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## African American Parents' HPV Vaccination Intent and Concerns

**Vetta L. Sanders Thompson,**

Health Communication Research Laboratory, Washington University in St. Louis, George Warren Brown School of Social Work, 700 Rosedale, Campus Box 1009, St. Louis MO 63112, Phone: (314) 935-3702

**Lauren D. Arnold, and**

Washington University in St. Louis, Department of Surgery, Division of Cancer Prevention & Control, Department of Anthropology, Public Health minor, 660 S. Euclid Ave., Campus Box 8100, St. Louis, MO 63110, Phone: (314) 454-8123

**Sheri R. Notaro**

Center on Urban Research and Public Policy, Washington University in St. Louis, Campus Box 1186, St. Louis, MO 63130, Phone: (314) 935-6831

Vetta L. Sanders Thompson: vthompon@gwbmail.wustl.edu; Lauren D. Arnold: arnoldl@wudosis.wustl.edu; Sheri R. Notaro: snotaro@wustl.edu

### Abstract

This study describes attitudes and social and environmental factors that affect African American parents' intent to vaccinate their daughters against human papillomavirus (HPV). Thirty African American parents of daughters aged nine to 17 years and no history of HPV infection completed semi-structured interviews. Interviews addressed factors that influenced intent to vaccinate, perception of community norms related to vaccination, vaccination scenarios involving place of vaccination, and vaccination prior to or after the child's initiation of sexual activity. A recurring theme was the influence of physician recommendation on African American parents' intent to obtain HPV vaccination for their daughters. Most parents reported that they could overcome barriers to vaccination, except vaccine costs and lack of insurance. While religious beliefs were important to parents, they reported that they would not interfere with vaccination decisions; fears of early sexuality due to vaccination were limited. The implications of these findings are discussed.

### Keywords

African Americans; HPV vaccination; cultural attitudes and beliefs

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African American women experience higher cervical cancer incidence and mortality than their Caucasian counterparts.<sup>1–3</sup> The prevalence of human papillomavirus (HPV) infection, which is associated with cervical cancer, is significantly higher in African American women as well.<sup>4</sup> Although HPV vaccination can substantially lower the risk of cervical cancer, data indicate that less than 20% of eligible girls are fully vaccinated.<sup>5</sup> Being of African American race has been correlated with both lower initiation and completion of the HPV vaccine series.<sup>6,7</sup> Given the higher cervical cancer burden in African Americans, understanding factors that affect HPV vaccination behaviors, including parental attitudes towards HPV vaccination of their daughters, is critical.

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### Conflict of Interest Statement

The second author owns Merck stock.

Given that HPV vaccination is targeted at preadolescents or young adolescents, vaccine acceptability to parents is a central issue, and it is important to understand parental concerns and information needs. Studies also suggest that parental attitudes influence adolescent attitudes related to intent to receive the HPV vaccine.<sup>8-10</sup> Constantine & Jerman completed a random digit dial household survey of parental intent to vaccinate in California.<sup>11</sup> Data from this survey indicated that African American and Asian parents were less likely to accept HPV vaccination.<sup>11</sup> However, the number of African American participants was limited (N=36), which affects confidence in the findings. Other studies have indicated greater skepticism among African American and Hispanic parents.<sup>12,14,15</sup> Many parents do not understand the rationale for the vaccine's target age range and the implications of a vaccination decision for their children at any age.<sup>11-15</sup> In addition, some parents have expressed concerns related to vaccine use and risky sexual behavior among adolescents, as well as mistrust of pharmaceutical companies promoting HPV vaccine use.<sup>11</sup> While there are other studies of barriers to HPV vaccine use,<sup>16-18</sup> results often are not reported for African Americans or other ethnic minorities included in the samples. Finally, the studies that do report on African American parental concerns were conducted in western or southern states. Geographic variation in vaccination suggests a need to understand whether there are regional variations in parental attitudes that may affect HPV intent to vaccinate.<sup>19</sup>

