# The Development of a Fotonovela for HPV Vaccine Education

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In partial fulfillment of the requirements for the Doctor of Nursing Practice

## Executive Summary

The goal of this project was to develop, with community input, a fotonovela that can be used to educate Latino parents about the HPV vaccine for the prevention of cervical cancer.

Despite the preventability of cervical cancer, 12,109 women were diagnosed with cervical cancer and 4,092 women died from cervical cancer in the United States in 2011. More Latina women are diagnosed with cervical cancer than women of other races or ethnicities. Studies have shown that HPV vaccination combined with cervical cancer screening could prevent close to 93% of cervical cancer cases. Despite this, a 2013 national survey showed only 37.6% of adolescent girls completed the HPV vaccine series. For Latina girls that number is even smaller. In order to increase awareness and knowledge about the HPV vaccine, culturally competent educational material needs to be available for Latino parents.

In Salt Lake City, the most common reasons Latino parents cited for not vaccinating their daughters were lack of knowledge, concerns about side effects, and costs. The research has additionally shown that parents with low-acculturation were more likely to report lack of information as the main barrier. That fact supports the need for culturally-targeted materials to promote HPV vaccination.

Objectives for this project included gathering qualitative information about the preferences and recommendations of Latino parents living in Salt Lake City regarding the creation of a fotonovela about HPV vaccination; developing a fotonovela with information about cervical cancer risks, the link between HPV and cervical cancer, and basic HPV vaccine information; determining community suggestions for improvement of the fotonovela and updating the fotonovela to include the input of local Latino parents; and disseminating the results through a poster presentation.

Through contact with community organizations in Salt Lake City, fifteen Latino parents were recruited to a focus group. The main goal of this focus group was to encourage ideas and input from the community regarding the development of a fotonovela. The main themes expressed in the focus group were determined and two plots were developed using these themes. After the drafting of the fotonovelas, an additional focus group was held to assess parents' preferences and recommendations for improvement. One fotonovela was chosen and was updated to incorporate these recommendations.

The main theme from the first focus group was that parents wanted information so that they could educate their children. Parents voiced that the information in the fotonovela should be presented by a provider or someone who has knowledge on the topic. They requested basic information about the recommendations for vaccination and about side effects. Parents were also interested in how HPV affects boys. The parents who participated in the second group voiced a preference for the first of the two fotonovelas. A few changes were made based on additional feedback, but in general parents had a very positive response to the fotonovelas.

This DNP project addressed the increased risk of cervical cancer among Latina women. With the recommended vaccination and screening, cervical cancer is a largely preventable disease. Previous research has identified many of the barriers to vaccination within the Latino community in Salt Lake City. This project aimed to address those barriers through the creation of culturally competent educational material, specifically a fotonovela.

My committee included Dr. Ana Sanchez-Birkhead, PhD, WHNP-BC, APRN; Dr. Gwen Latendresse, PhD, CNM, FACNM, Director, Nurse Midwifery/WHNP Specialties; and Dr. Pam Hardin, PhD, RN, Executive Director, MS & DNP programs. My content expert was Dr. Deanna Kepka, PhD, MPH, MA.

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## Problem Statement

A 2013 national survey showed only 37.6% of adolescent girls completed the human papillomavirus (HPV) vaccine series (Benard et al., 2014). Studies have shown that HPV vaccination combined with cervical cancer screening could prevent close to 93% of cervical cancer cases (Benard et al., 2014). Because vaccine administration is recommended when girls are 11 or 12 years old, parents are in a position to make vaccination decisions for their daughters. Despite the preventability of cervical cancer, in 2011 (the most recent year with data), 12,109 women were diagnosed with cervical cancer and 4,092 women died from cervical cancer in the United States (Centers for Disease Control and Prevention [CDC], 2014a).

More black and Latina women are diagnosed with cervical cancer than women of other races or ethnicities. Between 2004-2008, the incidence rate for cervical cancer among non-Latina women in the United States was 7 per 100,000, while the incidence rate among Latina women was 11 per 100,000 (CDC, 2014c). In some regions, one third or less of Latina girls has received the first dose of the HPV vaccine (Glenn et al., 2015). In some regions less than 50% of Latino parents are even aware of the link between HPV and cervical cancer (Glenn et al., 2015). In order to increase awareness and knowledge about the HPV vaccine, culturally competent education material needs to be available for Latino parents.

## Clinical Significance and Policy Implications

Genital human papillomavirus (HPV) is the most common sexually transmitted infection in the United States. There are more than 40 types of HPV that can infect the genital area. It is estimated that by the age of 50, 4 out of every 5 women will have been, at some point in their lives, infected with HPV. Ten percent of women who become infected with high-risk HPV on their cervix are at risk for cervical cancer (CDC, 2013).

HPV is responsible for more than 90% of cervical cancers (CDC, 2014b). There are currently three HPV vaccines: Gardasil 9®, Gardasil®, and Cervarix®. Each of the three vaccines has been through extensive safety testing and clinical trials, and they are all approved by the U.S. Food and Drug Administration (CDC, 2015b). The vaccines protect against the types of HPV that most frequently cause cervical cancer. Gardasil 9® and Gardasil® additionally protect against the types that cause the majority of genital warts (CDC, 2014d). Most health insurance plans cover HPV vaccination at no cost to the patient. For those patients without insurance, Vaccines for Children may help provide the vaccination at no cost (CDC, 2015a).

*Healthy People 2020* includes in its objectives a reduction in the incidence rate of cervical cancer to 7.1 per 100,000 women and a reduction in the death rate to 2.2 per 100,000 women (Benard et al., 2014). The CDC identifies the HPV vaccine as "promising" in the prevention of cervical cancer (Benard et al., 2014, Conclusions and Comments section, para. 5). Studies have shown the HPV vaccination combined with cervical cancer screening could prevent close to 93% of cervical cancer cases. Despite this, the vaccine remains underused and the results of the 2013 National Immunization Survey-Teen showed only 37.6% of adolescent girls completed the series (Benard et al., 2014).

If nothing is done to identify and address the barriers to vaccination and screening, women will continue to die from a disease that is predominantly preventable. Latino women face cervical cancer at higher rates than women of other races or ethnicities. Increasing vaccination rates among adolescent Latina girls is one way to help address this discrepancy. Because the vaccines are less effective once women have been exposed to HPV, administration is recommended when girls are 11 or 12 years old (CDC, 2015a). At that age, parents are in a

position to choose whether or not their daughters are vaccinated. It is therefore important to focus on the education of Latino parents. In order to address this population specifically, culturally competent education material may improve the understanding of HPV vaccination among Latino parents. The goal of this project was to develop, with community input, a fotonovela that can be used to educate Latino parents about the HPV vaccine. Fotonovelas are books or pamphlets that communicate a story, or in this case health information, through photos with accompanying text. Because fotonovelas are a popular form of entertainment in many Latino cultures (Unger, Cabassa, Molina, Contreras, & Baron, 2012), they may be a good choice for health promotion specifically within this population. Through the creation of a fotonovela, this project aims to address the gap in care of this specific population, leading to disease prevention and improved population health.

## Purpose and Objectives

The main purpose of this project was to improve Latino parents' knowledge regarding the HPV vaccine for the prevention of cervical cancer through the creation of culturally competent educational material.

Objectives:

1. Gather qualitative information about the preferences and recommendations of Latino parents living in Salt Lake City regarding the creation of a fotonovela about HPV vaccination.
2. Develop a fotonovela with information about cervical cancer risks, the link between HPV and cervical cancer, and basic HPV vaccine information, including the safety and efficacy of the vaccine.

3. Determine community suggestions for improvement of the fotonovela, and update the fotonovela to include the input of local Latino parents.
4. Disseminate the results through a poster presentation at the Utah Public Health Conference.

## Literature Review

The United States had made it a goal to reduce the number of cervical cancer diagnoses (Benard et al., 2014). Despite being a largely preventable disease, 12,109 women in the United States are diagnosed with cervical cancer and 4,092 women die of cervical cancer each year (CDC, 2014a). Included in the *Healthy People 2020* objectives are a reduction in the incidence rate of cervical cancer to 7.1 per 100,000 women and a reduction in the death rate to 2.2 per 100,000 women (Benard et al., 2014). This goal can be attained through vaccination and cervical cancer screening. Close to 93% of cervical cancer cases can be prevented if women receive the recommended vaccinations and cervical cancer screenings (Benard et al., 2014). Health promotional efforts should be focused on improving rates of both screening and HPV vaccination. This project focused on improving rates of HPV vaccination specifically within the Latino community, which is at a higher risk of cervical cancer.

