

Assessing Knowledge, Attitudes and Beliefs about Cervical Cancer, Human Papillomavirus
and HPV Vaccine among Shipibo-Konibo Women of Peru

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Abstract

Assessing Knowledge, Attitudes and Beliefs about Cervical Cancer, Human Papillomavirus
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Background: The Shipibo-Konibo ethnic group is one of the largest indigenous populations in the Peruvian Amazon. Due to economic, cultural, and geographical barriers, Shipibo-Konibo women are less likely to access cervical cancer screening and therefore are at higher risk for cervical cancer mortality. Objective: to learn how cervical cancer is understood from the perspective of Shipibo-Konibo women and to see what factors influence a woman's decision to vaccinate or not vaccinate her daughter. Methodology: Thirty in-depth, semi-structured interviews were conducted with Shipibo-Konibo women from a variety of different perspectives: urban, rural, with daughters who had and had not received the vaccine. Interviews were transcribed, coded and analyzed for themes. Main results: without exception, all women in the study perceived cervical cancer as a dangerous

disease and were in favor of their daughter receiving a vaccine that could protect them from cervical cancer. The main difference was: in the rural community, women had more medically accurate beliefs about the etiology of cervical cancer. In both communities, shame and poverty were identified as barriers to seeking preventive care and treatment for cervical cancer. Conclusions: These results are both encouraging, as the universal acceptability and perceived need of the HPV vaccine is high, and helpful in identifying areas of growth for future health education programs, especially surrounding risk factors for cervical cancer.

Introduction

Scope and Significance

Cervical cancer is the most common cancer among Peruvian women, with an age-adjusted incidence rate of 32.7 cases per 100,000 women per year.¹ This rate is higher than both the age-adjusted incidence rate of South America (22.2 cases per 100,000 women per year) and of the world (15.1 cases per 100,000 women per year¹). In Peru, 10.87 million women above the age of fifteen are considered at risk for the disease.¹ Each year, an estimated 4,636 women are diagnosed with cervical cancer and 1,715 women die from the disease.¹ If detected early, effective treatments are available. The Papanicolaou smear test is the most common way to screen for cervical cancer, though the visual inspection with acetic acid (VIA) is being introduced.² Estimates for lifetime screening coverage vary widely, depending on study site and population age, ranging from 50-87%²⁻⁴ but quickly drop to 38-42% coverage within the recommended 2-3 year interval.^{4,5} If a woman does get screened, there are often problems interpreting the results, informing the woman in a timely manner, and referring to treatment.^{2,6}

Human Papillomavirus (HPV) is an established cause of cervical cancer, with subtypes 16 and 18 accounting for 70% of cervical cancer cases worldwide.¹ An estimated 7.5% of Peruvian women are infected with HPV at any given time and the majority (68.3%) of invasive cervical cancer in Peru is due to infection with HPV subtypes 16 and 18.¹ The HPV virus has also been correlated with vulvar, vaginal, penile and anal cancers, though there is a paucity of data about the prevalence of these cancers in Peru.¹

Two vaccines are available that are over 90% effective⁷ in inducing immunity to the most aggressive HPV subtypes (16 and 18). The bivalent vaccine (Cervarix) protects only against subtypes 16 and 18 while the quadrivalent vaccine (Gardasil/Silgard) also protects against

subtypes 6 and 11, which cause genital warts.⁷ Gardasil was licensed in Peru in 2006 and Cervarix in 2009.⁸ Both vaccines are most effective when given before sexual debut. Unlike other sexually transmitted infections in which greater numbers of sexual partners confers more risk, women are at risk of acquiring HPV from their first male sexual partner,⁹ so vaccinating prior to puberty is recommended. Both vaccines are licensed in Peru and approved for girls above age 10. Since screening coverage is so low, vaccination is an important tool in reducing the burden of cervical cancer in Peru.