To address disparities in cancer incidence and mortality in an urban, Midwestern city, researchers from a Community Networks Program to Eliminate Cancer Disparities (PeCAD) conducted surveys and interviews to assess cervical cancer, HPV, and Pap smear knowledge among African American parents of females in the vaccination age range, as well as beliefs, attitudes, and structural barriers to HPV vaccination. An analysis of the interview data are presented in this paper. The primary aims of this project were to describe the cultural attitudes, social and environmental factors that affect African American parents' intent to vaccinate. The use of individual interviews permits consideration of how the expression of religious, sexual and health related values, in addition to the influence of significant others, affect African American parents' HPV decision making. This understanding can be useful in the consideration of education and intervention efforts.

## Methods

### Participants

Study recruitment took place between February and June of 2009. Data presented here include the qualitative portion of a larger study of African American parents' attitudes toward HPV vaccination. The parent study involved two hundred African American men and women who completed a survey study, with a subset of 30 participants selected for interview. The detailed methods used in the survey portion of the study are described in a separate paper.<sup>20</sup> All participants were residents of the St. Louis Metropolitan Statistical Area. Eligibility criteria for the survey and the interview were men and women who: 1) identified as African American, and 2) had a daughter nine to seventeen years of age with no history of HPV infection.

### Procedures

The Washington University in St. Louis' Institutional Review Board approved this study and consent procedures. We used several sampling strategies. Community organizations, including a reproductive health service, father support center, and two health centers were primary recruitment sites. Each African American patron present during operational hours was approached to determine eligibility. This strategy resulted in 21 completed interviews. In addition, a community sampling strategy<sup>21</sup> was used to diversify the sample and recruit individuals who did not participate in established organizations or seek healthcare from a

usual source. Homes in zip codes containing more than 75% African Americans were approached to solicit eligible participants. Nine interview participants were recruited using this sampling strategy.

Participants were approached by the African American principal investigator or one of two African American research assistants to complete a self-administered survey and received a \$25.00 gift card for participation. The person soliciting survey participation also requested interview participation. Every third participant who received an odd identification number was asked to complete an interview, which took between 45 and 60 minutes, until 30 participants (15% of the total sample) were interviewed. Refusal data were not recorded. Interviews were scheduled at participants' convenience and completed at their preferred location. The majority of interviews were completed in participants' homes (N=19), with five completed in a private interview room at the recruitment site and six completed in an interview room at the investigator's university.

All participants received a detailed explanation of the interview before providing consent and received an additional payment of \$30. Interviews were audio-taped and transcribed verbatim. The transcripts were reviewed for accuracy by a research assistant, using the audiotape and field notes.

### Interview Protocol

Interview questions were developed by the first author based on a review of the existing literature and surveys found in the literature.<sup>16, 22, 23</sup> The protocol used a problem centered interview format, with a focus on HPV, HPV vaccine knowledge, intent, and behavior, as well as facilitators and barriers to vaccination. Participants were asked to discuss their intent to have eligible children receive the vaccine, factors that influence intent or the decision to vaccinate (if a child received the vaccine), and their perception of community norms and concerns related to vaccination. Additionally, they were asked to respond to materials that presented HPV vaccination in the context of sexual health vs. cancer prevention, vaccination scenarios involving location of vaccination (private physician, community health clinic, health department, or facilities providing reproductive health services), and vaccination prior to or after the child's initiation of sexual activity. Interviewers listened for themes and followed up on topics relevant to issues raised in prior interviews. Interviewers maintained the protocol, which provided prompts to permit interviewers to guide participants back to the central issue being explored, obtain greater details on topics raised, and obtain elaborations of ideas that seemed important. Field notes developed after each interview described the setting and any notable participant observations.<sup>24,25</sup>

### Data Analysis

The research team comprised of a psychologist and two graduate research assistants developed initial rules and categories for coding after reviewing project goals, the content of the interviews, and the existing literature. The coding scheme was revised as coding proceeded to include omitted categories and assure that interview content was accurately represented. There were three statement types coded: anecdotes, general attitudes or beliefs, and statements specific to HPV. The HPV specific codes focused on positive or negative intent to vaccinate, attitudes related to vaccination encountered among physicians, family members, friends, and/or faith based community members, statements specific to religious attitudes, youth sexuality, vaccine knowledge needs and safety, and barriers to vaccination. Additional coding captured statements related to preferences for receiving vaccine information and administration.