### The Link Between Cervical Cancer and HPV

Prevention of HPV should be considered an important aspect of any initiative to prevent cervical cancer. More than 90% of cervical cancer cases are caused by genital HPV (CDC, 2014b). HPV can additionally cause anal cancer, oropharyngeal cancer, vulvar and vaginal cancer, and penile cancer (World Health Organization [WHO], 2014). HPV is the most common sexually transmitted infection in the United States and there are more than 40 types of HPV that can infect the genital area. It is estimated that 4 out of every 5 women will have been infected at

some point during their lives by the age of 50 (CDC, 2013). The prevalence of this disease and link to cervical cancer make HPV prevention a crucial and viable approach to preventing cervical cancer.

**The HPV Vaccine.** Currently available are three HPV vaccines: Gardasil 9®, Gardasil®, and Cervarix®. Each vaccine has been through years of safety testing and extensive clinical trials (CDC, 2015b). Each vaccine protects against the types of HPV that most often cause cervical cancer (CDC, 2014d). Most insurance plans cover the HPV vaccine at no cost to the patient, and there are programs such as Vaccines for Children that may help provide the vaccine at no cost to those patients who are uninsured (CDC, 2015a). Despite the safety and efficacy of these vaccines, only 37.6% of adolescent girls completed the series in 2013 (Benard et al., 2014).

***Vaccine efficacy***. The HPV vaccines are highly effective. The immune response after receiving an HPV vaccination is stronger than the response to a natural infection, allowing the HPV antibodies to remain in production long-term after vaccination (WHO, 2014). Studies have shown that antibody levels continue to be high for at least 8 years after vaccination (WHO, 2014).

***Vaccine safety.*** According to the Global Advisory Committee for Vaccine Safety, HPV vaccines have a very strong safety profile (WHO, 2014). The available vaccines are non-infections, as they do not contain any viral DNA or any live biological products. Pain at the site of injection is common, but that local pain typically resolves quickly and without intervention. During clinical trials, no serious adverse events (including new onset chronic disease) were recorded (WHO, 2014).

***Male vaccination.*** Interestingly, men often do not produce an antibody response to natural HPV infection (Stanley, 2014). Virtually all males, however, create antibodies in response to HPV vaccine. Vaccinating males offers a small benefit in the reduction of cervical cancer rates, but it also protects men against anal, oral, and oropharyngeal cancer. It has been shown that vaccinating boys as well as girls may be cost effective when the decrease in male HPV-related cancers is added to the decrease in the reduction of cervical cancer rates (Stanley, 2014). Providing education about the vaccination of boys may be a viable approach in increasing overall vaccination rates and decreasing rates of cervical cancer.

**Current Professional Recommendations.** The CDC, the American Academy of Pediatrics (AAP), the American Cancer Society, and the American College of Obstetricians and Gynecologists (ACOG) all recommend completion of the 3-dose series for girls between the ages of 11-12 (AAP, 2012; ACOG, 2015; Saslow et al., 2007). The CDC, AAP and ACOG have updated their recommendations to now also recommend vaccination for boys between the ages of 11-12. The extremely low rates of vaccination despite unanimous recommendation by governmental and professional organizations necessitates further inquiry into parents' knowledge about and perceived barriers to HPV vaccine administration.

## The Disparity

There is a significant disparity between ethnicities in the rates at which cervical cancer is diagnosed. Cervical cancer affects black and Latina women in the United States at higher rates than women of other races or ethnicities. The incidence rate of cervical cancer for non-Latina women in the United States was 7 per 100,000 between 2004-2008, while the incidence rate among Latina women was 11 per 100,000 (CDC, 2014c). Within many Latino communities, only a third or less of Latina girls have received the first dose of the HPV vaccine (Glenn et al.,

2015). Many studies have been conducted that examine the barriers to vaccination within the Latino community, and the results highlight similarities and differences between Latino communities in different regions.

## Current HPV Knowledge Among Latino Parents

Studies often focus on Latino parents because they are in the position to make vaccination decisions for their daughters. Very few Latino parents are aware that their daughters are at a higher risk of HPV (Glenn et al., 2015). In many regions, Latino parents are unaware even of the link between HPV and cervical cancer (Glenn et al., 2015). It is important to assess the knowledge parents have about cervical cancer, the HPV vaccine, and the perceived barriers to vaccination in order to appropriately address those barriers and improve rates of vaccination within the Latino community.

**Regional Variation in Knowledge.** Studies have shown wide variation in the awareness and beliefs of Latino communities in different regions. According to a study by Garcés-Palacio and Scarinci (2012), over one-third of Latina immigrants living in Alabama believed they were not susceptible to cervical cancer, while another one-third did not know whether or not they were susceptible. Only 30.4% believed that they were susceptible. The participants associated susceptibility with personal HPV or STI exposure and having a family member with cancer. Another study collected data in Los Angeles Country, Yakima Valley region in Washington State, and Houston and Lower Rio Grande Valley in Texas (Glenn et al., 2015). Less than a third of parents across three of the samples had concerns about the vaccine's effect on sexual behavior, infertility, or future health, while 60% of parents in one sample were concerned it may promote sexual behavior. Beliefs regarding efficacy of the HPV vaccine also varied greatly from 33% in one sample believing the vaccine was effective to 79% in another. The authors of this

study cited the importance of collecting local data in order to target the most prominent barrier within each particular community (Glenn et al., 2015).

**Barriers Within Salt Lake City.** Recent research has highlighted the perceived barriers to vaccination within the Latino community living in Salt Lake City. The most common reasons Latino parents cited for not vaccinating their daughters were lack of knowledge, concerns about side effects, and costs (Kepka, Warner, Kinney, Spigarelli, & Mooney, 2015; Warner et al., 2014). Even those parents with some knowledge often knew little about the specifics of the vaccine. While 77% of parents had heard of the HPV vaccine, 62.7% did not know it requires three doses (Kepka et al., 2015). This research had additionally shown that parents with low-acculturation were more likely to report lack of information as the main barrier. One study cited lack of education materials for Latino parents with low levels of acculturation as one reason for their lower level of knowledge on this topic (Kepka et al., 2015), which supports the need for culturally-targeted materials to promote HPV vaccine. During a focus group with Latino parents in Salt Lake City, one mother discussed her experience with her daughter's provider, saying when she asked him for information about the HPV vaccine, he handed her a brochure in English (Warner et al., 2014).

## Addressing Gender Roles in Culturally Competent Educational Material

There are different aspects of Latin culture, including gender roles, which should be addressed in educational material developed specifically for Latino communities. Gender roles within Latin culture may place Latina women at an increased risk of STI (Lee, Dancy, Florez, & Holm, 2013). The word *Marianismo* refers to the traditionally female gender role that promotes the belief that women should be virginal until marriage. This belief often leads to Latina women feeling too uncomfortable or nervous to talk about contraception with their sexual partners (Lee

et al., 2013). A literature review conducted by Lee et al. (2013) looked at factors that affect the sexual practices of Latino adolescents, as well as the shared aspects of five successful intervention programs. All five programs included STI knowledge, and four of the five included gender roles. The authors conclude that sex education must include "culturally appropriate and gender-relevant" material (Lee et al., 2013, p. 399).

Another aspect of this traditional gender role causes some Latina women to feel that seeing a gynecologist involves inappropriate behavior (Corcoran & Crowley, 2014). Previous studies have shown that some Latino husbands don't understand the point of gynecology appointments and even may become jealous (Corcoran & Crowley, 2014). Traditional gender roles are an important aspect of Latin culture that should be taken into consideration when creating educational material.

The gender roles present in Latino communities may also play a role in decision-making. In the Yakima Valley in Washington, the majority of Latina mothers feel that they need approval from her daughter's father prior to vaccination (Kepka, Ulrich, & Coronado, 2012). Among the same Latina mothers, belief that her daughter's father would approve of vaccination was shown to be associated with increased rates of vaccination acceptance (Kepka et al., 2012). This demonstrates the importance of discussing gender roles and considering both parents when creating educational material.

