPV and HPV vaccines. Health media campaigns by pharmaceutical companies promote HPV vaccines through commercials targeting mainstream young American females. While most commercials do feature certain minority groups, AI/ANs are not among them. Underrepresentation in current research and health media may be indicative of a larger communication problem regarding HPV among and for AI/ANs. Little has been done to evaluate the sources, methods or impact of HPV communication within AI/AN populations. Thus studies that examine HPV communication pathways and strategies targeted toward AI/AN communities are needed in order for health messages to reach this population and motivate safer sexual behaviors. Such messages may include emphasis on responsibility for obtaining HPV vaccination, as studies show that responsibility for one's own health and the health of one's family are of great importance (Hodge, 2011) and that messages are best when they are culturally appropriate (Hodge, 1993) and delivered by family or friends (CRIHB, 2007).

The purpose of this study was to explore communication pathways regarding the sources and influences of HPV information in a cohort of male and female American Indian college students in the Southwest U.S. For our purposes, information signifies the giving out of data and communication represents the success or failure of channels for disseminating information to people and communities. AI college students were selected as the sample for studying

information and communication regarding HPV for several reasons: 1) according to the National Health and Nutrition Examination Survey, HPV infection is most common among females between the ages of 20 and 24 (Kuo & Fujise, 2011); 2) HPV vaccination is recommended for preteen girls and boys age 11 or 12 years. HPV vaccine is also recommended for girls and boys ages 13 through 26 years and for boys ages 13 through 21 years, who have not yet been vaccinated (CDC, 2014); and 3) the National Center for Health Statistics found that the fewest number of medical visits occur during the ages of 15-24 for both males and females (Woodwell & Cherry, 2002).

This paper reports on common sources of HPV-related information and identifies barriers to HPV health messages reaching and disseminating within the AI college population. AI/AN research participants in prior studies have emphasized the need for visual and language compatibility with American Indians (using images of AI individuals with messages that are culturally sensitive and appropriate) (Hodge, 2011). We have found that AI/AN study participants tend to ignore culturally inappropriate messages (or meet them with silence), perhaps concluding that the message was not directed at them. Based on personal experience, we expected AI/AN individuals to ignore HPV health messages that did not target the AI/AN population.

Methods

Participants

A total of 53 AI students were recruited in 2009 from universities in California and Arizona. Although two focus groups were planned to be held at each university, one university recruited only 5 students so they held only one focus group. Each of the other three other universities conducted a first focus group which informed the second focus group, allowing for some small revisions in questions.

Procedures

Focus group sessions were planned to last up to two hours in duration in order to sufficiently saturate the topic of discussion. Focus group

facilitators posted recruitment flyers at AI Studies departments, student unions, and news boards. Interested participants were encouraged to contact the focus group facilitator to register or register the day of the session. Eligibility requirements included: 1) self-identified as AI; 2) between the ages of 18 and 26; and 3) enrolled as a college student. Approval was obtained from the researchers' university Institutional Review Board. Sessions were held in student union community rooms or conference rooms in the American Indian Studies department at each university. At each session the focus group facilitator read the consent form with the participants. Participants received a copy of the consent form for their records. Focus groups lasted approximately one hour. Each session was audio-taped to record key themes and messages. A \$25 gift card was offered to each participant as an incentive.

Measures

Focus group prompts included questions about participants' knowledge and attitudes towards HPV and the HPV vaccination. Focus group participants were asked about health beliefs and cultural influences that might affect their attitudes/knowledge towards HPV. Participants were probed about message barriers, including appropriateness of talking about HPV or STIs with family members and others. Additionally, participants were asked to identify communication pathways/resources for information they received about HPV or sexual health. To assess these communication pathways participants were asked: 1) where they would most likely look for information about HPV, and 2) from whom they would feel most comfortable receiving HPV information. Researchers asked if participants had heard anything about HPV or HPV vaccines, and if so, by which source/channel they received the information.

Concurrent data collection and analysis of each focus group informed the next focus group at each site including the need to explore new areas, verify findings, and/or change questions based on the initial focus group finding. The second group of focus groups had minor revisions to their list of questions; basically expansion on topics of historical trauma and

family reluctance to discuss topics of a sexual nature.