Each interview was coded by two people. Each coder read and coded assigned transcripts and then met with the partner to review codes and discuss any discrepancies until reaching consensus.<sup>24</sup> Because coding was iterative, many discrepancies in early coding were related to the addition of new codes or to the elaboration of existing codes. The consensus approach was used to resolve these issues and the coding of earlier text was revised to reflect the new coding. If coders did not reach consensus, the principle investigator made the final coding decision based on a reading of the transcript text, review of coding rules, and available survey data. Once coding was complete, all three team members met to discuss core ideas and general themes. The discussions yielded a set of attitudes about HPV vaccination intent and the factors that influenced parents' decisions, including community norms, HPV vaccination concerns, the role of beliefs about youth sexuality, and the role of religion and other barriers related to intent to vaccinate. These core findings were then refined and prioritized. The project's community advisory council reviewed and provided comments on these findings.

## Results

Interview participants include twenty-five women and five men, with an average age of 42.4 years (range: 26–60). All interview participants reported that there was a usual place where they took a child for, or a usual person who provided, sick or routine care (e.g. private physician, federally qualified and community health clinics). Sixteen participants reported the use of private health insurance for their children, and another ten parents reported that their daughters had some form of health insurance identified as Medicaid or State Children's Health Insurance Program (SCHIP). Four parents indicated that they and their children were uninsured.

The participant interviews offer insights into the factors that influence parental decisions about HPV vaccination. Six major themes were identified: the influence of physician recommendation, vaccine decision making, desire for information related to vaccine safety, youth sexuality, HPV vaccine costs, and religious issues affecting HPV vaccination decisions. Physician Recommendation. Physician recommendation was important in the decision to vaccinate due to interpersonal and professional factors. Most patients cited their trust of and long-term relationships with their child's provider. In addition, several parents noted the importance of medical history in the decision to vaccinate and the ability of the physician to weigh the family and child's health history when making a recommendation on HPV vaccination.

Parent (P): Just because that's who does all of her medical treatment. They know her medical history. They know her. So, I feel better with them providing her with any vaccinations or anything that she gets.

P: Well, like I say, he's been there since my kids been born. Plus he was my brother's pediatrician. He's (brother), like 26 years old. He's a family doctor you know. He's been going down the line. So I really do trust him.

Parents gave examples of the rationales that physicians offered for their recommendations, which included a history of chronic diseases such as sickle cell anemia and asthma. These parents indicated that the decision to vaccinate was to protect against infections that these chronically ill children would find more difficult to fight. Also, the child's sexual activity or lack of sexual activity and vaccine safety were reportedly rationales for physician recommendation to vaccinate.

P: Well, when she went for her physical, her pediatrician said that she wanted to wait for her to get the vaccination, because, I guess, the drug, or something with the

vaccination hasn't been FDA approved for at least five years. So she didn't recommend her to get it just yet.

Participants in this sample were less concerned about their own knowledge because they felt that they could discuss these issues and obtain the necessary information from their provider. While parents noted that they lacked knowledge and were unlikely to vaccinate in the absence of a physician recommendation, there were limits on the role of the physician in the final decision to obtain HPV vaccination for their daughters. Parents went on to indicate that the final decision about vaccination was theirs.

P: Her doctor was really pushing getting the vaccination. But I had to read up on it, get more information than I previously had. I try to impress upon my children the importance of being proactive about your own health.

### Vaccine Decision Making

Men and women agreed that the final decision about HPV vaccination for their daughter's was most often made by mothers, with father consultation as the mother perceived necessary.

P: I mean, because, you know, my husband leaves it up to me. My children, you know, it's just I've always handled things.

Most parents felt that the child could express feelings and concerns about vaccination, but ultimately the decision was made by the parent(s).

