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The HPV Vaccine: A Comparison of Focus Groups Conducted in South Africa and Ohio Appalachia

Shelley A. Francis and

Division of Health Behavior and Health Promotion, College of Public Health, The Ohio State University, 354 Cunz Hall, 1841 Neil Avenue, Columbus, OH 43210, USA

Mira L. Katz

Division of Health Behavior and Health Promotion, College of Public Health, The Ohio State University, 354 Cunz Hall, 1841 Neil Avenue, Columbus, OH 43210, USA

Division of Cancer Prevention and Control, Department of Internal Medicine, College of Medicine, The Ohio State University, Suite 525, 1590 North High Street, Columbus, OH, USA

Shelley A. Francis: sagfrancis@gmail.com; Mira L. Katz: mira.katz@osumc.edu

Abstract

Worldwide, cervical cancer is one of the leading causes of morbidity and mortality among women. Even though women in developing countries account for approximately 85 % of the cervical cancer cases and deaths, disparities in cervical cancer rates are also documented in developed countries like the United States (U.S.). Recently, formative research conducted in the U.S. and developing countries like South Africa have sought to gain a better understanding of the knowledge, beliefs, and attitudes about cervical cancer prevention, HPV, and the acceptance of the HPV vaccine. This study compares findings from two independent focus group studies. One study was conducted in a segregated township in Johannesburg, South Africa ($n = 24$) and the other study was conducted in Ohio Appalachia ($n = 19$). The following seven themes emerged during the discussions from both studies: HPV and cervical cancer; health decision making; parent–child communication; healthy children; HPV vaccine costs; sexual abuse; and HPV vaccine education. Findings from both studies indicate the importance of the role of mothers and grandmothers in the health care decision-making process for children and a lack of awareness of HPV and its association with cervical cancer. While there was interest in the HPV vaccine, participants voiced concern about the vaccine's cost and side effects. Some participants expressed concern that receipt of the HPV vaccine may initiate adolescent sexual behavior. However, other participants suggested that the HPV vaccine may protect young women who may experience sexual abuse. The importance of developing culturally appropriate educational materials and programs about cervical cancer prevention and the HPV vaccine were expressed by participants in both countries.

Keywords

HPV; HPV vaccine; Cervical cancer prevention; Vulnerable populations

Introduction

Cervical cancer remains a significant public health problem for women worldwide, with an estimated 529,409 new cases and 274,883 deaths in 2008 [1]. According to the World

Health Organization (WHO), women in developing countries account for approximately 85 % of cervical cancer cases and deaths [1]. In South Africa, a developing country, the age-standardized cervical cancer incidence rate (26.6 per 100,000 women) and the age-standardized cervical cancer mortality rate (14.5 per 100,000 women) are elevated compared to cervical cancer rates in the United States (U.S.; 5.7 and 1.7 per 100,000 women, respectively) [2, 3]. Factors contributing to the elevated cervical cancer rates in South Africa may be due to the increased human papillomavirus (HPV) prevalence among women with normal cytology in South Africa (21.0 %) compared to women in the U.S. (13.5 %) and lower cervical cancer screening rates (13.6 %) compared to cervical cancer screening rates among women living in the U.S. (84.0 %) [2, 3].

What is interesting to note, however, is that cervical cancer disparities not only exist between developing and developed countries, but are also documented among different population groups of women in developed countries [4–8]. For example, in the U.S., elevated cervical cancer incidence and mortality rates occur, respectively, among non-Hispanic Blacks (10.2; 4.3 per 100,000 females) and Hispanic females (11.5; 4.0 per 100,000 females) compared to non-Hispanic white females (7.5; 2.2 per 100,000 females) [9]. In addition, cervical cancer rates vary by geographic regions within the U.S., with cervical cancer disparities documented among females living in the Appalachian region of the U.S. [4, 5, 9]. Factors associated with cervical cancer disparities among women living in Appalachia include lack of knowledge, cultural beliefs about cervical cancer, the social environment, less education, increased poverty, provider-patient communication issues (e.g. lack of recommendation for screening), limited healthcare access and insurance, lack of follow-up of abnormal screening tests, increase HPV prevalence rates, as well as an increase in the prevalence of specific health behaviors such as risky sexual activity and tobacco use [10–12]. Many of these same factors have been identified in previous research in South Africa, in addition to past social inequalities and policies instituted during apartheid [1, 13–16].