Analyses

Following each focus group completion, audio-recordings of the sessions were transcribed verbatim to validate the accuracy of the data and to assess and inform the second round of focus groups. Transcriptions were coded using Grounded Theory (Glaser & Strass, 1967) methods for each of the focus groups. Codes were analyzed to form themes based on the most frequent and significant initial codes for all the focus groups. Themes formed the basis of categories and possible relationships between categories were identified. The authors collaborated in memo writing between coding for the first draft of the study results. The authors systematically coded and analyzed the data saturation. A theoretical framework was allowed to merge between themes and relationships between the themes.

Results

The sample consisted of 53 AI university students, 21 males and 32 females, with an average age of 22 years. Seventy three percent were members of a Southwest tribe; also represented were tribes from California, Oklahoma and other regions. A more than half of the participants were recruited from the University of Arizona. See Table 1.

During focus groups sessions participants were asked where they would most likely look for information about HPV. Sources of information were not mutually exclusive and were categorized as "internal" and "external" sources (see Table 2). Identified external sources of information included schools and pharmaceutical television commercials. Internal sources of HPV information were identified as friends, relatives and siblings – less frequently mentioned were parents and the tribal community.

External Sources of Information

Fifty-five percent of respondents reported they first received information about HPV in the

school setting during health classes. Another common primary source of information about HPV was identified as television commercials for HPV vaccines. One female participant explained that she first learned about HPV and HPV vaccines from television: “[The commercials] kept saying you should be vaccinated”. Another participant responded, “I didn’t really know anything about HPV until I heard it from the commercials” (Female). Of note, few respondents mentioned learning about HPV from the Internet or radio as a primary source; these channels were noted to be common sources for obtaining additional information once they heard about the HPV virus and the HPV vaccine. Only four respondents noted that their doctor/healthcare provider was the first to tell them about HPV. Few participants noted that their tribe or community was their source of information regarding HPV.

Table 1

Socio-demographic Characteristics
of American Indian College
Students (N=53)

| Characteristics | n (%) |
|------------------------|-----------|
| Gender | |
| Female | 32 (59.7) |
| Male | 21 (40.3) |
| Age | |
| 18 | 0 (0) |
| 19 | 5 (8.8) |
| 20 | 13 (28.1) |
| 21 | 13 (22.8) |
| 22 | 6 (12.3) |
| 23 | 7 (12.3) |
| 24 | 2 (3.5) |
| 25 | 2 (3.5) |
| 26+ | 4 (7.0) |
| Unknown | 1 (1.8) |
| Tribal Affiliation | |
| Southwest Tribe | 40 (70.2) |
| California Tribe | 5 (8.8) |
| Oklahoma Tribe | 5 (8.8) |
| Northern Plains Tribes | 3 (5.3) |
| Tribes | |
| Unknown/Other | 4 (6.9) |

Internal Sources of Information

A number of respondents commented that their primary source of health information was family

members. One female stated, “My mom...is the one that got information and told us about it” (Female). Aside from a few participants’ experience, parents were not reported as a common information source. Others specified that they were told about HPV by an older sibling or relative.

Table 2

External / Internal Sources of HPV Information
and Barriers Reported by AI Students (n= 53)

| | External Sources | n | Internal Sources | N |
|--|---------------------------------------|----|---|----|
| Sources of Information | | | | |
| | Television | 28 | Friends | 48 |
| | Commercials | 25 | Relatives | 40 |
| | Schools | 31 | Siblings | 51 |
| | Tribal community | 3 | Parents | 11 |
| | Doctor/clinic | 4 | | |
| Communication Channels (feel comfortable receiving HPV information) | | | | |
| | Television | 20 | Relatives, friends, siblings | 51 |
| | | | Parents | 3 |
| Barriers to Information | | | | |
| | Non-AI role models | 31 | Sanctions against discussion sexual-related topics Stigma | 48 |
| | Lack of information sources/isolation | 28 | | 38 |
| Preferred Source of Information | | | | |
| | Schools | 31 | Parents | 5 |
| | Healthcare clinics | 4 | Siblings | 10 |
| | Tribal health community events | 2 | | |