In 2008, a feasibility study for HPV vaccination introduction was conducted in four different regions of Peru, including the Amazon region of Ucayali.¹⁰ The program involved school-based vaccinations for girls aged nine and older, enrolled in 5th grade classrooms and demonstrated a coverage of above 82% (N=10,200).¹⁰ The study recommended school-based vaccination campaigns to achieve high coverage. The Peruvian Ministry of Health adopted a nation-wide school-based vaccination program in 2011 for girls aged 10-11.¹

Though acceptability of the HPV vaccine is high among the general population of Peru, previous studies demonstrate that Peruvian women have limited specific knowledge about cervical cancer and some confusion exists regarding the difference between cervical and uterine cancer¹¹. HPV is not widely recognized as a carcinogenic virus or as a sexually transmitted infection.^{11, 12} Lack of awareness about the causes of cervical cancer and available screening and treatment options affects women's health outcomes. Investigation of attitudes and beliefs about cervical cancer and factors involved in influencing women's decision to have their daughters vaccinated could be used to increase cervical cancer health literacy of Shipibo-Konibo women and to guide vaccination and screening outreach efforts.

Study Population

The Shipibo-Konibo ethnic group is the third most populous of Peru's 60 Amazonian indigenous groups.¹³ There are approximately 104 different Shipibo communities, with a total population of 22,517.¹³ This ethnic group is concentrated in the Ucayali river basin in the Amazonian province of Ucayali.¹⁴ Most Shipibo-Konibo people live in rural villages, but nearly 7,000 live in urban areas, including the provincial capital of Ucayali, Pucallpa, as well as the country's capital, Lima.¹⁵ In Lima, the majority of Shipibo-Konibo people live in a particular enclave called Cantagallo, which is a neighborhood of nearly 70 Shipibo-Konibo families in the eastern outskirts of Lima.¹⁴

The Shipibo-Konibo ethnic group is important to study because Shipibo-Konibo women are disproportionately vulnerable to cervical cancer due to economic, linguistic and geographic barriers to health care.^{16, 17} Because of these factors and others, many women turn to traditional healers for their health care.^{14, 17} In previous studies, women have expressed distrust of Ministry of Health facilities, making seeking screening or diagnostic care for cervical cancer particularly difficult.¹⁷ Women typically marry early and have limited knowledge of sexual health or contraception,^{16, 17} making them more vulnerable to HPV infection. High levels of seasonal migration within the region also broaden the sexual network and create opportunities for disease spread.¹⁶

Methods

Study Design and Overview

In-depth, semi-structured interviews with thirty Shipibo-Konibo women were conducted from July-Aug 2012, in two different settings. Fifteen interviews were conducted in the urban

community of Cantagallo and fifteen in the traditional Shipibo-Konibo community of San Francisco.

Cantagallo is located in the Peruvian capital of Lima and is the largest community of Shipibo-Konibo people in the region. Families live in closely clustered houses that are grouped by political affiliation. San Francisco is a rural community in the northern jungle province of Ucayali that is also ethnically predominantly Shipibo-Konibo and an hour drive away from the regional capital of Pucallpa. Families here live in houses that are spread out along the main road and river.

Both communities lack centralized water and sanitation facilities and depend on the sale of beautifully crafted artisan works for their livelihoods. Both have government-funded public health posts: Cantagallo shares its health post with a wider community and is within walking distance from Cantagallo and San Francisco's health post is within the community. Both communities have participated in the national HPV vaccination program and had previously established relationships with members of the research team (MB and IA).

All eligible participants were self-identified as Shipibo-Konibo women, aged 18-39, living in either San Francisco or Cantagallo. Women who had no knowledge of cervical cancer, were mentally incapacitated, under the influence of alcohol or other substances limiting their ability to participate in the study were excluded.

Ethics

Institutional review board (IRB) approval was granted at both the University of Washington and the Universidad Peruana Cayetano Heredia.

In each community, permission to conduct our study was granted by community leaders,

who then assisted us in identifying key informants. A scripted approach was used and verbal consent was obtained from each participant to conduct and digitally record the interview. Women were allowed to refuse with no adverse consequence. At the conclusion of the interview, participants were given a small cloth bag as a token of gratitude for their time.

Interviews were conducted in Spanish in the presence of a Shipibo language interpreter. Interviews lasted for approximately one hour and were conducted in a private area of the subject's choosing, either a room in their home, an area in their garden or an empty community space. Some participants requested the presence of a family member who remained with them during the interview.

The three researchers who conducted the interviews were women, two Peruvian and one American. At the time of the interviews, EC was a MD/MPH student, AB was training to be a researcher at the Indigenous Health Unit at Fundacion Cayetano Heredia and FC was working as a physician in Lima. All had undergone a Master's level training course in research methodology and had a demonstrated interest in improving the health of women and indigenous populations in Peru. Both translators used had extensive professional and personal ties to the communities in which we worked, which allowed us to gain community trust and identify nuances in the interviews. Confidentiality was ensured through previous agreement with translators and interviewees were given the option of refusing a translator.