**Fotonovelas as Health Promotion Tools**

A fotonovela is a book or pamphlet that communicates a story through photos with accompanying text. Fotonovelas have been used in the past as health education tools to convey information about diabetes, pesticides, tuberculosis, dementia, and HIV (Unger, Cabassa, Molina, Contreras, & Baron, 2013), but not the HPV vaccine. A study by Unger et al. (2013)

looked at the efficacy of a fotonovela to increase knowledge about depression and reduce mental health care stigma. While the study compared just one fotonovela to one text pamphlet, the fotonovela did cause a larger reduction in antidepressant and mental health care stigma. Additionally, it was more likely to be passed on than the pamphlet. The study looked at participants' attitudes only, so no conclusion could be drawn about treatment-seeking behavior. But the authors do conclude that health education delivered through culturally appropriate material is as effective as traditional material in delivering information, and more effective at changing attitudes. The authors consider entertainment-education such as fotonovelas a potentially useful option for health education in low-health-literacy populations (Unger et al., 2013).

An earlier study by Cabassa, Contreras, Aragón, Molina, and Baron (2011) was conducted to determine the opinions of Latino adults about the fotonovela "Secret Feelings" as a health education tool. The study looked at what participants liked, disliked, what they learned, and how they would choose to use the fotonovela. The participants found the fotonovela "accessible, clear, and easy to understand" (Cabassa et al., 2011, p. 842). They did recommend it be in color instead of black and white. The majority of participants also wanted more details about how the main character's depression affected her family, as well as more details about her recovery from depression. While this was an exploratory study that could not draw any conclusions about the effect of the fotonovela on attitudes or behaviors, the findings may help guide the creation of a fotonovela about HPV vaccination.

## Theoretical Framework

The Health Belief Model was used to guide this project. The Health Belief model was created by a group of social psychologists in the 1950s (Nursing Theories, 2013). They hoped to

discover why so few individuals participate in disease preventing health action. The model is focused on how an individual's perceptions of his or her susceptibility of a disease, the seriousness of the disease, the benefits of preventive action, and the barriers to the action affect the likelihood that the individual will actually participate in health-seeking behavior. It also illustrates how additional factors including demographic, sociopsychological, and cues from media influence an individual's perceived threat of a disease (Nursing Theories, 2013).

The Health Belief Model supports this project by demonstrating how the perception of threat and the benefits and barriers of action interact to affect preventive health action. The fotonovela created through this project will increase knowledge about HPV susceptibility and seriousness, as well the benefits and barriers to vaccination. It additionally aims to address other factors that influence perceived threat (such as advice from others) through the creation of cultural competent educational material that may be more likely to be shared than traditional material such as a pamphlet (Unger et al., 2013).

## Implementation

This project was orally presented as a DNP Project Proposal and passed. For the DNP Project Proposal defense PowerPoint, see Appendix A. The initial step of this project was to make contacts within the Latino community in Salt Lake City. Dr. Deanna Kepka and Dr. Ana Sanchez-Birkhead, this project's content expert and chair, have both previously conducted research within this community at Alliance Community Services and Comunidades Unidas. Correspondence occurred with staff at both locations and support for the project was received. Because this project includes human participants, an application was submitted to the University of Utah Institutional Review Board (IRB). Letters of support from staff at both Alliance Community Services and Comunidades Unidas were obtained and submitted with the application

(Appendix B). Additional documents submitted included a consent form (Appendix C), the focus group scripts (Appendix D), and a survey (Appendix E). The consent document was adapted from the IRB Consent Document Template. The first focus group script was written with open-ended questions with the goal of guiding a discussion. The questions were written based on information found during a literature review and included questions about potential plots, fotonovela graphics, gender roles, and more. The survey for the first focus group consisted mainly of demographic information.

Once the IRB application was approved, all the necessary documents were translated into Spanish by staff at Alliance Community Services, and an IRB addendum was submitted and approved. Through contact with Comunidades Unidas, fifteen Latino parents with children between the ages of 10 and 17 were recruited to a focus group. A sign-in sheet, an information sheet for participants, a comments sheet, a written protocol, and thank you bookmarks for participants were modified and then submitted to the staff at Alliance Community Services for translation into Spanish. Fifteen gift certificates were obtained from Smith's in the amount of $20 each. Food was ordered and brought to the focus group for participants. A native Spanish speaker with experience facilitating focus groups was present to guide the discussion. The focus group was audio recorded, using three different records placed throughout the room.

After an introduction and after participants finished eating, informed consent was obtained from all participants and they were asked to complete the demographic survey. Only the first page of the survey was given to participants, as the second page includes questions regarding the completed fotonovela. Recording started after all the documents were collected, and the facilitator used the focus group script in order to encourage ideas and input from the community regarding what information they would like to see in the development of a

fotonovela. Samples of fotonovelas were shared with the group to help stimulate discussion. After the discussion, any additional questions from participants were answered, and one gift card was given to each participant. The audio files were listened to in order to determine which had the best quality, and that file was then submitted to GMR Transcription for transcription and translation from Spanish into English.

The second main step of the project was to then develop the fotonovela, incorporating those ideas expressed during the focus group. With the assistance of the project chair, who is experienced in qualitative analysis, themes from the transcript were identified. These themes were used to decide the main topics of the fotonovela plots. Two drafts of fotonovela mock-ups were then created using those themes, as well as any additional themes left out but deemed important in order to properly convey the necessary information about the HPV vaccine. An extensive literature review was done in order to determine what information needed to be included. The Health Belief Model was also used to help identify and address those factors that influence health-seeking behavior.

The mock-ups were then passed on to a graphic designer who created layouts of the fotonovelas. Through contact with the graphic designer a photo shoot was scheduled and three Latino models were recruited. Based on the fotonovela mock-ups, photographs were taken showing conversations between two Latino parents and a healthcare provider. The photographs were inserted into the fotonovela layouts and the Spanish fotonovelas were printed for use at the second focus group. See Appendix F for the two fotonovelas in both English and Spanish.

Through contact with Alliance Community Services, nine Latino parents with children between the ages of 10 and 17 were recruited to a focus group. Nine gift certificates were obtained from Smith's in the amount of $20 each. Food was ordered and brought to the focus

group for participants. The documents from the first focus group including a sign-in sheet, an information sheet for participants, a comments sheet, a written protocol, and thank you bookmarks were used again during this focus group. An experienced Spanish-speaking facilitator was present to guide the focus group. The discussion was audio recorded, using three different recorders placed throughout the room.

After an introduction and after participants finished eating, informed consent was obtained from all participants. They were then asked to look over the printed fotonovelas and to complete the survey. Recording started after all the documents were collected, and the facilitator used the focus group script to encourage suggestions from the community regarding improvement of the fotonovelas. After the discussion, any additional questions from participants were answered, and one gift card was given to each participant. The audio files were listened to in order to determine which had the best quality, and that file was then submitted to GMR Transcription for transcription and translation from Spanish into English. The surveys were translated from Spanish to English by staff at Alliance Community Services.

Again with the assistance of the project chair, themes were identified from both the surveys and the focus group. These themes were then used to decide any changes that should be made to the fotonovelas. One fotonovela was chosen and was updated to incorporate these changes. See Appendix G for the final fotonovela.

The information gathered and final fotonovelas were used to create a poster (Appendix H) that was submitted and accepted for presentation at the Utah Public Health Conference. Presentation at this conference allowed for dissemination of the project to a larger audience and potentially to other communities that may benefit from this process.

## Evaluation

The first objective of this project was to gather qualitative information about the preferences and recommendations of Latino parents living in Salt Lake City regarding the creation of a fotonovela about HPV vaccination. This was accomplished by first developing contacts at Alliance Community Services and Comunidades Unidas. A focus group script and survey were successfully written and were approved by the project chair and content expert. An IRB application was submitted and the study was determined to be Exempt (Appendix I). The first focus group was completed in a timely manner and fifteen Latino parents participated.

The second objective was to develop a fotonovela with information about cervical cancer risks, the link between HPV and cervical cancer, and basic HPV vaccine information. A literature review was completed and the information that should be included in the fotonovela was determined. The main themes conveyed by parents during the focus group were successfully identified. The transcript was read multiple times and those ideas that were emphasized or recurrent throughout the discussion were noted and compared. Two fotonovelas were drafted including all the desired information. Both the project chair and the content expert approved the drafts, and the fotonovelas were successfully created with the aid of a graphic designer.

The third objective was to determine community suggestions for improvement of the fotonovela and to update the fotonovela to include the input of local Latino parents. This was accomplished through a second focus group. Nine Latino parents participated and completed the survey. Themes from the focus group were successfully identified and final changes were made to the chosen fotonovela. The project chair approved the final fotonovela.