In 2006, the HPV vaccine was approved by the U.S. Food and Drug Administration and recommended by the Advisory Committee on Immunization Practices for the prevention of cervical cancer [17]. The HPV vaccine was licensed for use in South Africa approximately two years later in 2008. With the availability of the HPV vaccine in South Africa and the U.S., independent cancer health disparities research teams sought to understand women's knowledge, attitudes and beliefs about cervical cancer prevention in both countries using similar formative research methodology. The purpose of this report is to compare findings about cervical cancer prevention, HPV, and the acceptance of the HPV vaccine among residents of two distinct geographic locations that face many similar yet different socio-environmental issues.

Methods

Focus groups about cervical cancer prevention were conducted among women living in South Africa and parents living in Ohio Appalachia. The Witwatersrand University and Case Western Reserve University Institutional Review Boards approved the protocol for the South Africa study and the Institutional Review Board of the Ohio State University approved the protocol for the study in Ohio Appalachia. A brief description of the methods used in each study follows.

South Africa

Participants were recruited from an antenatal clinic in a Black township within Johannesburg, South Africa, in the fall of 2008. A detailed description about the study design and recruitment are provided elsewhere [13, 18]. Briefly, participants were recruited

from a larger survey study that sought to examine women's knowledge, beliefs, and attitudes, about HPV and cervical cancer. After completing a survey, 24 women also agreed to participate in focus groups about cervical cancer prevention, HPV and the HPV vaccine. Participants provided written, informed consent prior to the start of the focus groups. Each group lasted about 90 minutes, was digitally recorded, and was facilitated by two trained moderators including one staff member who was fluent in eleven different local dialects. A third staff member took notes and assisted with group management. Participants were given ZAR 50 (\$5 US), a light meal, and travel vouchers in appreciation of their time.

Focus group discourse was transcribed verbatim and supplemented by handwritten notes. The analyst triangulation technique was used to analyze focus group data. This technique uses multiple analysts to review findings. Using grounded theory, recurring themes were identified and grouped according to grand thematic areas. Coding themes emerged after review of each question (within groups) and then were analyzed across all three groups.

Ohio Appalachia

Community members residing in Ohio Appalachia were recruited to participate in focus groups during the summer of 2007. Participants were recruited with assistance from members of local community-based cancer coalitions associated with the Ohio Appalachian Community Cancer Network. Community members posted flyers at various sites (e.g. health departments, libraries, etc.) throughout the different counties and also contacted local community-based agencies to spread the word about the focus groups. Community members were recruited for four types of focus groups: parents of young girls, women (18–26 years of age), community leaders, and healthcare providers.

To be eligible for the study, participants had to be 18 years or older, read and speak English, have a daughter who was 9–17 years of age, and provide written consent. A detailed explanation about the study design and findings has been previously reported [19]. Briefly, the focus groups were conducted using an interview guide based on the social determinants of health framework [20]. The groups lasted about one hour, were audio recorded, led by an experienced female moderator (MLK), and field notes were recorded by a research team member. Participants were provided with a \$25 gift card in appreciation of their time and a \$5 gift card to a local gasoline station to cover travel expenses.

Focus group discourse was transcribed verbatim, and transcripts were reviewed for accuracy. A code tree was developed based on the topics that emerged from the discussions, three research team members reviewed differences in coding and reached a consensus, revised the coding tree, and transcripts were coded using NVivo qualitative software (QRS International Pty. Ltd.). Findings from across the six focus groups of parents are included in this comparative study.

Results

Participants

South Africa—Three focus groups were conducted with 24 participants. Participants were females between 18 and 44 years old, had at least some education, with 50 % having completed secondary school (i.e., high school equivalent), and could read and speak English. All participants had at least one child, with 53 % having a daughter. Most (87 %) participants lacked medical aid (equivalent of medical insurance in U.S.).

Ohio Appalachia—Six focus groups were conducted with 19 participants (17 mothers and 2 fathers). Since HPV is a sexually transmitted infection, we thought it was important to also

obtain the opinions of fathers in our study. Participants had a mean age of 36 years, were white, and all participants had at least one female child (age 9–17 years of age). In addition, 11 of the parents were married and six of the parents had less than a high school education.