P: She and her mother would discuss it and we'd [father and mother] just make a decision for her.

P: Because at a certain age you do not be a part of decisions. I'd say when you at least 18; you can decide.

Many reported that they felt obligated to inform their daughters about HPV, the vaccine and why they believed the vaccine was or was not beneficial.

P: She was involved at the last minute. I gave her the pamphlet to read and talked to her you know. But other than that, no, I didn't go into detail or anything.

P: I would give her some information about it. Letting her know why she would have to take it. I: "What if she didn't want to take it?" P: I would find out why she wouldn't take it. We would discuss the pros and cons to help her make an informed decision.

Parents questioned the appropriateness of mandatory vaccination because of the likelihood of interfering with the parent's decision making role, perceived differences in children's risk of exposure to HPV, and possible religious objections.

P: No I can't say that I agree with that because I have a sister-in-law that Jehovah's Witnesses and they don't believe in a whole lot of stuff, so that they should force it on people.

P: Because if you feel that something is good for my child, that's not really right [to make it mandatory]; because some vaccinations, I just feel it might not be necessary.

### Vaccine Safety

In response to queries about barriers to vaccination, side-effects were most often cited. Many parents noted that they had seen very little information on the side-effects of youth HPV vaccination.

P: Well, when I first heard about it, I said, Okay. But, what about the side effects? Because we haven't really heard anything about the side effects.

When asked what side-effects would be of concern, they noted death, infertility, or risk of other diseases such as "autism". Participants indicated that they were not concerned about side-effects such as dizziness, nausea, pain and swelling at the injection site, or fainting.

P: No, those [dizziness, nausea, pain and swelling at the injection site, or fainting] could be like remedied. Because sometimes, while a young girl menstrual, she'll experience stuff like that. So that's minor, minor. Bigger issues are, you know, how it will affect her mentally and physically and, you know, skin irritation [skin breaks out in blotches] and you know, if she had swelling of the limbs and things like that.

P: If there is a 50/50 chance that it [HPV] would leave my child handicapped or something, that would turn me off.

P: Probably anything that would adversely affect her female organs, her reproductive organs, you know, or would cause damage to her like immune system or something like that.

P: My concern was would it make her menstruation act crazy, would she gain weight or change her eating habits, you know, would it affect her physical health. That was my concern.

One parent was very knowledgeable about the vaccine and discussed HPV vaccine safety in terms of a false sense of safety. She noted that the HPV vaccine did not protect against all strains of the virus and might lead youth to forget the health risks associated with strains that were not protected against.

Males were more likely to express concerns about the government's role in the development of the HPV vaccine and vaccination efforts and their implications for HPV vaccine safety. Several males noted that "Tuskegee had to be considered." Female participants expressed varied views, from dismissal of concerns related to experimentation to the importance of participating in vaccine and other research in order to improve community health.

P: No, they experiment on everybody. I mean, how do they think, the people will have to experiment to know what's good. I mean, they experiment on animals. Animals is animals, humans is humans, okay, so if they experiment on people that's your decision if you want them to experiment and for you to get help. I mean, they tell you when you get it, it's a risk.

P: They experiment on everybody with it though. It's not necessarily just black people.

## Youth Sexuality

Parents noted that they would see more urgency to HPV vaccination if they believed that their daughters were sexually active; however, sexuality was not the primary basis for making the HPV decision. Parents reported that the health of the child was the main factor in their HPV vaccination decision.

P: I explained to my daughter, it's not about trying to have sex or be grown. It's about your health, what's important for you. It's about cancer.

Parents also commented that they did not believe that HPV vaccination would encourage early sexuality. One parent stated, "the shot (is) not a hormone shot; it will not make them want to have sex." Parents did discuss that adolescents might not understand that they were only being protected against cervical cancer. This lack of understanding was discussed in

relationship to sexual risk taking among vaccinated youth. However, parents indicated that youth engaging in risky sexual behavior were likely to do so regardless of HPV vaccination status and that this was an issue of parent child communication and supervision.