Data Collection

We recruited 15 women from each community to participate in an in-depth semi structured interview. Participants were recruited using key informants in each community to identify the initial participants. Snowball sampling was used to recruit the remaining

participants. Within each geographic location, we recruited five members in three subgroups, in order to capture a diverse array of perspectives:

- a. Women with daughters who were vaccinated against HPV
- b. Women with eligible daughters who were not vaccinated against HPV
- c. Women with daughters who were ineligible for vaccination because they were younger than 10 years old

Prior to the interviews, our interview guide was pilot tested in each community with our Shipibo translators to ensure correct local terminology and smooth translation. This was particularly important as the Shipibo language has different ways to translate the word “virus” which was a key term in our study.

Researchers individually interviewed each study participant in Spanish in the presence of a Shipibo language interpreter. Interviews ranged from 30 min to 1 hour. Inquiry was guided by the Health Beliefs Model conceptual framework¹⁸ of how mothers support HPV vaccination of their daughters, based on their understanding of cervical cancer, HPV and the HPV vaccine (appendix 1). Topics explored are described in table 1.

Table 1. Knowledge, attitudes and beliefs about cervical cancer: topics explored interviews.

Knowledge	Attitudes	Beliefs
Cancer types	Impact of cervical cancer on women	Disease theory
Symptoms	Perceptions of HPV vaccine	Barriers to care
HPV knowledge	Preferred way to receive future education about cervical cancer	Risk factors
Vaccine knowledge		Perceived severity of cervical cancer
Prevention of cervical cancer		Perceived prevalence of cervical cancer

Data Analysis

Interviews were digitally recorded, transcribed word-for-word into Word and translated as required. Data analysis focused on characterizing perceptions of cervical cancer, the HPV vaccine and barriers to care. An integrative approach, combining a start list with iterative input based upon grounded theory^{19,20} was used to define and refine content themes.

Data were analyzed by hand by the researcher who conducted the majority of the interviews, (EC) with input from other researchers (MB, IA, AB). This method was utilized because one researcher had a high degree of familiarity and greater knowledge of the context of the interviews.²⁰ Handwritten notes taken by the researchers in the field were used to contextualize the interview texts. All transcripts were read through multiple times before any coding was done, and common themes were identified. These themes were added to the start list of codes, which formed the codebook. During the coding process, codes were combined and simplified to ensure reliability. Each transcript was coded again after simplification to ensure code stability. Disagreements in coding were settled by agreement with other researchers to ensure reliability.²⁰ Questions regarding medical terminology specific to Peru were deferred to MB and IA.

Themes were analyzed in the context of each individual interview and summarized across the three demographic subgroups in each study site. For the purposes of this manuscript, the analysis and results focused on these four themes.

- Disease theory of cervical cancer
- Risk and impact of cervical cancer
- Barriers to care
- Perceptions of the HPV vaccine

Representative quotations used were selected to illustrate the themes of interest.

Results

Participant characteristics

A summary of the demographic characteristics of the participants is listed in Table 2. Ages of participants ranged from 18-39, with a majority of participants older than 24. All participants had some level of education, with a majority having at least some secondary school education. All but four participants were either married or partnered, and all but one woman worked as an artisan. Shipibo women travel frequently to sell their handcrafted wares; about half of our respondents reported travel, and nearly half reported no travel in the past year.

Table 2. Demographic Characteristics of Participants (N = 30)

Characteristics	Cantagallo	San Francisco	Total
<i>Age range</i>			
18-24	1	3	4
25-31	5	5	10
32-39	9	7	16
<i>Education*</i>			
Primary school	3	3	6
Secondary school	8	10	18
Technical institute or community college	4	1	5
University	0	1	1
<i>Marital status</i>			
Single	1	2	3
Partnered	10	11	21
Married	4	1	5
Divorced	0	1	1
<i>Employment</i>			
Artisan	14	15	29
Secretary [^]	0	1	1
Cook [^]	2	0	2
Sales of medical devices [^]	1	0	1

Housewife	1	0	1
<i>Time spent away from community in the past year</i>			
None	5	6	11
> 1 month	2	4	6
1-3 months	5	4	9
4-6 months	3	1	4

* Each level indicates at least some, not necessarily completed.