Themes

Seven similar themes emerged from the focus groups conducted in both countries and include: awareness and knowledge about HPV, the HPV vaccine, cervical cancer and cervical cancer screening; health decision-making; parent–child communication; healthy children; HPV vaccine costs; sexual abuse; and HPV vaccine educational materials and programs. The different themes are described below with quotations selected from participants from both countries to illustrate each theme.

HPV and Cervical Cancer

Awareness and knowledge about HPV, the HPV vaccine, cervical cancer, and cervical cancer screening were mixed among focus groups within and between countries. Although many participants were aware of Pap tests to check for cancer, very few participants were aware of the association of HPV and cervical cancer, the elevated cervical cancer rates among women living in their specific geographic location, and how the HPV vaccine may protect young women from cervical cancer.

In South Africa, although some participants did not understand what cervical cancer was, others had some basic understanding of cervical cancer and cervical cancer screening. For example, one participant explained cervical cancer as: “Cervical cancer is where cells in your womb grow out of control and they need treatment. Uncontrollable growth of bad cells in your womb.” and that a Pap test checks for cervical cancer: “What I heard about it is...if you are to have it you must go and have a pap smear when you are a woman over the age you can go and check it for a Pap smear.”

In Ohio, women stated that they were not informed about the elevated cervical cancer rates in Ohio Appalachia. One participant stated: “I mean I knew very little. I mean I know what it is and I know that is why they do Pap smears to make sure you don’t get it. Things like that but not a whole lot.” Most residents talked about lung cancer or breast cancer being prevalent in their communities. Some Ohio Appalachia participants had a greater awareness about cervical cancer, with some women sharing that family members had been diagnosed with cervical cancer. One participant shared: “My mom never had a pap smear...until she had cervical cancer...and then she got older and she didn’t believe that it was sexually transmitted. I mean there are different types of cervical cancer and ways you can get it and everything but they’re sticking with the sexually transmitted part.”

During the focus groups, women’s knowledge about HPV and its association with cervical cancer were explored during the discussions. Participants in both countries had very limited knowledge about HPV and most were aware of it because of the HPV vaccine.

A participant in South Africa stated: “...they are so anxious to know about this HPV because no one knows about it, and for most of them, this is the first time they have heard about it.”

In Ohio Appalachia, many of the participants attended focus groups to learn more about the HPV vaccine. One participant stated: “Well my daughter has a doctor’s appointment tomorrow and they ask me are you getting this vaccine and I said I don’t know anything about it and then I saw this meeting so I came.”

Health Decision Making

Making the decision to have a child receive the HPV vaccine was discussed in most focus groups conducted in both countries. Focus group participants suggested that health care decisions for family members were mostly made by females in both South Africa and in Ohio Appalachia. The significant role that mothers and grandmother's play in this capacity are critical in developing future strategies to prevent cervical cancer.

South Africa participants reported that the grandmother may be involved in the health decision making process and was often looked to for health advice. In addition, participants mentioned that there was limited male (father) involvement in raising children or making health care decisions. Participants commented: "Most of the time it is the mother, but you also get advice from grannies and older people in the community and the clinic." and "Men, they do not take their role in parenting or in the children's life. Men just go to work in the morning, come back later. Often they just eat and sleep. He doesn't ask about the kids, how the kids spent their day. He doesn't want to know nothing about them. I leave him out of these decisions. Most of the time it is believed that it is the woman's role to raise the child."

In Ohio Appalachia, many similar issues were raised by participants. Examples of comparable statements were: "...a lot of Appalachian family's are very matriarchal. The grandmother and the mother tell everyone in the family how things are going to be." and "Mom looks to grandma to see how to answer things." In terms of male involvement, one participant reported speaking to a father about the HPV vaccine but noted that he was generally not involved in the decision making process. In this case, she wanted to keep him informed that she was considering the vaccine for their child: "...and I called him and spoke to him about the vaccine just to make sure that he didn't have an issue, so, you know, but generally he is not involved but I thought since this one had controversy surrounding it you know I thought he should know."

Parent-Child Communication

A significant concern voiced among focus group participants in both countries was that the HPV vaccine brought up issues associated with parent-child communication regarding topics associated with sexual behaviors, including sexually transmitted infections.