P: Getting them the vaccination, no, that's not a sign. Now putting them on birth control, that's a sign of permission.

P: I guide them, even my son. You know, I talk about abstinence all the time. So guide them. After they graduate and get out of my household, that's fine. But while they're here no. I know they're young, and I know they're human and things come up. But, I don't think it really give them permission to have sex.

The age of the child was discussed as a part of concerns about sexuality. Parents expressed reluctance to vaccinate girls as young as nine years old. Parents stated that they were less concerned about sexuality at this age, which was believed to inform risk of infection. Parents reported that they had time to protect their daughter's health. Most expressed a preference that HPV vaccination not be discussed before age 12.

### Vaccine Costs

When costs and religious issues were not discussed, participants were queried about these issues. Parents indicated that private insurance or Medicaid coverage made vaccination feasible given the cost of the series of shots. Among those parents who were unaware that HPV vaccination involved three shots, costs were not viewed as a barrier. Among parents that were unaware of the HPV vaccine associated costs, the researchers provided this information to gain insight into how this knowledge of HPV vaccine related costs would affect their attitudes about HPV vaccination. Many parents were shocked at the costs and this led to more extensive discussions of this issue. Those with insurance were less concerned, but indicated that coverage by their insurer would determine whether the vaccination was provided. Uninsured parents expressed caution toward HPV vaccine uptake. They discussed the need to assure that they would not incur medical bills that they were unable to pay.

P: It's only going to affect my decision to a point; if it's something that I deem necessary or we (husband) deem necessary, then it's going to happen.

P: I mean as long as it's within reason and it's something that I feel I could pay for and afford, then no cost would not affect my decision. If it's not like an outrageous price.

### HPV Vaccine and Religious Issues

Religious concerns were discussed when queried, but participants did not believe that the issue affected their decisions about their own child(ren). Participants who expressed a devout commitment to their religious beliefs stated that they would pray for guidance, but many indicated that church leaders and doctrine could not decide the issue of HPV vaccination.

P: Yeah, yes, I did. I always trust God first. I always pray for guidance and protection. And if it's something He put on this earth to help His people, then yes, you know, I want that to be given to my daughter. I'm led by the Holy Spirit. It lead me to make the right decision that this would help her, you know, then yeah.

One participant noted the importance of a "spirit of discernment", in which religious beliefs, prayer and spiritual guidance are used to make individual decisions.

P: God has his place because—and that is at the head, but there are certain decisions, you know he gives you the spirit of discernment too. So there are decisions that you are gonna have to make whether he is involved in it or not.

Participants speculated that parents from some religious denominations, such as Jehovah's Witness, might have stronger objections. There was also discussion of whether older members of the church could be relied upon for advice and guidance as new health issues and treatments emerged because of their tie to "old fashioned" beliefs.

P: I could talk to my mother about it, but that would not go into my decision making process. Not that I don't trust my mother's opinion, but she knows less than I do about it.

## Discussion

This paper adds to the literature on African American HPV vaccination attitudes and presents data using a Midwest sample. African American parental interviews suggest confidence in the ability to obtain HPV vaccination for their age eligible daughters. Although parents in this sample expressed confidence, they admitted that they sometimes lacked necessary HPV knowledge and often relied on their physicians for information to fill this knowledge gap. While religious, religion did not appear to be a barrier to HPV vaccination and these parents dismissed concerns that HPV vaccination would result in early or promiscuous sex. There were however concerns about and a desire for information related to HPV vaccine safety and costs, as well as age of vaccination.

Consistent with the literature,<sup>8-10</sup> the strong role that physician recommendation plays in African American parents' intention to obtain HPV vaccination for their daughters was noted. Parental discussions of HPV decision making for their daughters suggest that physician recommendations are likely to be followed in the context of an established patient-provider relationship. Physicians were also seen as a source of information in the absence of knowledge. As other researchers have noted,<sup>11,15</sup> there were a number of concerns related to vaccine safety, but these did not generally seem to be reflective of medical mistrust. Parents noted that they had not heard or found much information on serious side effects (changes in menstruation, reproductive ability or overall health) from the vaccine. It appears that serious side effects would affect HPV vaccination intent more than more immediate side effects (pain, swelling at vaccination site, fainting) most often described. Fathers expressed some mistrust of the vaccine based on the government's role in its development, but deferred decisions about vaccination to mothers, most of whom rejected these concerns.