^ Secondary form of employment, in addition to being an artisan

Themes

Disease theory of cervical cancer

An individual's disease theory of an illness is their way of understanding a disease and what causes it. Many factors shape disease theory, including education, religion and cultural environment. This is distinct from the actual pathophysiological mechanism of disease, and reflects the individual's perceptions and attribution of disease. In our study, Shipibo women living in either community had both areas of overlap and distinct ideas about what causes cervical cancer.

Nearly all the participants across both settings and all subgroups endorsed cervical cancer being caused by sexual transmission. They cited multiple sexual partners as a risk factor in developing the disease. Several women discussed the need to take care of their male partners by disclosing any sexual symptoms to them and limiting their own number of sexual partners.

They say that men can give it to women and women can give it to men. – CG 14

Because it happens through sexual intercourse that we are infected, that our husbands and partners infect us, and this affects the uterus. – SF 9

Through sexual intercourse [sic] that a lot of times we women don't take care of ourselves, and we get wounds, and if we don't get them treated, it can produce cancer. – SF 3

I would tell my husband [if I were sick] because he is the one who is with me the most. And sometimes we have sex and he has to know if I have a disease so that it doesn't affect him as well. – CG 6

It's a virus that is contracted from sex, that men can give to us or we can give to men. – CG 5.

Another theme that surfaced among many women in both communities was the need for clearing the uterus of any products of conception after a birth or loss of pregnancy (abortion or miscarriage). Women referred to this as a “cleaning” that was particularly necessary to remove any retained products of conception or blood that would deteriorate in the uterus and cause cervical cancer. Variations on this theme included too many pregnancy losses would cause cancer, herbs or medications taken to expel the products of conception would cause cancer and giving birth at home was perceived as a risk factor because women wouldn't be able to get a dilation and curettage after the delivery.

Sometimes women who get pregnant lose the pregnancy. After the abortion, it's necessary to do a cleaning. Because we don't know, maybe something remained [in the uterus], right? That could form a wound and could start the disease [cervical cancer]... My vaginal cleaning that they always do in the hospitals. Always. – CG 15

They hide their abortions and don't alert anyone or go to the health center. And no one does the cleaning inside [the uterus], and it [products of conception] just stays there. Cancer comes from that too. – CG 8

The biggest cause [of cancer] is that women have had miscarriages or botched abortions. So, all of these things can happen because of it... [They are done] secretly. In the houses, women themselves do them. They induce abortions by taking medicine or by manipulating their uterus. It could be from that too that diseases can start. –SF 13

Some women take- those that don't want kids – take plants. I don't know how, but that can also cause cancer. – SF 2

Women that have recently given birth, maybe because of a bad cleaning, that blood was left behind and coagulated. That can produce cancer. – CG 9

One difference between the two communities was the attribution of cervical cancer to a virus. Nearly half the participants in San Francisco mentioned a virus as the causative agent in their interviews, in contrast to only one woman in Cantagallo. Most women had never heard of the Human Papilloma Virus before; the ten percent that knew about HPV tended to be mothers of daughters who had received the vaccine. One woman was familiar with it because she had been diagnosed with HPV and subsequently treated with biopsy and follow up Pap smears. However, the conception of “virus” varied among women, sometimes merging with the concept of a small insect like a worm or flea.

A virus, like a worm... little bitty so that we can't see it and we find it in our bodies.
– SF 3

Human papilloma virus, I said, right? It's... they told us it's like a worm, like a flea, something like that. So, mostly we refer to it as a little worm, like a bug that makes the cervix sick.
– CG 15

The cancer virus is a black worm. – SF 14

More theories emerged in Cantagallo about cervical cancer disease theory than in San Francisco, which tended to cluster around sexual transmission of a virus, with a few women attributing cervical cancer to resuming intercourse too soon after delivery and one woman mentioning casual contact. Other theories mentioned by participants in Cantagallo included mother to child transmission *in utero* and through breast feeding, multiparity, lack of spacing between births, inadequately treated vaginal and urinary tract infections, and carrying weights during menstruation.

