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Get Vaccinated! & Get Tested!: Developing Primary and Secondary Cervical Cancer Prevention Videos for a Haitian Kreyòl-speaking Audience

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Abstract

Although routine screening reduces cervical cancer rates between 60-90%, thousands of women worldwide are diagnosed with the disease on an annual basis due to inadequate screening. Haitian women in South Florida experience a disproportionate burden of cervical cancer with disease rates four times higher than the average for women in Miami. An ongoing community based-participatory research (CBPR) initiative to assess and reduce this burden reveals that a complex interplay of factors contributes to lack of access to screening in this community including socioeconomics, language barriers, and traditional understandings of health and disease. In an effort to address some of these barriers and encourage uptake of primary and secondary cervical cancer prevention strategies, two videos on cervical cancer prevention were created using a CBPR framework. The video screenplays were created by a Haitian screenwriter using evidence-based medical information provided by academic researchers. The films feature Haitian actors speaking a Haitian Kreyòl dialogue with a storyline portraying friends and family discussing human papillomavirus (HPV) disease and vaccination, Papanicolaou (Pap) testing, and cervical cancer. Focus groups held with Haitian women in South Florida suggest the films are engaging, feature relatable characters, and impact knowledge about HPV, cervical cancer development, and current prevention recommendations.

Keywords

cervical cancer; community based participatory research (CBPR); Haitian Kreyòl; video intervention; prevention

Introduction

The Papanicolaou (Pap) test has been widely adopted since the 1940s and is credited with decreasing rates of cervical cancer incidence and mortality. When broadly and regularly utilized, Pap smear screening can reduce disease burden by at least 80% (National Cancer Institute, 2014; Baezconde-Garbanati et al, 2013). Due to widespread use of the Pap test in the United States, cervical cancer is no longer the leading cause of cancer death among women (U.S. Cancer Statistics Working Group, 2014). However, thousands of women are still diagnosed with cancer of the cervix in the U.S. on an annual basis; the majority of such women are racial and ethnic minorities, foreign-born, uninsured, less educated, and socioeconomically disadvantaged (Scarinci et al, 2010; Goel et al 2003; Baezconde-Garbanati et al, 2013). These disparities are due to complex structural and cultural issues that limit access to screening and appropriate follow-up (Watson et al, 2008). Efforts to uniformly reduce the burden of cervical cancer therefore aim to address such barriers to screening uptake and utilization throughout the life course. (McGraw and Ferrante, 2014).

Cervical Cancer Programming in Little Haiti, Miami

In South Florida, Haitian women living in the Little Haiti neighborhood of Miami experience the largest burden of cervical cancer in the region, with incidence rates that are higher than that of any other racial or ethnic minority (Kobetz et al, 2009; Kobetz et al, 2012). While the incidence of cervical cancer in the Miami metropolitan area is 9/100,000, the rate in Little Haiti is over four times higher: 38/100,000 (Scarinci et al, 2010; Kobetz et al, 2011). In an effort to understand and address this disproportionate share of cervical disease, Patne en Aksyon (Partners in Action) was founded in 2004. Patne en Aksyon is a campus-community partnership between community members in and around Little Haiti (including key stakeholders, community-based organizations, and community health workers) and academic investigators from the University of Miami Miller School of Medicine. The partnership was designed using the principles of community-based participatory research (CBPR), where community participation is involved at all phases of the research process and community oversight for partnership activities is provided through a community advisory board (CAB) (Kobetz et al, 2009). CAB membership reflects the demographics of the surrounding community, with members including community leaders, religious leaders, and health professionals from in and around Little Haiti as well as staff members from the Jay Weiss Institute for Health Equity at the University of Miami. Board meetings are held bi-monthly at the Center for Haitian Studies which is a primary care clinic and community center located in Little Haiti. The establishment of this partnership has fostered an in-depth exploration of the factors that contribute to and perpetuate the high rates of cervical cancer among Miami's Haitian women. These forces are complex and include lack of financial resources, uninsurance, immigration status, language barriers, and

traditional conceptions of health, illness, and treatment (Menard et al, 2010). Importantly, the partnership is also explicitly intended to help to address these barriers through the design and implementation of linguistically and culturally appropriate intervention strategies under the guidance of the CAB.