The last objective was to disseminate the results of the project to a larger audience through a poster presentation at the Utah Public Health Conference. The application for poster presentation was submitted on time and was approved (Appendix J). The poster was successfully presented at the conference.

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| Objective 1:<br><br>Gather qualitative information about the preferences and recommendations of Latino parents living in Salt Lake City regarding the creation of a fotonovela about HPV vaccination. | Implementation 1:<br><br>1. Created contacts at Alliance Community Services and Comunidades Unidas. This was facilitated by consulting Dr. Kepka and Dr. Sanchez-Birkhead who have both done previous research projects with these organizations.<br><br>2. Created a focus group script to help guide the focus group discussion.<br><br>3. Submitted project for IRB approval, revised project as necessary.<br><br>4. Scheduled and conducted the focus group. | Evaluation 1:<br><br>1. Communication was established with contacts at both Alliance Community Services and Comunidades Unidas.<br><br>2. A focus group script was developed and approved by the project chair.<br><br>3. The project was approved by the IRB.<br><br>4. The focus group was conducted, with 15 Latino parents present and participative. |
| Objective 2:<br><br>Develop a fotonovela with information about cervical cancer risks, the link between HPV and cervical cancer, and basic HPV vaccine information, including the safety and efficacy of the vaccine. | Implementation 2:<br><br>1. The main themes expressed during the focus group were determined.<br><br>2. An extensive literature review was completed regarding HPV vaccination information including safety and efficacy.<br><br>3. This information was used, along with the themes taken from the focus group, to develop a plot or simple storyline to convey information | Evaluation 2:<br><br>1. Relevant themes were identified from the focus group.<br><br>2. Information from the literature was incorporated into the fotonovela.<br><br>3. A plot or story line was successfully developed.<br><br>4. Two fotonovelas were created with the aid of a graphic designer. The project chair approved the fotonovelas. |

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| | about HPV vaccination.<br><br>4. Photographs were taken to depict the storyline in a short fotonovela. | |
| Objective 3:<br><br>Determine community suggestions for improvement of the fotonovela. Update the fotonovela to include the input of local Latino parents. | Implementation 3:<br><br>1. Using the same contacts previously established, a second focus group was arranged.<br><br>2. A written, open-ended survey about suggestions for improvement of the fotonovela was created.<br><br>3. The participants were given the survey.<br><br>4. Final changes were made to the fotonovela to include the recommendations voiced by Latino parents in the community. | Evaluation 3:<br><br>1. A written survey was developed and approved by the project chair.<br><br>2. A second focus group was scheduled and was conducted with 9 participants who completed the survey.<br><br>3. Final suggestion from the focus group were appropriately incorporated into the fotonovela. The project chair approved the fotonovela. |
| Objective 4:<br><br>Disseminate the results to a larger audience through a poster presentation at the Utah Public Health Conference. | Implementation 4:<br><br>1. Submitted application to the Utah Public Health conference.<br><br>2. Presented at the conference. | Evaluation 4:<br><br>1. Application was submitted by the deadline, and the project was presented at the conference. |

## Results

### Focus Group One

Fifteen Latino parents participated in the first focus group. The demographic results can be found in Appendix K. One of the main overarching themes during the focus group was that parents want information. They want to be educated so that they are able to educate their children. When asked whom the conversation should be between, the majority of parents voiced that a provider should be presenting the information. One mother stated, “The character should

be trained and have knowledge, and be able to help people and inform them." Another mother said, "When you go to the clinic to take them to do their physical, the doctor is there, and the mother goes with the child." One mother stated, "Children usually talk with their friends first before talking with their parents," but a different mother voiced that it would be unrealistic for friends to be talking about the vaccine. She stated, "If we put a girl with another girl, they won't talk about it unless they talk of it as gossip."

When asked if the conversation in the fotonovela should include talking about someone who was diagnosed with cervical cancer, there was a slightly more mixed response. Most parents believed it to be more important to present the information. "I think preventing—like, how they're taught, instead of someone who had it." Their main concern seemed to be lack of basic information. Many parents explained that they had not received adequate information about the vaccine. One father said, "If the parents don't want to, the children can't do anything." He voiced that if parents don't have the necessary information, then "they will not be able to help their child." One mother said her son asked her, "They told me it's a disease, and that you have to get vaccinated, but they didn't tell us—what is it? How is it transmitted?" Mothers also voiced the need to include fathers in educational material. One mother said, "I feel that this is something that not only as a mother I should know, but also the father should know." Later when participants were asked if the mother, the father, or both should be the one who made the decision, all participants said both.

Many parents had questions about the ages at which vaccination is recommended, and many seemed unsure about the recommended number or doses and the timing of each dose. Another theme during the focus group was questions about side effects. One mother voiced that she was concerned because her son developed a fever after vaccination. The provider explained

that it was a normal reaction, and the mother agreed to continue with the other doses. Another mother said, "I would like to know what are the symptoms they are going to feel after the vaccine, and what are the secondary effects that the vaccine can have in the future."

When asked if the vaccine should be presented as prevention for cancer or a sexually transmitted disease, all parents answered with cancer. "Because the word 'cancer' even if you don't want to, you only think of death. So if you say, 'If I get vaccinated, or I vaccinate my son, it's going to prevent his death. Yea I'll give it to him." They did however believe that it should be included in the fotonovela that HPV is a sexually transmitted disease. The also asked that the fotonovela include symptoms of the disease.

Lastly, parents talked extensively about how HPV affects boys. One mother stated, "I heard that men have the virus, but it isn't developed the same way as it is in women. He can transmit it, but he can't develop it." Parents seemed confused about and requested clarification regarding why boys should receive the HPV vaccine.

**Focus Group Two**

Once the fotonovelas were complete, a second focus group was held in order to learn parents' opinions regarding the fotonovelas as well as any recommendations for improvement. Nine Latino parents participated in this focus group. The demographic results can be found in Appendix K.

**Survey Results.** The feedback from the surveys was mainly very positive. When asked what they found effective about the fotonovela, parents had reassuring remarks. One parent wrote, "I like that it is a Hispanic family and that the person who is explaining is Hispanic also." Another parent wrote, "Everything is good. It provides information that is very understandable and completed." When asked what changes they recommend, parents had only a few

suggestions. One mother recommended excluding the information that HPV is a sexually transmitted disease. She wrote, "I felt blocked from the beginning with the introduction of one of the brochures. From the moment that it mentions so straight forward that this is a sexually transmitted infection. First thing I thought was – this does not apply to my kids…" There were a few comments about the photographs. One parent suggested including a picture of kids on the cover of the fotonovela and another suggested the provider should be closer to the parents. Some parents thought nothing should be changed. One wrote, "None, everything is good," and another wrote, "It is perfect…"

All of the parents indicated that they are more likely to vaccinate their children after seeing at least one of the fotonovelas. One parent wrote, "It is more clear and easier to know the importance of the vaccine and the reasons why to be vaccinated. When asked if they thought the fotonovela would be effective, all parents said yes except for one who said maybe. One parent wrote, "No more explanations are needed. It is very clear and it is not difficult to understand." Another wrote, "As a tool of education is would be excellent because the information is explained in a simple and effective way to the community."

**Analysis of the Transcription.** Similar themes were voiced during the focus group discussion. Most parents voiced a preference for the first fotonovela, which shows a provider speaking with both a mother and father. During the focus group one parent voiced, "I think this one is better because it is sort of more direct to the point, and it informs what the papilloma is." Another stated, "This one with the parents is more understandable with less technical vocabulary." Another stated, "The answers are very well focused and they are very simple and very practical." Parents voiced that they were glad it showed both a mother and father. One parent stated, "They are both parents of the children and it is important that as a couple they are

both informed." Another comment was that, "Both parents are focused on what they are explaining and you see that they are interested to learn in order to protect their children." Parents also liked that the fotonovela clarified that the vaccine was also for boys and that it included information about side effects. Parents additionally appreciated that the fotonovelas were in Spanish and used Latino models, including the provider. One parent stated, "They wouldn't feel so comfortable asking questions regarding the papilloma if the doctor was not Hispanic."

A concern that one parent voiced was that the first fotonovela started with the fact that HPV is a sexually transmitted infection. She stated, "I saw is that it says that the HPV is an infection which is sexually transmitted, so I thought this doesn't apply to me because my son is not sexually active." A different parent did voice that, "I like it because I didn't know that the papilloma was a sexually transmitted infection."