Because they always told us that [cervical] cancer comes from ... when we give birth, sometimes after about a month we have sex with our husbands. Sometimes they say [the uterus] isn't ready, that sometimes it's a year before we're healed from giving birth. – SF 1

And it can be transmitted... at the moment when she sleeps with her daughters...through the heat of her body. – CG 12

Interviewer clarifying: When they are pregnant, mothers can transmit cancer to their babies? Yes, because of the blood, through the blood, right? – CG 4

When [I'm] breastfeeding, sometimes [my breasts] fill with too much milk, a lot, a lot of milk. And sometimes, this hurts and forms like a little ball. [I] believe that this ball is where the fleas live that can transmit [cervical] cancer to the baby. – CG 13

Well, we know [a woman gets cervical cancer] if she has sexual relations at a young age, or she has kids continuously. – CG 5

[A person gets cervical cancer] from poorly treated vaginal discharge. – CG 14

And [my mother, who died of cervical cancer] never went to the hospitals, never went to checkups and sometimes when she had her menstrual period, she strained herself carrying heavy things and all that. She never took care of herself. – CG7

Risk and Impact of Cervical Cancer

Women who were older, had multiple children, and were not mutually monogamous in their sexual relationships were seen by most women as being at high risk. Though some women did believe that younger women and girls were at risk and one woman expressed her worry that her three-year-old daughter might have cervical cancer because her undergarments were stained.

Nearly all participants identified cervical cancer as one of the most feared diseases among women, many equating it with HIV in severity. Most women had a female friend or relative with cervical cancer and had seen first hand the impact the disease had on individual women and their families. Loss of employment, social isolation due to illness, inability to be

intimate with her partner and inability to tend to her children were all consequences women in our study identified with cervical cancer.

The woman who has cancer is always worried, sad...grieving and isolated from her family.
– SF 10

It would be bad, well, how would she want to do anything? She couldn't. She would be tired, be in bed all the time, exhausted. She couldn't even work. She'd suffer from this, all the pain, no? –
CG 8.

Many women mentioned that intercourse would be limited or impossible for a woman with cervical cancer. Their opinions varied on how this could impact their relationships with their partners. Some thought husbands could be understanding and supportive, while two women raised the concern of rape.

Many men get mad because women don't want to have sex because they're a bit unwell, but the man doesn't listen and sometimes takes them by force, no? – SF 9

An important aspect of abstaining from intercourse was also “dieting.” In the Shipibo culture, our respondents explained, it was important to abstain from certain foods and behaviors in order for the body to recover from an illness, including cervical cancer.

Culturally, there are fish that you can't eat because they...help the wound grow. There are fruits that also cannot be eaten because they can also directly affect the wound. And you can't have sexual intercourse... Like pineapple, orange, papaya. They are fruits that culturally, for the Shipibos, rot quickly. [They are not eaten] so that you don't rot on the inside. Carnivorous fish that have strong teeth, like piranhas, like “huasacos,” these [can't be eaten]. – CG 11.

Several women viewed the “dieta” as an essential part of the treatment.

There are many women who have died, receiving treatment, but not following the “dieta.”
– CG 11

Barriers to care

Two main barriers to both screening for cervical cancer and treatment were identified in our interviews: Shame and poverty. Women discussed shame as embarrassment to have a Pap smear or gynecological exam done, especially by male providers.

If our husband during the day doesn't see us, just at night- and now a doctor? Or a nurse? They're afraid and embarrassed and so they don't want to. – SF 11

Two women cited poor treatment given to them at health facilities because of their Shipibo race and one woman cited rumors that male providers touched their patients inappropriately.

A lot of times the neighbors have...well they're afraid to go to the health post because they'll be embarrassed. Or if it's not embarrassment, it's fear that the others are going to discriminate against them, or that they'll feel belittled. They don't say anything because they don't want anyone to look down on them, to tell them they have this [disease]. – SF 9

Shame was also discussed as a barrier to treatment within families. Participants recounted discovering their female relatives or neighbors had cervical cancer only when her symptoms were so severe she could no longer hide them.

For the Shipibo woman, it's really difficult to talk about and have her partner see her genital parts. And [my] aunt said absolutely nothing to anyone – not to her kids or her mother or her husband. So, it was only when it was really advanced, and she was lying in bed, unconscious, that we were able to see. – CG 12

However, nearly all participants had had at least one Pap smear themselves and would disclose any symptoms to their families and health care providers. One woman went to have a gynecologic exam every 6 months, just to see how she was doing.

Participants also identified poverty as a barrier to seeking screening and treatment for cervical cancer. One woman noted that Pap smear results are often delayed for months, but paying a higher fee can expedite results. Treatment is expensive, and sometimes families cannot afford it.