South African participants reported talking to their children about a variety of health topics, including sex. Some participants identified with religious tenets regarding premarital sex and shared the following comments: "I feel like everyone should learn, and talk to the children especially when it comes to sex. I believe there is no reason to hide, because if you hide the children won't know the truth especially at seven years old." and "I think that it [premarital sex] is wrong, but there is nothing we can do, but I also tell them to protect themselves against diseases that you can get sexually, but, uh, with my kids I think I would teach them after they are married and also that goes with religious means, teach them to go to church, and the Bible. I believe the Bible keeps you away from a lot of trouble and to keep sexual intercourse until after marriage."

Many participants from Ohio Appalachia were very concerned about the message the HPV vaccine would send to their daughters. Participants stated: "... they are indicating that our girls are going to want to be sexually active? And I don't know I guess I was more worried about what message does it send to my child?" and "...because I felt like it indicated that my daughter was going to be sexually active. And you know, maybe I'm in denial. You're not going to want to think of that. That at twelve years-old she's going to be sexually active." Yet other participants thought that the HPV vaccine may be an opportunity to improve communication with their children about sex. One mother stated that she told her daughter: "...don't be afraid to go to the doctor or talk to your mom about anything."

Healthy Children

In the focus groups, participants discussed how the HPV vaccine may benefit the health of their children. Women expressed concern about their children's health and the challenges associated with keeping them healthy. Many of the participants both in South Africa and Ohio Appalachia stressed that they had to protect their children and keep them safe. For example, a South African participant expressed: "...foremost desire to care as best they could for their children..." and in Ohio Appalachia this was expressed as: "...you know as a parent I owe it to her to protect her in any way I can." and "...I am just concerned for my daughter."

Although most comments about the HPV vaccine were positive, some participants' did express concern about the vaccine's short and long-term side effects and that their children might initiate sexual activity after receiving the HPV vaccine. South African participants expressed positive thoughts about the HPV vaccine: "We feel ok because it's a chance to be healthy." and "...childhood vaccinations are a proper defense against preventable disease." Parents in Ohio Appalachia stated: "...after I talked to a pediatrician because I wasn't quite sure because I have the two girls, and I was kind of apprehensive at first but the more I read about it the more I felt that it was a good thing to do." Some parents in Ohio Appalachia expressed concern with the number of vaccines that are recommended for their children and the risk associated with the vaccines. One participant stated: "But I think all vaccines...there is a risk with everything that you do...you have to weigh the risks and the benefits."

Participants raised concern about short and long-term side effects associated with the HPV vaccine. A South African parent voiced: "I would be concerned of long term effects of the drug, how it would affect my child later on." This same concern about long-term side effects with the HPV vaccine was voiced in Ohio Appalachia. One parent from Ohio Appalachia stated: "I think for me I would just want to know what the side effects are...what side effects they'll have or have years down the road." Other parents in Ohio Appalachia decided to wait to vaccinate their daughters until more data became available about any long-term effects of the HPV vaccine. As expressed by one parent: "...because I'm very cautious about new vaccines. I want to see, you know, has it been tried and true before my child gets it and then there's a problem with it. We were kind of holding off awhile to see if there are any side effects or problems with the vaccine because it is relatively new."

The concern that the receipt of the HPV vaccine may be misinterpreted by their child as permission to initiate sexual activity was expressed by some parents in South Africa and Ohio Appalachia. Although this concern was not expressed by all parents, it was a topic raised in most focus groups. One South African parent stated: "Our kids take things their own way. When you give your child the vaccine she thinks you are giving her permission to go and sleep around. So the important, the best thing is that you sit down with your child and give her the reasons why you are allowing them to take the vaccine." An Ohio Appalachian parent stated: "...but I've heard people complain, you know, that it is giving an out for you kids to have sex if you get this vaccine."

HPV Vaccine Costs

In addition to concerns about the long-term effects, participants from both countries expressed concern about the cost of the vaccine. During the discussion of cost, a distinct difference was noted from parents about the involvement of government in their lives.

In South Africa, many of the participants voiced the opinion that the government should underwrite the costs of the HPV vaccine. However, some participants did feel that individuals should pay something for the vaccine and that it should not be free. One participant stated: "It depends on the price. But I think that the government should at least

try to make it a reasonable price so we can afford it, allow us to pay for it because we cannot always get something for free. It must be a reasonable cost.”