Parents also voiced that they didn't like that the fotonovela says that the vaccine is "a good way to help protect our family." One parent said, "I feel like it's something contagious and that I want to vaccinate my son so that he doesn't transmit it to the rest of us." Parents instead suggested changing it to, "We want to protect our children and help them to be as healthy as possible."

Another recommendation parents had was to include children having a conversation with the doctor. One parent said, "I can tell them what I think but a doctor is much better because she's the one who really knows." This sentiment was slightly conflicting with the opinion of the parents in the first focus group, who stated they wanted information for parents so that they could educate their children themselves. Since the photographs have already been taken, including children in the photographs is not feasible within the scope of this project. It is something that may be kept in mind for future projects. Another parent in the second focus

group stated, “I liked the fact that the parents have the final decision, especially when the children are small.” This idea aligned more closely with the opinion that parents voiced during the first focus group.

While one parent requested more information, another stated, “The idea is that it shouldn’t be so technical because the first thing is that people get the message, but if you have any doubts when you visit the doctor… he will explain.”

Feedback on the graphics included that the image of a syringe didn’t look like a syringe to a few of the parents. One parent recommended changing the image to a photograph of someone receiving an injection.

Feedback on the second fotonovela included that parents didn’t like that the mother said she would like to talk to her husband before making a decision. One mother said, “It’s like we can’t make a decision.” One parent also didn’t like the question on the front that asked, “Would you like your children to receive the vaccine today?” Another didn’t like that it said, “Talking with your spouse” because it made it sounds as though the vaccine is for adults. One parent didn’t like that it said four of five women have HPV at some point during their lives because it was a statistic that focused on girls. While parents did voice specific recommendations for improvement, in general feedback was very positive. The participating parents voiced that they found the fotonovelas to be effective and that they would be more likely to vaccine their children after reading them.

**Changes Made to the Fotonovela.** Based on this feedback the first fotonovela was chosen and updated. The first dialogue box no longer includes that HPV is a sexually transmitted infection. This is included later in the fotonovela, so that the initial emphasis is on cancer prevention. The second update was to change the last dialogue box to say, “I think it

sounds like a good way to help our children be as healthy as possible." This is similar to the last dialogue box in the second fotonovela, and parents voiced a preference for this wording. Additionally, the picture of the syringes no longer includes cartoon calendars beneath the syringes so that it is not as confusing. Lastly, an additional resource was added to the back panel of the fotonovela.

### Limitations

The limitations to this study include the small number of participants. Participants were a convenience sample and their input may not be generalizable to the rest of the Latino population living in Salt Lake City. Parents may have agreed to participate because HPV was a subject of interest to them, so they may have already had more knowledge about the topic than the general population. Additionally, this fotonovela has not been tested to determine its efficacy.

## Recommendations

This project explored the process of how to create culturally competent educational material. The final product of the project is a fotonovela that may be used to educate Latino parents about the HPV vaccine. Future research should be done in order to test the efficacy of the fotonovela using a larger sample of participants. Once the fotonovela is determined to be a valid tool, it may be distributed to parents at clinics and at community organizations such as Alliance Community Services and Comunidades Unidas. The testing of the efficacy of the developed fotonovela is beyond the scope of this project.

This project may act as a guide in other communities so that culturally competent educational material may be created in different locations. The current literature emphasizes the need for educational material that addresses the specific barriers within each community. While this specific fotonovela was created with the input of Latino parents living in Salt Lake City and

may not be useful in a different city or state, the process used to gain community insight and create culturally competent material may be useful in many settings.

## DNP Essentials

The Doctor of Nursing Practice (DNP) Essentials refer to the core competencies that should be incorporated into the roles of all advanced practice nurses (American Association of Colleges of Nursing, 2006). These essentials provide a framework that each DNP curriculum should follow. This DNP Scholarly Project addresses DNP Essential VII in particular. Essential VII is *Clinical Prevention and Population Health for Improving the Nation's Health*. This Essential supports the importance of health promotion through disease prevention and risk reduction. Additionally, this Essential cites the necessity of addressing the cultural and socioeconomic aspects of care in the promotion of population heath.

This DNP project addresses the increased risk of cervical cancer among Latina women (CDC, 2014c). With the recommended vaccination and screening, cervical cancer is a largely preventable disease (Benard et al., 2014). Previous research has identified many of the barriers to vaccination within the Latino community in Salt Lake City (Kepka, Warner, Kinney, Spigarelli, & Mooney, 2015). This project addresses those barriers through the creation of culturally competent educational material, specifically a fotonovela. Through the creation of a fotonovela, this project addresses the gap in care of this specific population, leading to disease prevention and improved population health.

## Conclusion

The goal of the project was to develop, with community input, a fotonovela that can be used to educate Latino parents about the HPV vaccine for the prevention of cervical cancer. Despite the preventability of cervical cancer, in 2011 (the most recent year with data), 12,109

women were diagnosed with cervical cancer and 4,092 women died from cervical cancer in the United States (CDC, 2014a). More black and Latina women are diagnosed with cervical cancer than women of other races or ethnicities (CDC, 2014c). In order to increase awareness and knowledge about the HPV vaccine, culturally competent educational material needs to be available for Latino parents.

Objectives for this project included gathering qualitative information about the preferences and recommendations of Latino parents living in Salt Lake City regarding the creation of a fotonovela about HPV vaccination; developing a fotonovela with information about cervical cancer risks, the link between HPV and cervical cancer, and basic HPV vaccine information, including the safety and efficacy of the vaccine; determining community suggestions for improvement of the fotonovela, and updating the fotonovela to include the input of local Latino parents; and disseminating the results through a poster presentation.

Through contact with community organizations in Salt Lake City, fifteen Latino parents were recruited and participated in a focus group. The main goal of this focus group was to encourage ideas and input from the community regarding the development of a fotonovela. The next step was to determine the main themes expressed in the focus group and develop a plot or storyline. Two fotonovelas were then created using these, as well as any additional themes deemed important in order to convey necessary information about the HPV vaccine. After the drafting of the fotonovelas, an additional focus group was held to assess parents' preferences and recommendations for improvement. One fotonovela was chosen and was updated to incorporate these recommendations.

This DNP project addresses the increased risk of cervical cancer among Latina women. With the recommended vaccination and screening, cervical cancer is a largely preventable

disease (Benard et al., 2014). Previous research has identified many of the barriers to vaccination within the Latino community in Salt Lake City (Kepka, Warner, Kinney, Spigarelli, & Mooney, 2015; Warner et al., 2014). This project aimed to address those barriers through the creation of culturally competent educational material, specifically a fotonovela.

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# Appendix A

# The Development of a Fotonovela for HPV Vaccine Education

Jocelyn Yale, BSN, SNM

In partial fulfillment of the requirements for
the Doctor of Nursing Practice degree
9/23/2015

## Background

In 2011

- 12,109 women were diagnosed with cervical cancer
- 4,092 women died from cervical cancer (CDC, 2014a)

Between 2004-2008, the incidence rate for cervical cancer was

- 7 per 100,000 among non-Latina women
- 11 per 100,000 among Latina women (CDC, 2014b)

## Problem Statement

- 37.6% of adolescent girls complete the HPV vaccine (Benard et al., 2014)
- Vaccine administration is recommended when girls are 11 or 12 years old
- Culturally competent education material needs to be available for Latino parents
- The main purpose of this project is the creation of a fotonovela with community input

## Significance & Policy Implications

- *Healthy People 2020* objectives include a reduction in the incidence rate of cervical cancer and a reduction in the death rate (Benard et al., 2014)
- 93% of cervical cancer cases could be prevented with HPV vaccination combined with cervical cancer screening (Benard et al., 2014)
- Through the creation of a fotonovela, this project aims to address the gap in care of the Latina population, leading to disease prevention and improved population health

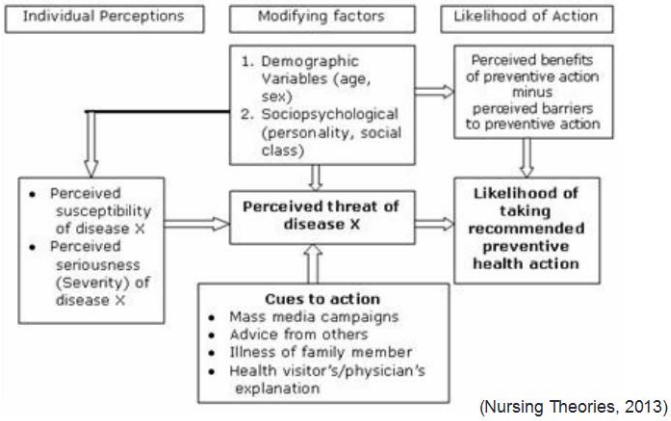
## Objectives

- #1: Gather qualitative information about the preferences and recommendations of Latino parents living in Salt Lake City regarding the creation of a fotonovela about HPV vaccination
- #2: Develop a fotonovela with information about cervical cancer risks, the link between HPV and cervical cancer, and basic HPV vaccine information