Communication Channels

After discerning common sources of HPV information focus group members were probed to identify who they would feel most comfortable receiving HPV information, specifically preferred channels of communication about HPV transmission, prevention, cancer screening, etc., as well as the influence of the channels. Twenty students who reported learning about HPV from television noted significant influence, responding to the

information they received with health-seeking behaviors. One female commented that after hearing about HPV vaccines on television, “I went and got vaccinated just because HPV I guess leads to cervical cancer”. Another responded that after watching a commercial, “that’s when I started asking questions”.

Internal sources of HPV information, such as siblings, relatives and friends were the most frequently mentioned people with whom participants preferred to communicate and tended to have the most influence. The nature of the relationship between communicators, however, appeared to play an important role in participants’ comfort and receptiveness to communication, acting as a facilitator or a barrier. For example, for those few participants who reported parent-child relationships that were characterized as open, communication about HPV was acceptable and encouraged. “When we do not have the answer or we want more information we can openly just go to our parents and just ask them questions...They want us to be knowledgeable, be careful” (Female). Another participant noted, “My mom has always told me right up front about these things because she wants me to be safe” (Female). However, in most cases parents were not preferred pathways for communication (n=3). A “traditional” Native upbringing, viewed as reserved, was related to limited/no communication regarding HPV. “My parents are really traditional like that and to have them talk to me about (STIs) is kind of weird” (Female). One female noted, “My mom and my dad never talk to me about that stuff... a lot of traditional families see it as a taboo where is not really supposed to be talked about” (Female). Many respondents commented that discussions about HPV would turn to talking about sexual activity and pregnancy. Pregnancy was perceived as the paramount issue governing conversations with parents, eclipsing concern about STIs. “HPV, that’s probably the last thing that would be on my parents’ mind. I think they worry about me having a child” (Female). In these more traditional parent-child relationships, communication regarding HPV was non-existent and discouraged for the most part.

Other family members, siblings in particular, were mentioned frequently as important communication sources; many participants noted sharing their knowledge about HPV and STIs with younger siblings as well. Both genders reported discussing STIs with siblings (n=51), although HPV was still a mostly unfamiliar topic. One respondent commented, “My sister and my little brother, they ask me the questions, I guess I am the only they would talk about it (with)” (Female). Evident was a perceived sense of responsibility to impart the information to siblings as a means of protection; “Yes, I talked to my little brothers with them about (STIs)...I’m the oldest with my siblings, so I want to make sure all my brothers are aware of it” (Male). However, pregnancy was not mentioned as a reason for HPV discussions with siblings, as it was with parents. “I talked to my brothers about it, and basically I always tell them to be safe...always use protection” (Male). Communicating with other relatives was also noted; uncles in particular. “I’m the oldest in family so I have to talk to my uncles. They talk to me and say be careful and not trust anyone and to always protect yourself” (Male). Communication within these relationships was perceived to be both acceptable and influential.

While siblings and internal sources (such as other relatives, n=51) were mentioned most frequently as channels of communication surrounding HPV, friends were also reported to play a significant role in discussing HPV (n=48). One female noted, “I think everything I learned was either from my friends or school” (Female). Communication with friends was reported most frequently between peers of the same gender. In addition, conversations with friends did not center on pregnancy, but prevention of infection, as well as HPV vaccination.

One female stated, “Me and my friends talk about all the shots we get...I know we talked about HPV and another one of my friends she actually got the vaccine” (Female). It was reported that while comfort levels in communicating with friends was generally high, information received was not necessarily perceived to be accurate or absolute. For example, one male stated that he “talked about

(HPV) with my friends and they didn't really know. They were just kind of casual about [it]"

Stigma and HPV

Stigma associated with communication about sexuality and HPV emerged from the data as an important theme with regard to message barriers. Seventy percent of participants shared that there was a stigma associated with seeking information about HPV and discussing sexual activity with parents or elders. Respondents commented that due to the sensitive subject matter, HPV was viewed as taboo, and they generally would not feel comfortable communicating with their parents and vice versa. According to the participants, mention of sex or STIs in a discussion with parents would likely elicit disapproving reactions and negative perceptions about the person discussing the topic. This reaction was explained to be more common among older generations. One participant specified, "In my family we really do not talk about sexual activity or anything like that" (Female). Another female participant commented,

"I think there is like still a stigma with sex...generations ago it was a tool of procreation, a sign of love and affection... When you brought in colonization and boarding schools it started to become this evil thing. It became something to be shameful...our communities really can't talk about sex" (Female).