Video Development and Filming

Recent meetings with the CAB revealed a desire to increase the use of technological resources in research programming such as audiovisual and computer equipment for community outreach efforts. Prior focus groups completed by Patne en Akasyon supported this suggestion by revealing that many women in Little Haiti are obtaining health information, including information on cervical cancer, through Haitian Kreyòl media sources such as television and radio (Kobetz et al, 2011). These findings dovetail with guidance from the United States Community Preventative Services Task Force who recommends the use of small media, including videos and printed materials, for increasing knowledge of and action on cervical cancer screening based on strong evidence (Guide to Community Preventative Services, 2005). With funding provided by the National Cancer Institute's Community Networks Program (Grant Number: U54 CA153705), the Patne en Akasyon team decided to create two educational films on cervical cancer prevention for a Haitian audience in Haitian Kreyòl. While cervical cancer prevention videos have been designed in languages including English, Spanish, and Vietnamese (for example please see Byrd et al, 2013; Montealegre et al, 2014), these are the first videos produced on this topic for monolingual Haitian Kreyòl-speakers. Given that Haitian Kreyòl is historically a spoken language with only a recently-established orthography, videos are seen by the research team as having the potential to reach a wider audience of Kreyòl speakers than written educational materials (Barbee et al, 2010).

The overall structure for the videos was determined by the CAB with input from the research team in compliance with funding specifications. Two separate videos were planned, the first to cover secondary prevention via cervical cancer screening, the second to discuss primary prevention through vaccination against HPV. Much of the formative research for the videos was generated through nearly ten years of work by Patne in Akasyon. This previous work indicated some important components to incorporate into the videos including: (i) discussing the association between HPV and cervical cancer; (ii) clarifying the difference between HPV and human immunodeficiency virus (HIV); (iii) addressing beliefs that the HPV vaccine is linked to sexual promiscuity; (iv) discussing the use of feminine hygiene practices; and (v) conveying the fact that HPV infections and cervical cancer can be asymptomatic (Barbee et al, 2010; Menard et al, 2010; Kobetz et al, 2011; Kobetz et al, 2012).

After generating a basic framework for the videos, the specifics of video content were developed through a series of formal and informal interviews between a community health worker (CHW) working with Patne en Akasyon and community members in Little Haiti. Following these exploratory interviews, the CHW led focus groups to inquire more deeply into the technical and medical information that should be included in the videos as well as discuss the type of storyline the target audience would find engaging and relatable. Focus

group questions were developed by the Patne en Aksyon research team. Several important insights were obtained through these qualitative investigations: (i) a storyline that revolved around Haitian characters confronting cervical cancer and HPV vaccination was preferred over a purely educational format; (ii) a dramatic storyline in a soap opera style was suggested; (iii) participants felt the videos should incorporate men and the perspective of fathers; (iv) the video scripts were suggested to be adaptable to radio as many focus group participants listened to Haitian radio as a primary news source.

After this series of consultations with members of the Little Haiti community, the CHW drafted two screenplays with medical and scientific information from the University of Miami research team. These drafts were provided to a Haitian screenwriter who was able to adapt them and create a set of characters with two separate but related videos on cervical cancer screening and HPV vaccination following a Haitian storyline. The videos incorporated medical information throughout. Both screenplays were written in Haitian Kreyòl. The scripts were revised several times by the research team for medical accuracy and then shared with the CAB. The CAB edited the scripts with respect to storyline and cultural content. The screenwriter then completed a final draft of the videos with English translation.

With the scripts complete, an open call was held to recruit actors. Using social networks and word of mouth, a group of volunteer actors auditioned for the videos and were assigned roles. All actors were fluent in Haitian Kreyòl and English. Before filming, a Haitian producer was hired to oversee filming, directing, and production. Location scouting for filming was completed by the screenwriter and research team and focused on establishments in the Miami area that cater to Haitian patrons. Filming took place over two days at a Miami restaurant and the private home of a Haitian family. Meals were provided to the actors while the screenwriter and producer received stipends for their contributions. Upon completion of the filming, the producer edited the videos and added English subtitles and credits. The completed videos were provided to the screenwriter, research team and CAB for final review and approval by all parties.

The Videos

Atansyon Pa Kapon Ann Te Tes/Get Tested!

The running time for Get Tested is 9:23. The dialogue is entirely in Haitian Kreyòl with English subtitles. This video takes place at a Haitian restaurant with a group of friends including three women (Caroline, Vanessa, and Anne-Marie) and one man (Ernesto). Caroline, Vanessa, and Anne-Marie are old friends while Ernesto is Vanessa's husband and a physician. The women start dinner with a discussion of their friend Mirlande, who was recently diagnosed with cervical cancer. They are very surprised and discuss the fact that Mirlande hadn't seemed sick recently. Ernesto explains that it is very common to not have any symptoms of cervical cancer in early phases, and emphasizes the importance of detection with Pap tests well before any symptoms would appear. Caroline then admits she does not know what the cervix is, so Vanessa gives her an explanation of the relevant anatomy. When Anne-Marie asks what causes cervical cancer, Ernesto answers that it is HPV. The women ask for clarification on the difference between HPV and HIV, which

Ernesto provides. When Ernesto leaves for the restroom, the women break into a discussion of Mirlande and the fact that she “sleeps around” and whether this may have contributed to her developing cervical cancer. Vanessa dispels the myth that only promiscuous women get cervical cancer by explaining that even one sex act can lead to HPV contraction and that condoms do not offer full protection from the virus. However, they all agree that condoms are still important for protection against HIV and other infections. As the scene ends, the three women discuss the fact that they all should protect themselves from cervical cancer by seeking screening, no matter how busy they are in their daily lives.