## Objectives

- #3: Determine community suggestions for improvement of the fotonovela, and update the fotonovela to include the input of local Latino parents
- #4: Disseminate the results through a poster presentation

## Theoretical Framework: Health Belief Model




(Nursing Theories, 2013)

## Literature Review

- Very few Latino parents are aware that their daughters are at a higher risk of HPV (Glenn et al., 2015)
- In many regions, Latino parents are unaware even of the link between HPV and cervical cancer (Glenn et al., 2015)
- A lack of education materials for Latino parents with low levels of acculturation is one reason for their lower level of knowledge about the HPV vaccine (Kepka et al., 2015)

## Literature Review

- A fotonovela is a book or pamphlet that communicates a story through photos with accompanying text
- A study by Unger et al. (2013) found that a fotonovela about depression
  - caused a larger reduction in antidepressant and mental health care stigma
  - was more likely to be passed on


(CDC, 2011)

## Implementation & Evaluation

| Objectives | Implementation | Evaluation |
|---|---|---|
| Gather qualitative information about the preferences and recommendations of Latino parents living in Salt Lake City regarding the creation of a fotonovela about HPV vaccination | 1. Create contacts<br>2. Create a questionnaire<br>3. Submit project for IRB approval<br>4. Schedule and conduct focus group | 1. Communication will be established<br>2. A questionnaire will be developed and approved<br>3. Project will be approved by the IRB<br>4. 5-10 parents will participate in a focus group |
| Develop a fotonovela with information about cervical cancer risks, the link between HPV and cervical cancer, and basic HPV vaccine information | 1. Determine the main themes expressed during the focus group<br>2. A plot or storyline will be developed<br>3. The themes as well as information about the vaccine will be used to create a short fotonovela | 1. Relevant themes will be identified and approved<br>2. A plot or story line will be successfully developed<br>3. A fotonovela will be created |

## Implementation & Evaluation

| Objectives | Implementation | Evaluation |
|---|---|---|
| Determine community suggestions for improvement of the fotonovela, and update the fotonovela to include the input of local Latino parents | 1. Create a written, open-ended questionnaire<br>2. A second focus group will be arranged and conducted<br>3. Final changes will be made to the fotonovela | 1. A written questionnaire will be developed and approved<br>2. 5-10 parents will participate in a second focus group<br>3. The fotonovela will appropriately incorporate final suggestions from the focus group |
| Disseminate the results through a poster presentation | 1. Submit application to the EBP Poster Fair<br>2. Present at the poster fair | 1. Application will be submitted by April 15th, and the project will be presented at the poster fair |

## Summary

- This DNP project addresses the increased risk of cervical cancer among Latina women (CDC, 2014b).
- With the recommended vaccination and screening, cervical cancer is a largely preventable disease (Benard et al., 2014).
- Previous research has identified many of the barriers to vaccination within the Latino community in Salt Lake City (Kepka et al., 2015).
- This project will address those barriers through the creation of culturally competent educational material, specifically a fotonovela.

## Future Project

- The scope of this project entails the creation of the fotonovela with community input
- A later project may include testing the efficacy of the fotonovela on a larger scale

## Acknowledgments


- Committee:
  - Dr. Ana Sanchez-Birkhead, PhD, WHNP-BC, APRN
  - Gwen Latendresse, PhD, CNM, FACNM, Director, Nurse Midwifery/ WHNP Specialties
  - Pam Hardin, PhD, RN, Executive Director, MS & DNP programs
- Content Expert:

  Dr. Deanna Kepka, PhD, MPH, MA

  Dr. Kekpa is an assistant professor at the College of Nursing and an investigator at Huntsman Cancer Institute. Her focus is on preventing cervical cancer among Latinas in the United States.

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# Appendix B

**ALLIANCE COMMUNITY SERVICES**
***Providing Diversity Services and Promoting Cultural Awareness***
***www.alliance-community.org***

November 18, 2015

To Whom It May Concern,

Alliance Community Services is pleased to support the project in regards to The Development of a Fotonovela for HPV Vaccination Education. We understand that the goal of this project is to develop, with community input, a fotonovela that can be used to educate Latino parents about the HPV vaccine for the prevention of cervical cancer. The incidence rate for cervical cancer among Latina women in the United States is significantly higher than the incidence rate among non-Latina women. Through the creation of a fotonovela, this project aims to address the gap in care of the Latina population, leading to disease prevention and improved population health.

I, on behalf of Alliance Community Services, agree to hold a focus group at our location in December 2015 or January 2016 and to help recruit 10-12 Latino parents with children ages 11-17 living in the Salt Lake City area. The focus group will be conducted in order to gain qualitative information about parents' opinions regarding HPV vaccine educational material. A translator will be available for the focus group, so participants may be Spanish-speaking. Incentives including food during the focus group and gift cards will be provided to each participant. I agree to maintain contact with Jocelyn Yale, the project lead, and will help facilitate the scheduling and logistics of the focus group. I understand the purpose and significance of this project.

By working together, we can enhance our individual efforts to reduce the burden of cancer in Utah.

Sincerely,

Sara Carbajal-Salisbury
Health Programs Director
sara@alliance-community.org

University of Utah Institutional Review Board

November 19, 2015

**Re: The Development of a Fotonovela for HPV Vaccination Education**

To Whom It May Concern,

The goal of this project is to develop, with community input, a fotonovela that can be used to educate Latino/a parents about the HPV vaccine for the prevention of cervical cancer. The incidence rate for cervical cancer among Latina women in the United States is significantly higher than the incidence rate among non- Latina women. Through the creation of a fotonovela, this project aims to address the gap in care of the Latina population, leading to disease prevention and improved population health.

I, on behalf of Communities United, agree to hold a focus group at our location in February 2016 and to help recruit 10-12 Latino/a parents with children ages 11- 17 living in the Salt Lake City area. The focus group will be conducted to gain qualitative information about parents' opinions regarding a fotonovela developed for HPV vaccine education. A translator will be available for the focus group, so participants may be Spanish-speaking. Incentives including food during the focus group and gift cards will be provided to each participant. I agree to maintain contact with Jocelyn Yale, the project lead, and will help facilitate the scheduling and logistics of the focus group. I understand the purpose and significance of this project.

Sincerely,

Luis Garza, MPA
*Executive Director*
Comunidades Unidas
luis@cuutah.org

# Appendix C

## Consent Document

### BACKGROUND

You are being asked to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you want to volunteer to take part in this study.

The purpose of the study is **to develop, with community input, a fotonovela that can be used to educate Latino parents about the HPV vaccine for the prevention of cervical cancer**.

Despite the preventability of cervical cancer, women continue to die from this disease each year, and Latina women die at a higher rate than any other race or ethnic group. Studies have shown that HPV vaccination combined with cervical cancer screening could prevent close to 93% of cervical cancer cases. In order to increase awareness and knowledge about the HPV vaccine, culturally competent educational material needs to be available for Latino parents. The main goal of this focus group is to encourage ideas and input from the community regarding the development of a fotonovela. By participating in this study, you can help provide information that will be used to create educational material that will hopefully increase HPV vaccination rates.

### STUDY PROCEDURE

It will take you approximately 60 minutes to complete this study. As part of this study you will be asked to take part in a focus group and complete a survey. A bilingual Spanish facilitator will be present to lead the focus group. Questions will be asked about your preferences and recommendations regarding an educational fotonovela. The focus group session will be audiotaped and the recordings transcribed by a transcribing service.

### RISKS

The risks of this study are minimal. You may feel upset thinking about or talking about personal information related to human papillomavirus (HPV), cervical cancer, or HPV vaccination. These risks are similar to those you experience when discussing personal information with others. If you feel upset from this experience, you can tell the researcher, and he/she will tell you about resources available to help.

