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HPV and Cervical Cancer Education Needs among HIV Positive Haitian Women

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Abstract

Background—Haitian Immigrant women, the largest growing Black ethnic group in Miami, experience the highest rates of cervical cancer and account for one of the largest populations diagnosed with HIV/AIDS in South Florida. Using community-based participatory research methods, we conducted a pilot study to examine HPV/cervical cancer knowledge and identify intervention preferences among HIV positive Haitian women.

Methods—Community health workers (CHWs) conducted three focus groups with 21 HIV-positive Haitian women. All sessions were conducted in Haitian Kreyol, digitally recorded, and later interpreted and transcribed into English. The first focus group assessed HPV/Cervical Cancer Knowledge; the second session explored HPV/Cervical Cancer considerations specific to HIV positive women, and the third focus group discussed HPV/Cervical Cancer screening and intervention preferences. Data analysis was guided by a grounded theory approach.

Findings—Our sample had limited HPV/Cervical Cancer knowledge. Misconceptions about screening, transmission, and treatment were common. Participants felt stigma by providers negatively impacted the care they received and stigma by the community diminished social support. Strong support for culturally-tailored interventions to improve HPV/Cervical Cancer knowledge was expressed. Although no participants had previously participated in research, all were willing to participate in future trials.

Conclusions—There is critical need for culturally relevant interventions to improve HPV/Cervical Cancer knowledge among HIV-positive Haitian women.

Keywords

HPV among HIV positive women; HIV-positive Haitians; HPV/Cervical Cancer education; CHW interventions; HIV and Cervical Cancer

Introduction

Nearly 80 million Americans are infected with HPV and 14 million new infections occur annually (CDC, 2014). Though most HPV infections do not cause cancer, nearly all cervical cancers are caused by high-risk or oncogenic HPV (Schiffman et al., 2007). In Miami, Black women are more likely to be diagnosed with cervical cancer than any other female demographic group (FDCS, 2004). This disparity is most prominent among Haitian immigrant women, who represent the largest Black ethnic sub-group in South Florida

(FDCS, 2004; Sohmer, 2005). Though cervical cancer is preventable and often treatable, particularly when detected early, it is more likely to occur among females who do not receive routine Papanicolaou (Pap) smears. (Moyer, VA, 2012; Franco EL, Duarte-Franco E, Ferenczy, 2001). Haitian women in Miami are less likely than non-Haitians to receive routine Pap smears (Kobetz et al., 2009). As a result they suffer from disproportionate cervical cancer incidence and mortality.

Multiple factors contribute to this disparity, including lack of insurance, limited healthcare access, low education level, limited English proficiency, immigration and citizenship issues as well as cultural barriers (Kobetz et al., 2009; Centers for Disease Control, 2013; Saint-Jean & Crandall, 2005; Lillie-Blanton & Hudman, 2001; Guendelman, Scauffler, & Pearl, 2001; Flores, Abreu, & Olivar, 1998; The Henry Kaiser Family Foundation, 2000). In addition, this disparity may be exaggerated for Haitian women with HIV. Research shows that people living with HIV experience higher rates of HPV infection (National Cancer Institute, 2012; Konopnick, De Wit, Clumeck, 2013).

In South Florida, Haitians account for one of the largest populations in South Florida diagnosed with HIV/AIDS (Miami-Dade Dept of Health, 2012). Although HIV is now a treatable chronic disease, Haitians are less likely than other groups to succeed in HIV treatment and often experience suboptimal outcomes (Colasanti et al, 2012). Due to the stigmatization of both HIV and cancer in the Haitian community, existing barriers to cervical cancer screening are likely compounded for Haitian women living with HIV (Kobetz et al., 2009; Saint-Jean, Metsch, & Gomez-Marin, 2011).

To help improve our understanding of the cervical cancer educational needs among Haitian women living with HIV, we conducted three focus groups among 21 HIV positive Haitian women in Miami. We explored cervical cancer knowledge, screening behaviors, stigma related to HIV disease and identified potentially effective intervention methods to improve knowledge about HPV, cervical cancer, and screening resources accessible to this population. We also sought to determine level of interest in this group of women about participating in future research studies and clinical trials.

Methods

Partners in Action

Our overall research approach was informed by community-based participatory research (CBPR) strategies (Israel, et al 2001). CBPR invites community participation throughout the entire research process, and in recent years, has emerged as an important methodology to help investigators develop a rich understanding of cultural and social norms regarding disease prevention among the medically underserved. In South Florida's Haitian community, our ongoing CBPR efforts are governed by a campus– community partnership known as Patnè en Aksyon (Partners in Action), which has been described previously (Barbee, Kobetz, Menard, 2009; Kobetz, Barbee, Diem, 2009). This partnership involves active participation of community leaders from Little Haiti, as well as, an interdisciplinary team of investigators from the University of Miami. The partnership's ultimate goals are to reduce the excess burden of cervical cancer experienced by Haitian women and to improve

the general health status of women in Little Haiti. A strength of CBPR is the capacity to reduce skepticism of research investigations that often prevails in underserved communities such as Little Haiti.