The second scene features Anne-Marie on a phone call with Caroline. She explains that she just had a Pap screening from her doctor and that the procedure was straightforward and professional. She encourages Caroline to seek screening for herself.

An Nou Pran Vaksen/Get Vaccinated!

The running time for Get Vaccinated! is 13:47. This film is also in Haitian Kreyòl with English subtitles. The scene takes place at the home of Annette and Gaspard, a Haitian couple with two children. When the film starts, Annette is shown looking through a pile of bills. She notices a pamphlet on HPV vaccination that was mailed to her by her children's pediatrician. She flips through the pamphlet and considers aloud whether she should vaccinate her children. Gaspard comes home and the two proceed to discuss the pamphlet. Gaspard expresses his concerns with vaccinating their 15 year old daughter against a cancer that is associated with a sexually transmitted infection, stating that he feels it is better to wait until she is 18 and an adult. Mirlande, Annette's sister, then arrives and proceeds to tell Gaspard and Annette that she was recently diagnosed with an abnormal Pap test where she was found to be HPV positive. She is still waiting for further information from her doctor on follow-up. Annette expresses shock over the diagnosis, and the three break into a discussion on HPV vaccination. Mirlande encourages Annette and Gaspard to vaccinate their children. Gaspard questions whether the vaccination will “give the children ideas” and encourage promiscuity, but Annette states she feels they have taught their children well and that the vaccine will not influence them to engage in sexual behavior. Mirlande clarifies that HPV is associated with cancers besides cervical cancer and that boys should also be vaccinated as they can spread the virus and develop HPV-associated cancers. She also addresses Annette's concerns over side effects and the cost of vaccination, encouraging her to speak to the pediatrician about the vaccine and vaccination assistance programs. Annette asks if there are any herbal remedies for cervical cancer, and Mirlande states that vaccination and screening are the best tools for fighting cervical cancer and to consult with her medical provider on these issues. Mirlande also encourages Annette to seek screening with a Pap test herself as she admits it has been a while since she has seen her doctor. At the end of the video, Gaspard agrees that their children should receive the vaccine and he will take them to the doctor the next day. Annette says that she will also go for her Pap test. Mirlande expresses relief stating that she wishes she had the option to vaccinate when she was a child because she may have been able to avoid her present situation.

Evaluation

With the videos complete, the project has now entered the evaluation phase. The CAB is overseeing these plans in partnership with the research team. The videos have been screened in a series of focus groups held in Palm Beach and Miami-Dade Counties, two areas of South Florida with large Haitian populations. As the videos were created and filmed in Miami, it was felt by the research team that evaluating them among a Haitian population living outside of the immediate Miami area would provide insights as to the applicability and acceptability of the videos among different populations of Haitian immigrants living in the U.S.

A total of three focus groups have been held. The first was hosted at a community-based organization in Belle Glade, Florida, a city on at the western edge of Palm Beach County. Belle Glade is a suburban/rural setting surrounded by sugar cane farms and large populations of migrant farmworkers. Twelve participants, all women, attended this session. Two focus groups were held in the urban center of Miami, one at a non-profit organization that works with Haitian women, the other at a Haitian church. Both of these sessions were attended by nine women and one man for a total of 20 participants between the two Miami focus groups (18 women and 2 men). The three focus group sessions enabled us to screen the videos for and hold semi-structured pre- and post-video discussions with 32 participants. Attendees at all of the focus groups identified as Haitian and spoke Haitian Kreyòl. All focus groups were conducted in Haitian Kreyòl. Each session consisted of a pre-video guided discussion, a screening of the videos, and a post- video guided discussion. The focus group guides were developed by the research team and consist of a series of pre- and post-video questions. The outcomes assessed include pre- and post-video attitudes on screening and vaccination and stated intention to take part in screening and vaccination-related behaviors (and promote such behaviors among friends/family); pre- and post-video knowledge of cervical cancer pathology, screening and prevention; and acceptability of the video structure including characters, dialogue, and storyline.