It was discussed that it is a fear among AI youth/young adults that if a person asks about an STI with AI parents or grandparents, they will be viewed as sexually active or infected. For example, one female participant stated, "I truly believe that we can't talk about [HPV] and if you bring it up with elders, they might think you are a floozy or what are you trying to do..." (Female). Another mentioned that discussing HPV vaccines is similarly taboo, "if you are talking about a vaccine that has anything to do with protecting someone when it comes to sex they are going to say it is sinful and bad so we are not going to talk about it" (Female). A different view presented was by a female who commented positively on the barrier to

communication about HPV, STIs or sex with parents, stating, "that's a way of protecting you, saying you should not be asking questions or wanting to know things about because you should not be doing it in the first place" (Female).

Barriers to HPV Information

Findings from this study indicate that AI college students want to obtain information regarding HPV, but they report facing message barriers when they seek such information. Many participants reported that they would like to be educated more about HPV and other health issues that may affect them, but noted that for the most part they do not know what to ask or how. Participants expressed that these barriers are particularly prevalent in rural AI communities. One female explained,

"...if you are from a rural area you are embarrassed... you don't know how to ask those types of questions about those types of things... I think that's one of the biggest things that prevent Native people learning about certain diseases. Things do happen but you don't talk about it, so in a way it's like it's not happening... and if you want to learn about it you don't know how to ask about it. And if you do ask about it people are like 'why did you ask that?'" (Female).

It was explained that in remote communities, as well as urban settings, the common sentiment is that little information is readily available on HPV and AIs possess very few opportunities to seek out information from receptive family members or others. Participants voiced frustration over difficulty in finding resources to answer their questions. If they were seeking information on a separate health issue un-related to sexual activity, such as diabetes or nutrition, participants responded that their initial preferred resource would be their parents or grandparents; however, this was not the preferred communication pathway for HPV discussions.

Inadequate Representation in Health Media

Health messages received from mass media campaigns for HPV vaccines emerged as an

important theme in this study's findings. The college students discussed the influence of watching commercials about the vaccine, and their perceptions of HPV within the context of that media source. Eighty percent of participants interpreted the commercials to imply that only females are affected by HPV, as only females are depicted in the commercials. One participant noted, "The Gardasil commercials came out a couple of years ago and that's just [targeting the] mainstream American public... and it's really marketed toward young females" (Female). In addition, some participants reported being aware of the absence of AI persons depicted in commercials; participants interpreted the lack of representation as signifying low HPV risk in their communities. Additionally, numerous participants commented that had the commercials included a more diverse range of minority actors/actresses, particularly AIs, they might have better understood that HPV prevention is something they should participate in. Several participants shared that warnings regarding side effects stood out to them, shaping perceptions that negative aspects of vaccination outweighed the benefits explained earlier in the commercials. However, despite reports that it is common for AIs to receive HPV educational information from television and commercials, those avenues for information were noted to have "barely scratched the surface...if you just generally ask a specific minority community...maybe they don't have TV, maybe they don't have access to those kinds of ads, or healthcare... they wouldn't know about it to begin with" (Female). Other avenues for information/communication that provided trusted, in-depth information and could effectively reach AIs were requested.

Reducing Message Barriers

Several participants offered recommendations for improving communication within AI communities. One female remarked, "talking about [HPV] with your families makes you more comfortable with wanting more information and talking to your doctor about it and not making it such a taboo to talk about. And that goes along with other STD's or HIV/AIDS, I don't think people are comfortable talking about it and I think that starts with your family." Another

commented that the big picture, the welfare of the community, is often missed in health education about STIs. One male stated that discussions should center on what AI community members need to do "in order to stay safe and stay away from cancer - that if you put it in those terms and not necessarily terms of sex - that might be an easier way to approach it."