*We will do everything possible to keep the information you share while participating in the focus group private from those not associated with the project. Thus, we ask you and the other participants to keep the focus group discussion confidential. Still, there is a chance that a group member might mention your comments or name in a later conversation. Consequently, we cannot guarantee that no one will share what you have said after they leave.*

### BENEFITS

There are no direct benefits for taking part in this study. However, we hope the information we get from this study may help develop a fotonovela that may be used to help increase rates of HPV vaccination and decrease rates of cervical cancer.

**CONFIDENTIALITY**
Your records from this study, including the focus group transcript, audio files, and survey responses, will be kept in locked filing cabinets and on password protected computers throughout the duration of the study. The research team will use the recording, transcript, and surveys to analyze the themes discussed and create a plot or storyline. Others who will have access to your information for this study are the University's Institutional Review Board (the committee that oversees research that involves human participants) and authorized members of the University of Utah who need the information to perform their duties (for example: to ensure integrity of the research).

If we share your information with anyone else outside the University of Utah, you will not be identified by name, social security number, address, telephone number, or any other information that would directly identify you unless required by law. There are some cases in which a researcher is obligated to report issues, such as serious threats to public health or safety. For example, if you disclose information that gives study staff a reason to believe that a child or disabled or elderly adult has been subjected to abuse or neglect, study staff will report that information to Child Protective Services, Adult Protective Services, or the nearest law enforcement agency to the extent required by law.

**PERSON TO CONTACT**
If you have questions, complaints, or feel you have been harmed as a result of participation, please call Jocelyn Yale at (612) 247-1058.

**Institutional Review Board:** Contact the Institutional Review Board (IRB) if you have questions regarding your rights as a research participant. Also, contact the IRB if you have questions, complaints or concerns which you do not feel you can discuss with the investigator. The University of Utah IRB may be reached by phone at (801) 581-3655 or by e-mail at irb@hsc.utah.edu.

**Research Participant Advocate:** You may also contact the Research Participant Advocate (RPA) by phone at (801) 581-3803 or by email at participant.advocate@hsc.utah.edu.

**VOLUNTARY PARTICIPATION**
Participation in this study is voluntary. You can choose not to take part. You can choose not to finish the focus group or not answer any question without penalty or loss of benefits. By participating in this interview, you are giving your consent and authorization to participate and allow us to use information from the focus group.

**COSTS AND COMPENSATION TO PARTICIPANTS**
There are no direct costs for participating in this study other than transportation to and from the focus group. To thank you for your time, we will provide you with a $20 gift card for participating in the focus group.

**CONSENT**

By signing this consent form, I confirm I have read the information in this consent form and have had the opportunity to ask questions. I will be given a signed copy of this consent form. I voluntarily agree to take part in this study.

_____
Printed Name of Participant

_____ _____
Signature of Participant Date

_____
Printed Name of Person Obtaining Consent

_____ _____
Signature of Person Obtaining Consent Date

**WITNESS STATEMENT:**

The participant was unable to read or sign this consent form because of the following reason:

☐ The participant is illiterate
☐ The participant is visually impaired
☐ The participant is physically unable to sign the consent form. Please describe:

_____

_____

☐ Other *(please specify)*:

_____

_____

I confirm that I was present as a witness for the consent process for this study. I confirm that the participant named above was read the information in the consent document and that the participant has agreed to take part in the research study.

_____
Name of Witness

_____ _____

Signature of Witness Date

**WITNESS STATEMENT: (For Non-English Speaking Participants Only)**
Consent was obtained from the participant using a short form for non-English speakers. The short form is available in the participant's language and this (long) consent form was read to the participant using an interpreter.

As a witness, I confirm that I was present for the complete consent process for this study. I confirm that the participant named above was read the information in this consent document in a language he/she understands and that the participant has agreed to take part in the research study.

_____
Name of Witness

_____ _____
Signature of Witness Date

# Appendix D

## Focus Group 1 Script

Welcome everyone, and thank you for your willingness to participate in this focus group. *We will do everything possible to keep the information you share while participating in the focus group private from those not associated with the project. Thus, we ask you and the other participants to keep the focus group discussion confidential. Still, there is a chance that a group member might mention your comments or name in a later conversation. Consequently, we cannot guarantee that no one will share what you have said after they leave.*

The goal of this project is to develop, with community input, a fotonovela that can be used to educate Latino parents about the HPV vaccine for the prevention of cervical cancer. Despite the preventability of cervical cancer, women continue to die from this disease each year, and Latina women die at a higher rate than any other race or ethnic group. Studies have shown that HPV vaccination combined with cervical cancer screening could prevent close to 93% of cervical cancer cases. In order to increase awareness and knowledge about the HPV vaccine, culturally competent education material needs to be available for Latino parents. The main goal of this focus group is to encourage ideas and input from the community regarding the development of a fotonovela. *We would like to ask that everyone take turns speaking and do their best not to speak over the other participants, so that we can easily hear people when they speak.* Are there any questions before we get started?

Ask parents:

1. In the fotonovela, who should the conversation be between? (Mom and daughter, doctor and patient, two friends? A combination?)

2. Would it be more convincing if it were just a conversation about vaccination or if they were discussing someone who was diagnosed with cervical cancer?

3. Would reframing this as a vaccine for cervical cancer prevention rather than prevention from a sexually transmitted infection prevention make you more likely to vaccinate your child/children? Should we include that human papillomavirus is a sexually transmitted infection? Or just reference human papillomavirus as the virus that causes cervical cancer?

4. Would cartoons/drawings or pictures be better? Does it matter?

5. Should both parents (mother and father) be addressed as decision makers in the fotonovela? Should it be geared toward one or the other?

6. What are your ideas for what you would like to see in this material?

Thank you for your participation in this focus group. We greatly appreciate your willingness to talk with us today. Your responses will be used to help develop culturally competent educational material about HPV vaccination.

## Focus Group 2 Script

Welcome everyone, and thank you for your willingness to participate in this focus group. *We will do everything possible to keep the information you share while participating in the focus group private from those not associated with the project. Thus, we ask you and the other participants to keep the focus group discussion confidential. Still, there is a chance that a group member might mention your comments or name in a later conversation. Consequently, we cannot guarantee that no one will share what you have said after they leave.*

The goal of this project is to develop, with community input, a fotonovela that can be used to educate Latino parents about the HPV vaccine for the prevention of cervical cancer. Despite the preventability of cervical cancer, women continue to die from this disease each year, and Latina women die at a higher rate than any other race or ethnic group. Studies have shown that HPV vaccination combined with cervical cancer screening could prevent close to 93% of cervical cancer cases. In order to increase awareness and knowledge about the HPV vaccine, culturally competent education material needs to be available for Latino parents. The main goal of this focus group is assess your preferences and your recommendations for improvement of the fotonovela. The fotonovela will be updated to incorporate these recommendations. You will additionally be given the opportunity to write down your thought after the discussion. *We would like to ask that everyone take turns speaking and do their best not to speak over the other participants, so that we can easily hear people when they speak.* Are there any questions before we get started?

Ask parents:

1. What is your first impression of this fotonovela?

2. What do you like or find effective about this fotonovela?

3. What changes do you recommend for improvement?

4. Are you more likely to vaccinate your child/children now that you have seen the fotonovela? Why or why not?

5. Do you think this fotonovela would be effective in increasing HPV vaccination rates? Why or why not?

6. What are you final thoughts about the fotonovela?

Thank you for your participation in this focus group. We greatly appreciate your willingness to talk with us today. Your responses will be used to help develop culturally competent educational material about HPV vaccination.