In the U.S., many children from low-income families are eligible for the Vaccine for Children Program (VFC), a federally-funded program which pays for the HPV vaccine. Although many participants from Appalachia feel strongly about government not invading their privacy, no one voiced their opposition to the government paying for the HPV vaccine. For children not eligible for the VFC program, the cost of the HPV vaccine was voiced as a significant barrier by some participants. An Ohio Appalachia participant shared the following thoughts: “We are really lucky that we have insurance that covers it because at first the cost was very prohibitive. And as soon as we found out that it was covered we were all like, ‘oh okay we’re going to go get this vaccine’.”

Sexual Abuse

Issues relating to sexual abuse came up in several focus group discussions about the HPV vaccine in both countries. In South Africa groups, women mentioned that the vaccine might offer protection to young girls if they were raped. In Ohio Appalachia focus groups, the topic of rape emerged as parents discussed possible reasons for vaccinating their daughters. Although many parents voiced the opinion that their young daughters were not sexually active, one participant’s concern about sexual abuse was voiced: “Well I mean no one wants to think about this but if my daughter abstinence is the reason I talk to her about...but what if she were raped? What if she were attacked? You know if that happens to you, than you would have a higher chance of contracting a sexually transmitted disease because of the type of person who attacks you so I think you can have abstinence and the vaccine and they’re not contradictory.”

HPV Vaccine Education

The lack of awareness and understanding about HPV and its association with cervical cancer was evident by the discussions that took place in all focus groups. Participants from both countries expressed the need for additional educational materials and programs about cervical cancer prevention, HPV, and the HPV vaccine for themselves and their children.

An Ohio Appalachia participant expressed: “I think more information is needed on HPV in general. A lot of people don’t even really understand what it is.” Another participant in Ohio suggested: “...Sometimes people don’t know what to ask. They don’t have a question to ask. You know and maybe if somebody else had asked the question then they would have said well yeah I wanted to know that.” This idea of sharing information also emerged in a South Africa focus group, when a participant stated: “We need a place where we can talk about that. In church, we can’t. In a women’s group after we could talk about it.”

Although many parents suggested that they would not have a problem discussing the HPV vaccine with their children, other participants in both countries suggested that they could use additional assistance on how to discuss cervical cancer prevention, HPV, and the HPV vaccine with their daughters.

In addition to the similar themes that emerged from the different countries, there were also a few differences that were also raised by the focus group participants from the different countries. In South Africa, the women discussed the importance of keeping their children healthy, concerns about premarital sex and how premarital sex was viewed differently for males versus females, their source of health information came from providers, family, traditional healers, and the media (e.g. newspapers, radio), and women expressed a desire to learn how to talk to their children about sexual and reproductive health issues. In Ohio Appalachia, the parents also thought that cervical cancer was caused by other factors (e.g.

hereditary and environmental issues), their source of health information varied from media (e.g. TV and the internet) to family members and friends, and participants stated that the Appalachian culture etc (e.g. religious, conservative, etc.) plays a significant role in their life.

Discussion

This comparative study is one of the first studies to contrast cervical cancer prevention, HPV, and the HPV vaccine findings among residents living in two very distinct settings in different countries. Key findings about the HPV vaccine voiced by focus group participants in both countries were: there is a lack of awareness of HPV and its association with cervical cancer; although there were positive thoughts about a vaccine to prevent cancer, several concerns were expressed about the short and long-term side effects of the vaccine, concern that the receipt of the HPV vaccine may influence adolescent sexual behavior, the cost of the vaccine; and the importance of mothers (and grandmothers) in health care decision making for family members. One unexpected issue that was raised in focus groups conducted in both countries was that the HPV vaccine provided protection to women who may experience sexual abuse in the future. Participants in both countries also expressed the need for understandable cervical cancer prevention, HPV, and HPV vaccine educational materials and programs.

Our comparative study findings indicate that regardless of geographical location, racial and ethnic differences, and culture, parents' share many of the same concerns about the health of their children, including cervical cancer prevention and the HPV vaccine. For instance, it is interesting, but not surprising that the focus group discussions in an urban segregated Black township in South Africa and in rural Ohio Appalachia mentioned the significant role that mothers and grandmothers play in health care decisions for family members. In addition, participants from both countries acknowledge that extended families play a role in rearing children and making decisions about their welfare while conceding that fathers' may have a limited role in health decision making and child-rearing. This finding is important and consistent with other studies, because mothers/grandmothers also play a critical role in teaching and role modeling about health-related issues to their children [21–23].