Findings from the focus group discussions suggest that the videos increase knowledge of cervical cancer pathogenesis, positively impact attitudes towards the HPV vaccine, and influence intention to screen and vaccinate. None of the participants at any of the focus group sessions reported having heard of HPV prior to screening the videos, though participants in all three groups, including male participants, indicated that they had heard of cervical cancer before. After viewing, participants were able to verbally articulate the causal link between HPV and cervical cancer as well as the fact that prevention of cervical cancer and HPV transmission can begin in childhood through vaccination. For example, a woman at a Miami session stated after watching the videos: “[HPV] can give many types of cancer. It can cause the development of cervical cancer” while another woman stated “[Its} a virus. It can cause the development of cervical cancer.” Two women identified the HPV vaccine specifically as a “prevention tool” for cervical cancer.

Participants in all three focus groups stated that they would recommend both HPV vaccination and Pap testing to eligible friends and family after viewing. Participants in all groups were also able to state recommended ages for HPV vaccination. Every participant in one of the Miami-based focus groups indicated they would ask their healthcare provider

about HPV vaccination for their child. A grandmother in the other Miami group stated: “I would definitely encourage my grandchildren to get it.” Similar support for vaccination was seen in West Palm with one woman saying: “Before I said I wouldn’t give [the vaccine] to my child, but after seeing the woman in the video give it to hers, I would do so as well.”

Participants uniformly commented that the videos were clear and understandable. Several stated that they felt the videos were too short. A participant in Miami stated the following:

“I think that the message is clear through the videos. Because when the videos were playing I recall the seminar that was held at the church about this very same thing, but when you watch the videos you’re more likely to remember what was discussed because of the actors and story line. Everything you need to know about the problem is told through the children and parents in the video and makes it easier to remember. And they played their roles well...all the questions that we could think of asking were already asked in the video.”

The findings from these focus groups provide evidence of the ability of these videos to resonate with, inform, and educate their target audience, with potential to impact future screening and vaccination behavior based on participants’ stated intentions. Further evaluation will be directed towards measuring video impact on actual behavior and completing in-depth, one-on-one interviews with viewers to further elucidate their impact.

Dissemination

In terms of video distribution, both movies are currently available online for free for access by anyone. They are also detailed and available in an article published on CES4Health, an open-access, peer-reviewed online resource for disseminating health education resources around the world (Frett et al, 2013). The videos have been screened at one of the member notfor-profit organizations of Patne en Akasyon and the research team is currently working with the CAB on additional plans for dissemination, including a film premier night that can be paired with screening and vaccination efforts. Because the scripts for the videos were intentionally written for easy adaptation to radio, Patne en Akasyon plans to turn the scripts into a radio program. This would allow for easy distribution through Haitian radio, a media cornerstone in the Haitian community.

Other plans for dissemination under discussion include screening the videos at medical offices, churches, and schools using tablets or computers. Results from the three focus groups indicate that the videos raise some important discussion questions among viewers. For example, women at the focus group in Palm Beach County asked why guidelines explained in the videos recommend Pap testing every three years, while their providers have asked them to come for annual screening examinations. Women also sought more information on why boys are recommended to receive HPV vaccination if they don’t have a cervix. These important questions suggest that pairing the videos with an educational session and information on primary and secondary prevention efforts in the community could provide an inclusive intervention strategy that can effectively increase knowledge of and action on cervical cancer prevention among Haitian immigrants following viewing and discussion. Importantly, research with Vietnamese women in California indicates that combining media approaches with group education sessions led by a CHW has a greater

impact on screening behavior and knowledge compared to a media approach alone (Mock et al, 2007). Patne en Akysyon has the infrastructure and experience required for implementing a CHW-driven intervention for screening the videos should this be decided on as part of the long-term dissemination plan. Given the positive findings from the focus groups, these dissemination plans are currently under development by the research team in conjunction with the CAB.

Discussion

We created two short videos on primary and secondary cervical cancer prevention in Haitian Kreyòl. These films are part of Patne en Aksyon, an ongoing CBPR project to decrease the burden of cervical cancer in Little Haiti, Miami. The videos therefore fit into a broader initiative to uncover and address the factors that drive disproportionately high rates of cervical cancer among Haitian women living in South Florida. Lack of routine screening and a high burden of HPV disease have been shown to be two factors that are perpetuating elevated rates of cervical cancer in this population, among many others (Kobetz et al, 2012; Menard et al, 2010). These videos were created in an effort to help address these issues in a culturally-tailored, linguistically appropriate way. Media-based interventions, including those that utilize tailored videos, are proving to be promising strategies for encouraging uptake of cervical cancer prevention services in persistently underscreened populations in the U.S., including among Mexican immigrant women, Vietnamese women, and African-American women (Byrd et al, 2012; Mock et al, 2007; Yancey et al, 1995). These videos are the first of their kind to be created specifically for a Haitian audience and have undergone qualitative evaluation via focus groups in Miami-Dade and Palm Beach Counties, Florida with findings indicating that the videos impact knowledge and stated intention to screen and vaccinate.

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