Contrary to previous findings,<sup>13, 16</sup> parents in this sample did not express concerns that HPV vaccination would lead to early or increased youth sexuality. There were concerns about vaccinating very young girls because they were perceived as less likely to be sexually active. This view suggests that parents are not aware of the reasons for the targeted ages for HPV vaccination, which is consistent with the findings of previous studies.<sup>11-15</sup> This suggests an opportunity for education; parents should be helped to understand that the goal is to vaccinate girls before they become sexually active in order to increase the likelihood of vaccine efficacy. The attitudes related to religion and religious beliefs were also somewhat different from those of previous studies.<sup>13,16</sup> While religion and religious attitudes were important to parents in this sample, they would not interfere with decisions made about their children's health. Parents were confident in their ability to use prayer and personal guidance from God to make health decisions and expressed less reliance on church leadership. Parents reported an awareness of sexual attitudes and beliefs within the community, church, and family that would suggest negatives attitudes toward HPV vaccination, but contrary to earlier studies, these attitudes were not prevalent among parents in our sample.

Most parents interviewed reported that they could overcome barriers to vaccination, which have previously been associated with low vaccination rates. However, consistent with previous studies,<sup>10</sup> parents indicated that insurance coverage and reasonable costs were factors that they had to consider. Parental concerns related to costs suggest an opportunity for education. The costs for the vaccine and lack of insurance should not represent a barrier because HPV vaccination is covered under the Vaccine for Children program. If this information were readily available to uninsured parents it might increase vaccination by allaying fears related to costs.

### Implications

The addition of findings from a Midwest sample to the literature may provide information that can inform educational campaigns to assist African American parents to make informed decisions about HPV vaccination. New educational materials will be most useful to African American parents if they discuss both short and long term side effects of HPV vaccination, while also examining their seriousness. Health promotion and education materials should include the most recent and accurate information on the side effect profile of the HPV vaccines now available. Parents should also be informed of the Vaccine for Children program that can assist with the costs of obtaining the HPV vaccination series. A new tool might also assist parents by allowing them to weigh the side effects, benefits, costs and any other individual, social or cultural concerns they might have to make the best decision for their child and family circumstance. This suggests that some parents might find a decision tool helpful. However, the most important activity will be working with the healthcare community to assure that African American parents and their age eligible children have an opportunity to discuss sexual behavior and sexually transmitted infections, including HPV, with their provider to facilitate informed decision making and action, using their preferred source of information and consultation. This focus on the healthcare community should also include linking African American parents and their children to healthcare resources. An emphasis should be placed on ensuring the establishment of good patient-provider relationships so that the appropriate discussions take place.

### Limitations

Researchers and health educators should carefully consider the limitations of these interviews when considering their utility in other settings and populations. It is possible that the lack of diversity among survey administrators and interviewers augmented the responses of study participants producing socially desirable comments. Although an effort was made to include African Americans of diverse background, the participants were not representative of a national or local sample of African Americans. Therefore, there may be greater numbers of individuals with healthcare and physician relationships in this sample, which may limit the generalizability of our findings. This sample was composed of volunteers, and it is impossible to know how individuals who chose to participate differ from those who did not; refusal rates and data on those refusing were not collected. Finally, these interviews were completed before the approval of Cervarix and before Gardasil was approved for men and only parents of girls were interviewed and parental comments were focused on what they knew about Gardasil.

### Conclusion

The findings of the current study suggest that African American parents, in consultation with trusted healthcare providers, expect to exercise strong influence over HPV vaccination of their daughters. While larger, long term studies of HPV vaccination attitude, intent, and behavior are needed, this study suggests HPV and HPV vaccination information needs can be addressed through these healthcare relationships and in targeted educational materials and decision tools.

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