Because they say that we women practically don't have any economic power, so the only thing left to us is to take good care of ourselves, to protect ourselves with medicinal plants. – CG 2

One woman simply put it,

If you don't have money, you can't save your life. – CG 1.

Though all the respondents lived within walking distance of a health post, many women cited the experience of older relatives who lived in remote areas and were not able to access health facilities or screening exams as a factor leading to developing advanced cervical cancer.

Perceptions of the HPV vaccine

Every single one of our participants was in favor of the HPV vaccine for their daughters. In both communities, mothers of daughters who had been vaccinated were the most knowledgeable about HPV and the HPV vaccine. Despite the fact that the other participants had not heard of HPV or the HPV vaccine, once it was explained to them, all participants were in favor of the vaccine.

At first [I] was worried because ... [I] didn't understand why they would give her the vaccine at this age. After they explained it, [I] felt happy...that [my] daughter had received it, that she was chosen to have the vaccine. – SF 7

When asked, all but one participant said they felt their families would be supportive of the vaccine as well. One woman said it didn't matter to her if her family agreed or disagreed, that the decision to vaccinate was between her and her daughter.

One theme that emerged in Cantagallo that didn't in San Francisco was the importance of informing the parents, including the father, about the vaccine and the possible side effects, prior to their daughters receiving the vaccine.

I would not have any problem and would not be worried if they assured me, gave me good information and that person was trustworthy, and the information was also given to my husband.
– CG 13

Women had varying opinions regarding the ideal age for HPV vaccination. Most women asked were supportive of the current vaccination recommendations, at ten years old.

Maybe sometime in the near future, at a young age, my daughter could become pregnant. So the virus could affect her. Better said, this age [for vaccination] is good. – SF 10

But, several felt that it would be logistically easier to have the HPV vaccine incorporated into the newborn vaccine series.

It would be good at a younger age, like the baby they vaccinate. It would be better to be a part of the newborn vaccines...So that it's part of the vaccine card. – SF 9

It would be better if it were the same as the rest of the vaccines they give to the newborns, at three months, six months, four months. I'd prefer it more if it was like that, so that it would be more effective, just like the other vaccines. And so that there would be a way to keep track, like the other [vaccine record] cards. It would be the same and there it could integrate into that group of vaccines. – SF 2

One woman felt the vaccine would be more effective at an earlier age, but didn't elaborate on why. Another thought that it would be better to delay vaccination until girls were older and could decide for themselves if they wanted the vaccine.

No women had any concerns about the vaccine that would deter them from having their daughters vaccinated. The only concern that was raised was one woman in Cantagallo wanting to make sure the vaccinations were being done correctly.

Well, they could place the vaccine badly, or they could make an error about the medicine, or the person who places it could be a trainee. – CG 12

In response to other community members who might have some misgivings about the vaccination, one woman had this to say:

Yes, I too said that with [my daughter] when she was little. “Ay, I don’t want them to vaccinate her because she will cry.” But later I thought, “I’m wrong.” Look, it’s okay that she cries. Crying is not going to kill her. It would be worse if a disease got her. – CG 15.

Discussion

This study is the first to explore how cervical cancer and HPV are perceived within women of the Shipibo-Konibo community. We explore beliefs about cervical cancer, HPV and the HPV vaccine in the context of the Health Belief Model. Within this model, we specifically explored women’s attributions, or disease theory of cervical cancer, their perceived risk of cervical cancer, perceived harm of cervical cancer, knowledge about HPV and their attitudes towards the HPV vaccine for their daughters.

The key findings of this study were:

1. Two beliefs that emerged in both communities were that cervical cancer was sexually transmitted and that retained products of conception or blood in the uterus after pregnancy could cause cervical cancer.
2. Geographic differences were seen in attribution of cervical cancer and importance of vaccine information for parents, and subgroup differences were seen in increased knowledge about HPV among mothers of vaccinated daughters.
3. The concept of “virus” is diverse.
4. Cervical cancer was perceived as a dangerous disease with detrimental impact on a woman’s health, economic independence and social identity.