Discussion

Human papillomavirus infection is highly prevalent among AI/ANs and is particularly high among high school and college-age females age 14 through 24 years (Bell, Schmidt-Griminger, Patrick, Ryschon, Linz, & Chauhan, 2007; CDC, 2010). Focus groups among American Indian college students at four Southwest universities identified communication pathways for seeking and obtaining HPV etiology and inoculation information. Findings indicated that students obtain HPV information from external sources such as the media, and that they actually preferred to communicate with siblings, relatives and physicians about HPV. In addition, cultural barriers often prohibit the ability of students' ability to seek information and to discuss HPV concerns with internal sources.

College students in this study identified the Internet, educational institutions and television commercials as their preferred external source of HPV information. This finding is consistent with a CDC study that reports the Internet, interpersonal, print, and broadcast media as popular avenues for HPV information (Friedman & Shepard, 2007). Schools and television commercials, in particular, were common information sources for study participants. Although siblings were identified as a frequent source of HPV information, less frequently mentioned sources were parents and the tribal community.

Preferred communication pathways for discussing HPV issues were internal sources such as siblings and relatives. Local clinic physicians were also identified as a preferred communication linkage. These sources allowed students to not only obtain information, but to discuss their fears, concerns and issues regarding

potential adverse events and future harmful effects. These communication pathways, although preferred, were not always available as they were often compounded by access barriers.

Barriers to HPV communication included lack of information sources, stigma, traditional viewpoints limiting discussions related to sexuality, and under-representation of AI/ANs in the health-related media. Isolated AI/AN communities and limited healthcare resources reduces the communication pathways choices. In addition, the stigma associated with a sexually transmitted infection, coupled with traditional cultural prohibition regarding active discussions about sexuality reported by study participants, compounds the problem of barriers to communication pathways of HPV information.

Reducing healthcare access barriers, particularly accessibility to HPV vaccinations, HPV screening and STI treatment, is paramount for closing knowledge and communication gaps (Ragin et al., 2009). Education and health messages must take into account AI/AN cultural perspectives, as well as informational and communication preferences. Strategies to reduce information/ communication gaps include improving inter-family communication and facilitating school-based, clinic-based and tribal community health events about protecting sexual and reproductive health.

This study focused on college students and therefore may not generalize to all members of AI/ANs communities. However it does provide important information as to the sources of information and preferred communication pathways of young AI/AN college students. Because the sample may have included individuals who possessed more educational opportunities and access to information about HPV than other AI/ANs, the findings are significant in that it signals a need for increased attention to HPV education and vaccinations, especially to younger and less educated members of the community. Expanding communication pathways may increase AI/AN

knowledge, attitudes and beliefs regarding HPV, and would go far in reducing the stigma associated with HPV communication and information seeking behaviors.

Based on the data presented, we recommend strategies to reduce gaps in information and communication surrounding HPV. These strategies must include culturally appropriate multi-media messages utilizing actors that reflect the community's minority population and messages that are acceptable to the culture. By actively distributing the messages to healthcare agencies, pharmaceutical and research industries, as well as those receiving the messages, such as AI communities, parents and young adults – a more comprehensive body of knowledge will be disseminated regarding the HPV infection, prevention and vaccination. In addition to improving access, we posit that education and health messages coming from all industries must take into account traditional cultural perspectives, as well as informational and communication preferences expressed by AIs in our study and others in order to address the numerous data gaps identified by research (Joseph, Clark, Bauchner, Walsh, Mercilus, Figaro, Bibbo, & Perkins, 2012). Targeted research should identify culturally-appropriate messages about preventing HPV and other STIs to be shared along reported key communication channels in a way that is agreeable to both the deliverers and receivers of the information. Researchers must also develop and test educational materials and intervention methods that incorporate cultural traditions and beliefs regarding HPV, STIs, and sexuality.

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