# Appendix E

**FOCUS GROUP SURVEY**

**The Development of a Fotonovela for HPV Vaccine Education**

**We would like some demographic information so that we know the population that is being represented in this focus group. Your information will be kept private and confidential. If you have any questions, please feel free to ask your facilitator or members of the research staff.**

**1. What is your age? _____**

**2. What is your gender?**

[ ] Male
[ ] Female

**3. Are you married?**

[ ] Yes
[ ] No

**4. How many children do you have? _____**

**5. What are the ages and gender of your children?**

| | Age | Gender |
|---|---|---|
| Child 1 | | [ ] Female [ ] Male |
| Child 2 | | [ ] Female [ ] Male |
| Child 3 | | [ ] Female [ ] Male |
| Child 4 | | [ ] Female [ ] Male |
| Child 5 | | [ ] Female [ ] Male |
| | | |

**6. Have any of your children received the HPV vaccine series?**

[ ] Yes
[ ] No
[ ] I am unsure

**7. Do you plan on having your children receive the HPV vaccine series?**

[ ] Yes
[ ] No
[ ] Some, but not all of my children. Please explain: _____
[ ] I am unsure

**8. What is your race or ethnicity?**

**9. What is your preferred language (what language do you speak at home)?**

[ ] Spanish
[ ] English
[ ] Other: _____

**We would additionally like to provide you the opportunity to write down your thoughts about the fotonovela that you were just shown. You may repeat the opinions you voiced during the focus group and/or include information you did not voice.**

**10. What did you like or find effective about this fotonovela?**

**11. What changes do you recommend for improvement?**

**12. Are you more likely to vaccinate your child/children now that you have seen the fotonovela? Why or why not?**

**13. Do you think this fotonovela would be effective in increasing HPV vaccination rates? Why or why not?**

**Thank you for participating in this survey. Your responses are valuable in helping us develop ways to improve HPV vaccination in Utah.**

# Appendix F

**Figure 1** Fotonovela 1 English

**Figure 2** Fotonovela 2 English

**Figure 3** Fotonovela 1 Spanish

**Figure 4** Fotonovela 2 Spanish

# Appendix G

**Figure 5** Final Fotonovela English

**Figure 6** Final Fotonovela Spanish

# Appendix H

# The Development of a Fotonovela for HPV Vaccine Education

Jocelyn Yale, BSN, DNP student
Midwifery/Women's Health Specialty

The University of Utah
College of Nursing

## PURPOSE

Develop, with community input, a fotonovela that can be used to educate Latino parents about the HPV vaccine for the prevention of cervical cancer.

## BACKGROUND

- Despite the preventability of cervical cancer, 12,109 women were diagnosed with cervical cancer and 4,092 women died from cervical cancer in 2011 in the U.S.
- More Latina women are diagnosed with cervical cancer than women of other races or ethnicities
- Studies have shown that HPV vaccination combined with cervical cancer screening could prevent close to 93% of cervical cancer cases
- Despite unanimous recommendation by governmental and professional organizations, a 2013 national survey showed only 37.6% of adolescent girls completed the HPV vaccine series. For Latina girls that number is even smaller.
- Research done in Salt Lake City has shown that parents with low-acculturation were more likely to report lack of information as the main barrier to HPV vaccination
- **That fact supports the need for culturally competent education material to increase awareness and knowledge about the HPV vaccine among Latino parents**

## METHODS

1. Through contact with community organizations in Salt Lake City, 15 Latino parents were recruited to a focus group. The main goal of this focus group was to encourage ideas and input from the community.
2. The next step was to determine the main themes expressed during the focus group
3. A fotonovela was then created using these, as well as any additional themes deemed important
4. After the drafting of the fotonovela, an additional focus group was held to assess parents' preferences and recommendations for improvement. The fotonovela was then updated.


## RESULTS

The themes expressed by parents included:

- The need for information specifically for parents
- Information presented by a provider
- Information presented with prevention in mind
- An emphasis on cancer prevention
- Decision-making including both parents
- Vaccine information including timing, dosing, and side effects
- Information about vaccinating boys

## CONCLUSIONS

- This DNP project addresses the increased risk of cervical cancer among Latina women
- With the recommended vaccination and screening, cervical cancer is a largely preventable disease
- **This project explored the process of how to create culturally competent educational material. The final product of the project is a fotonovela that may be used to educate Latino parents about the HPV vaccine.**
- Future research should be done in order to test the efficacy of the fotonovela using a larger sample of participants

## ACKNOWLEDGMENTS

The project chair was Dr. Ana Sanchez-Birkhead, PhD, WHNP-BC, APRN and the content expert was Dr. Deanna Kepka, PhD, MPH, M.A.
Thank you to Comunidades Unidas and Alliance Community Services for their support of this project.

# Appendix I

INSTITUTIONAL REVIEW BOARD
THE UNIVERSITY OF UTAH

75 South 2000 East Salt Lake City, UT 84112 | 801.581.3655 | IRB@utah.edu

**IRB:** IRB_00088014

**PI:** Jocelyn Yale

**Title:** The Development of a Fotonovela for HPV Vaccine Education

**Date:** 12/29/2015

Thank you for submitting your request for approval of this study. On 12/29/2015, a designated IRB member has determined that your study is exempt from further IRB review, under **Exemption Category 11**. Note the following delineation of categories:

- Categories 1-6: Federal Exemption Categories defined in 45 CFR 46.101(b)
- Categories 7-11: Non-Federal Exemption Categories defined in University of Utah IRB policy at http://irb.utah.edu/_pdf/IGS - Exempt Research 090113.pdf

You must adhere to all requirements for exemption described in University of Utah IRB policy (http://irb.utah.edu/_pdf/IGS - Exempt Research 090113.pdf). This includes:

- All research involving human subjects must be approved or determined exempt by the IRB before the research is conducted.
- All research activities must be conducted in accordance with the Belmont Report and must adhere to principles of sound research design and ethics.
- Orderly accounting and monitoring of research activities must occur.

# Appendix J

# Poster Session Details

As of: 3/1/2016

**2016 Utah Public Health Conference and UPHA's 100 Year Anniversary Gala**
April 11-13 ~ Sheraton Hotel ~ Salt Lake City

## Presenter & Poster Details

| *Presenter Full Name and Degrees:* | *Presenter#* | *Organization:* |
|---|---|---|
| **Jocelyn Yale** | **1010** | **University of Utah** |

*Poster #:* **401.02**

| *Date:* | *Times:* | |
|---|---|---|
| **April 12** | **11:00 AM** | **11:30 AM** |
| | **1:30 PM** | **2:00 PM** |

*Poster Title:*
**The Development of a Fotonovela for HPV Vaccine Education**

## Poster Details

*Short Description:*

The goal of this project was to develop, with community input, a fotonovela that can be used to educate Latino parents about the HPV vaccine for the prevention of cervical cancer.
Despite the preventability of cervical cancer, in 2011 (the most recent year with data), 12,109 women were diagnosed with cervical cancer and 4,092 women died from cervical cancer in 2011 in the United States. Studies have shown that HPV vaccination combined with cervical cancer screening could prevent close to 93% of cervical cancer cases. Despite unanimous recommendation by governmental and professional organizations, a 2013 national survey showed only 37.6% of adolescent girls completed the HPV vaccine series. For Latina girls that number is even smaller. In some regions, one third or less have received the first dose of the HPV vaccine. In order to increase awareness and knowledge about the HPV vaccine, culturally competent education material needs to be available for Latino parents.
The objectives of this project included gathering qualitative information about the preferences and recommendations of Latino parents living in Salt Lake City regarding the creation of a fotonovela about HPV vaccination; developing a fotonovela with information about cervical cancer risks, the link between HPV and cervical cancer, and basic HPV vaccine information; and lastly determining community suggestions for improvement of the fotonovela, and updating the fotonovela to include the input of local Latino parents.

# Appendix K

**Table 1** Demographic Survey Results from Focus Group 1 (N=15)

| | N | Range (Mean) |
|---|---|---|
| Age | | 33-49 (39) |
| Gender | | |
| Female | 14 | |
| Male | 1 | |
| Marital Status | | |
| Married | 11 | |
| Other | 4 | |
| Number of children | | 2-5 (4) |
| Age of children (years) | | 3 months-30 (12) |
| Any children have received HPV vaccines | | |
| Yes | 6 | |
| No | 8 | |
| Unsure | 1 | |
| Plan to have children receive HPV vaccines | | |
| Yes | 12 | |
| No | - | |
| Some, but not all children | - | |
| Unsure | 3 | |
| Ethnicity | | |
| Hispanic/Latino | 15 | |
| Preferred Language | | |
| Spanish | 15 | |
| English as well as Spanish | 1 | |

**Table 2** Demographic Survey Results from Focus Group 2 (N=9)

| | N | Range (Mean) |
|---|---|---|
| Age | | 40-47 (43) |
| Gender | | |
| Female | 6 | |
| Male | 3 | |
| Marital Status | | |
| Married | 8 | |
| Other | 1 | |
| Number of children | | 2-5 (2) |
| Age of children (years) | | 7-23 (15) |
| Any children have received HPV vaccines | | |
| Yes | 5 | |
| No | 4 | |
| Unsure | - | |
| Plan to have children receive HPV vaccines | | |
| Yes | 7 | |
| No | - | |
| Some, but not all children | - | |
| Unsure | 2 | |
| Ethnicity | | |
| Hispanic/Latino | 9 | |
| Preferred Language | | |
| Spanish | 9 | |
| English as well as Spanish | 1 | |