5. Though few women had heard of the HPV vaccine, all were in favor of their daughters receiving vaccination.

Characterization of cervical cancer as being sexually transmitted is similar to women's conceptualization of cervical cancer in Zambia,²² Kenya,²³ Portugal,²⁴ and among Mexican immigrants to the United States.²⁵ However, the belief that retained blood or products of conception from a pregnancy could deteriorate in the uterus and cause cancer is not a common theme identified elsewhere in the literature, nor is it pathophysiologically correct. However, the idea that some sort of insult to the female reproductive tract could cause cancer, whether through sexually transmitted infections, retained products of conception, trauma or an inadequately treated urinary tract infection, recurred within our study and is described elsewhere in the literature.²⁵ Elucidating this belief provides an opportunity for educators to directly address and correct this misconception.

We deliberately selected women from very distinct communities and with differing vaccination status of their daughters in order to capture a diversity of perspectives as well as to identify any clustering of themes within a particular subgroup, to better inform educational and outreach messages regarding cervical cancer and HPV vaccination.

The main difference in disease theories between communities was the range and density of beliefs women expressed. In San Francisco, more women held a narrower beliefs about the etiology of cervical cancer, centering around a virus that was sexually transmitted and the concept of needing a dilation and curettage to "clean" the uterus after each ended pregnancy. In Cantagallo, there was a lower density of a wider range of beliefs, meaning that fewer women concurred on an explanation of cervical cancer.

There were three main themes that emerged differentially within subgroups:

1. Women in San Francisco had a more accurate medical understanding about cervical cancer disease as the result of a viral infection
2. Women with vaccinated daughters, in both communities, had at least some level of understanding about the HPV vaccine
3. Women in Cantagallo identified the importance of good information about the vaccine prior to providing consent for their daughters to be vaccinated

San Francisco women likely shared the belief that cervical cancer was due to a virus due to the excellent education and outreach efforts of a midlevel provider at the local health post. Several women cited the health post as a source of health information, and this particular provider as giving educational talks about cervical cancer and addressing screening during health visits. This is both heartening and disappointing. It is encouraging to witness the positive impact one provider can have on the health of a community, but disappointing because medical education is contingent on one provider, rather than built into policies of the national health system. Another explanation is possible confusion in Cantagallo of HPV with the more well-known virus - HIV. While not a widespread belief, several women believed the virus causing cervical cancer could be transmitted from mother to child *in utero* or through breastmilk. Similar confusion was found among Haitian women by Kobetz and colleagues, and calls attention to the need for educational outreach to differentiate specifically HPV from HIV.²⁶

We were not surprised to see that women with vaccinated daughters had a greater knowledge regarding the HPV vaccine than women with daughters who had not been vaccinated. Interestingly, not all mothers in our study were informed their daughters had been vaccinated. In Cantagallo, where HPV vaccines were administered in a school-based program, not all mothers

received and/or understood the permission slips for HPV vaccination for their daughters; consequently, we had two instances where the girls themselves confirmed their vaccination when we approached the mother about her inclusion in our study.

Perhaps because the vaccination program in Cantagallo was school-based rather than community-based, women in Cantagallo illustrate the importance of pre-vaccination information for both parents. In San Francisco, where the vaccine program is community-based, few women raised this concern. According to our participants, announcements about the availability of HPV vaccines were made over the town loudspeaker; parents brought their daughters to the health post, where they were able to interact with health care personnel, ask questions and get information directly; in contrast, parents in Cantagallo were not able to interact directly with health care personnel at the time of vaccination.

A fascinating element of our interviews was women's diverse conception of virus as a small worm, leech or flea. This concept makes sense from both a phenomenological and linguistic standpoint. Participants repeated symptoms related to them by friends or relatives with cervical cancer that something was "eating them" from the inside; it is a logical conclusion then that "something" would be a familiar element of the natural world, like an insect. There is also no word in the Shipibo language for "virus," and so the insect metaphor is often employed in translation from Spanish. A similar issue was encountered among women in Zambia, in which a precise term for "cervical cancer" in the Nyanja/Bemba language could not be identified.²² There is clearly a need to unify terminology, especially in the context of educational outreach for women with low levels of education who may not be able to differentiate metaphor from a realistic description and fear that a flea causing cervical cancer could leap onto them, as one woman mentioned in our study, causing her unnecessary anxiety and distress.