An unexpected finding voiced by participants in both studies was concerns about the potential for young women to be exposed to HPV if they were sexually assaulted or abused. Previous studies have identified early initiation of sexual activity and high levels of sexual abuse in communities as a potential reason to begin administering the vaccine as early as age nine [24, 25]. This recommendation is not surprising given the high levels of gender-based violence reported in South Africa [26, 27]. Our findings suggest that administering the HPV vaccine as part of a primary cancer prevention program may provide future protection if exposed to HPV during forced sexual activity.

Findings regarding lack of knowledge about HPV and its association with cervical cancer were consistent with previous studies [14, 15, 24, 28, 29]. Women in South Africa and Ohio Appalachia, as well as in other regions in the U.S. have limited knowledge about HPV and its association with cervical cancer. In both countries, a number of participants commented although they had heard of cervical cancer and cervical cancer screening, this was the first time they had heard of HPV and were not aware of how the virus was acquired or that HPV may cause cancer. Like previous cancer prevention strategies, awareness and acceptance of the HPV vaccine as a new cancer prevention tool will take time, especially among underserved populations. In addition, critical to the HPV vaccine acceptance is the recommendation of the vaccine by a health care provider [30].

Given that participants identified lack of knowledge about HPV, HPV vaccine, and cervical cancer to be a barrier to HPV vaccination; it makes sense that participants from both countries expressed the need for educational materials and programs about cervical cancer prevention and the HPV vaccine. Participants in both countries also expressed an interest for the inclusion of communication skills training in HPV vaccine programs to assist them with discussing the HPV vaccine with their children and with their healthcare providers. Since HPV is a sexually transmitted infection, many parents voiced that they would have difficulty discussing the HPV vaccine with their children, which has been reported in a previous study [31].

The findings from this comparative study illustrate that regardless of race/ethnicity, culture, and geographic location, parents share similar concerns about keeping their children healthy. The introduction of new cancer prevention tools, like the HPV vaccine, need to include understandable educational materials and programs that address potential vaccine barriers. This is especially critical for increasing HPV vaccine coverage among populations with elevated cervical cancer rates and with less health care access.

Limitations

This comparative study should be interpreted with several limitations. First, the study in South Africa and the study in Ohio Appalachia were conducted independently, thus we did not use the same focus group guide or facilitators. Although the questions may have differed in the two studies, similar themes about the HPV vaccine and cervical cancer prevention emerged from the focus groups conducted in both geographic locations. In addition, experienced focus group facilitators were used in each country to minimize the domination of the conversation by any one participant and to keep the discussion focused on the topic. Second, the studies were conducted slightly over one year apart. This difference in timing of the focus groups is minimized because the different studies were conducted subsequent to approval of the HPV vaccine in their respective countries. Third, the focus groups conducted in both countries used convenience sampling and thus the findings are not generalizable to all residents in either country. Fourth, participants in the focus groups may have known someone or had a personal or family history of cervical cancer or abnormal Pap test. Although this personal experience may have had some impact on the focus group discussion, obtaining a variety of perspectives about cervical cancer prevention is important. Fifth, any differences documented between countries may be due to cultural differences in meaning of cancer or sexually transmitted infections. Finally, although focus group methodology has limitations, this comparative study allowed us to gain a better understanding of some of the similar and different issues associated with cervical cancer prevention, HPV, and the acceptance of the HPV vaccine among two distinct populations.

The strengths of this comparative study include exploring a global cancer problem from the perspective of residents from different countries. The emergence of common themes about the HPV vaccine from focus groups conducted in very different geographic locations tells us about critical information to incorporate in cervical cancer prevention materials and programs that could be used globally in regions where women face a significant burden from cervical cancer. In addition, this comparative study highlights the importance of mothers in making health decisions for children and the value placed on protecting women from cervical cancer in the future.

Conclusion

In conclusion, focus group participants in South Africa and Ohio Appalachia lack knowledge about HPV and the association of HPV and cancer. In addition, participants expressed similar HPV vaccine barriers and cultural attitudes about protecting their children

that should be considered when developing strategies to increase HPV vaccination rates. It is our charge as public health practitioners and researchers to use these findings to develop culturally appropriate cancer prevention educational materials and programs in order to decrease cervical cancers rates globally.

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