Our study supports the perception of cervical cancer as a dangerous, detrimental disease already well established in the literature.^{25, 27, 28} In our conceptual model, mothers were the primary factor in determining whether their daughters should be vaccinated, and thus her perception of cervical cancer as a dangerous disease would likely be an internal cue to action for her to recommend vaccination for her daughter. However, this has proven not be the case, both in our study and others examining decision-making frameworks in Peru.²⁹ Instead, we discovered that sometimes the mother had no influence at all, as in the case in Cantagallo in which girls were vaccinated in school without their mother's awareness. But parental perception of vaccines does make a difference in many communities, as it informs how receptive a community is to school-based vaccination programs and how willing a girl is to be vaccinated.²⁹

Our last finding was also consistent with previous research in Peru: that women support the HPV vaccine for their daughters.^{11, 29} In our study, the only reservation cited was to have good information from a reliable source prior to their daughters being vaccinated. This is entirely reasonable and expected as a part of informed consent for medical care. Vaccines in general have excellent uptake in Peru¹¹ and are widely viewed as acceptable. But the connection between the HPV vaccine as a protector from cervical cancer was not well understood by the participants in our study.

The knowledge gap in understanding the connection between cervical cancer and HPV is an important one to focus on for future educational outreach efforts. In our study, as with others, women fear cervical cancer.^{22, 23, 26} Despite this internal cue, they were not prompted to action on behalf of their daughters to have them vaccinated against HPV. Our study intentionally included women whose daughters were eligible but not vaccinated against HPV, thinking there might be a concern or other deterrent from vaccination. Instead, we found universal acceptance

of the vaccine; the lack of vaccination stemmed from mothers not knowing that the vaccine existed, what disease it prevented, and how to obtain it for their daughters. This indicates both an unmet need for vaccination and need for education and outreach to parents in conjunction with vaccination efforts.

Recommendations

At the end of each interview, we asked women what format they would choose if they wanted to communicate important information about cervical cancer and its prevention to the wide community. The vast majority recommended educational talks, in Shipibo and Spanish languages, given to small groups of 8-10 women by someone with a health background. This format would allow more intimate conversation, eliminate the power dynamic between patient and provider inherent in a clinic visit, and permit women with more experience with cervical cancer or the HPV vaccine to do peer-to-peer teaching.

This format could easily be leveraged to address knowledge gaps identified in this study. Probably the most important gap is to ensure that families of eligible girls are aware of the HPV vaccine and how to obtain it. Pilot studies of school based HPV vaccination programs indicated coverage levels of 80%⁸ but coverage levels among the communities we interviewed have not been published. As evidenced by our study, communities implement the vaccine program in different ways: some are school-based and others are community-based,³⁰ and parents need to be aware of their local resources. Another important gap to address is the correct etiology of cervical cancer, dispelling myths about other causes, especially retained blood or products of conception deteriorating and causing cervical cancer, and establishing a clear connection between protection from cervical cancer and the HPV vaccine.

Barriers to cervical cancer screening, treatment and prevention identified in this study were poverty and shame. As one member of the Peruvian health system put it, “cervical cancer attacks those with bare feet.”³¹ While both screening via Pap smears and prevention through the HPV vaccine are free, both are dependent upon the availability of the medical staff, equipment and facilities, which are not free. Treatment is also prohibitively expensive for relatives of women we spoke with. Because treatment is so costly, it is imperative to leverage educational formats to education women about prevention of cervical cancer. Equally important is encouraging policy and hiring practice changes that allow for the appropriate training of health professionals to be qualified to read and interpret Pap smear slides and support system changes that allow those results to be delivered in rural areas in a timely manner.³¹ Addressing the issue of shame is also important. This may already be changing from the one generation to another, with this cohort of women feeling much more comfortable seeking gynecologic care and disclosing to family members. However, while they are outliers in this study, the few instances of perceived racism and discomfort with male providers should be taken seriously and investigated further. Perceived discrimination can be an opportunity for health professionals to learn more about Shipibo culture, engage in cultural humility and be accountable to the community they serve. Simple cost-free interventions that could increase patient comfort and access to screening include having a female health worker or a *promotora* in the room during exams by male providers, as well as explaining the procedure and allowing women time to relax before pelvic exams to minimize muscle contraction and pain.

Limitations

This study was limited by a small sample size and to a small ethnic group in two distinct

parts of Peru, so is not generalizable to the general public. In addition, none of the researchers were fluent in the Shipibo language themselves, so some of the nuances may have been lost in translation.

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Appendix 1: Conceptual Framework