Community Health Workers

As agreed to with our community partners, community health worker (CHWs) would be the study personnel primarily responsible for recruiting study participants and collecting study data in this study. CHWs are respected lay members of the community who are trained to use community-based strategies to help their peers improve specific health outcomes (Bhutta et al, 2010). The CHWs in the study were women of Haitian descent, who spoke English and Haitian Kreyol fluently, and were knowledgeable about community norms and cultural mores. They were formally supervised by a large Haitian serving community-based organization, whose leadership is active in Patnè en Aksyon, and is well respected throughout Little Haiti. The affiliation between the CHWs and this organization was, in many ways, critical to the study's success. By providing the study a "community home," we did not encounter many barriers to implementation and, perhaps more importantly, were able to maintain compatible infrastructure to support future research studies in this community.

A standardized study manual created by University of Miami investigators was used to train CHWs on participation in research and data collection (Kobetz et al, 2013). The manual provided didactic instruction on the logistics of participant recruitment, study implementation, and the principles of qualitative data collection strategies, including focus groups. As part of the training, each CHW also completed the Collaborative Institutional Training Initiative, an online certification program for conducting human subjects research, as mandated by the university IRB.

Participant Recruitment

Eligibility criteria included women who self-identified as Haitian, were diagnosed with HIV, had not had their uterus removed, and were between 30 and 60 years of age. Following UM IRB approval, CHWs attended HIV clinics known for serving the Haitian community and approached potential participants in the waiting room before or after their appointment. Additionally, participants were recruited through the network of HIV providers who treat patients in Little Haiti and surrounding areas. Providers and potential participants learned about the study through descriptive fliers and letters that were disseminated to relevant clinics and community based agencies. Upon identifying potential participants, an IRB-approved screening assessment was used to determine eligibility for focus group participation.

Focus Groups

In August and September 2011, three focus groups were conducted over an eight-week period by CHWs in a classroom located at Jackson Memorial Hospital, South Florida's public safety-net hospital. A semi-structured guide developed collaboratively by Patnè en Aksyon's academic and community partners was used to initiate discussions on five specific domains: (1) HPV/Cervical Cancer knowledge, (2) HIV issues associated with HPV

screening; (3) HPV/Cervical cancer screening behaviors; (4) HPV/cervical cancer research targeting HIV positive females; and (5) methodological preferences for an effective HPV/cervical cancer education intervention.

After informed consent was obtained from each participant, the CHWs conducted the three focus groups in Haitian *Kreyol*. Each group lasted from 60–90 minutes and ended after participants answered all questions and the discussion came to a natural ending. After each focus group, participants were given a \$25 gift card to compensate for their time spent participating in the research. The sessions were digitally recorded, and later interpreted and transcribed into English by the CHWs. CHWs maintained logs of all study related procedures they performed and time that each step of the protocol was completed on data collection forms. These forms were reviewed weekly by the study PI to ensure study fidelity and to offer constructive feedback to the CHWs if steps were performed out of order.

Data Analysis

Following a grounded theory approach, three researchers independently reviewed the focus group transcriptions to identify emergent themes in participant responses or the transcript of the groups. Grounded theory allows for a systematic assessment of salient themes that naturally emerge from the data (Corbin & Strauss, 2007). Such themes offer a framework for understanding participants' responses to research questions of interest. Themes and subthemes were determined by words and phrases from participants and then open coding was used to assign *NVIVO codes*, allowing researchers to further capture the meaning of emergent themes (QSR Software, 2013). Researchers' personal observations about associations between emergent themes were also recorded throughout the coding process. All points of difference in coding results were discussed among researchers until a consensus was achieved. Following analysis, the interpretations of the data were shared with community members who provided anecdotal responses that confirmed the data reflected the experiences and perspective of the target population.

Results

Demographic characteristics

As shown in Table 1, all participants were HIV-positive women between 30 and 60 years of age, who were born in Haiti and living in Miami. Most (90%) of the women had been living in the United States for more than five years. The majority were single (58%) or never married (39%) and cared for three or more children (82%). Many indicated that they were employed (67%) or self-employed (30%) and most practiced Catholicism (95%). All participants had health coverage through Ryan White funding which is available for all low income persons with HIV and covers all needed health care services (HRSA HIV/AIDS Programs, 2012).

Cervical cancer and HPV knowledge

The key themes from focus groups are listed in Table 2. Participants revealed limited knowledge and several misconceptions about HPV and cervical cancer. There was little to no knowledge of HPV transmission and its role in cervical cancer. Participants were

unaware of cervical cancer screening guidelines and reported no knowledge of the HPV vaccine. Most participants believed that HPV was similar to HIV in that medication was necessary to treat it and that there is no way to eliminate the disease after infection. Participants also believed a diagnosis of cervical cancer prevented women from bearing children and that cervical cancer ultimately leads to death.

“If you have the Cancer, you can not have babies anymore.”

“Vaccines are good but there’s no vaccine for sex infections. HPV is like HIV, there’s no cure.”

Cervical cancer screening education and behaviors

While all of the women in the focus group reported having had received a Pap test in the previous year, none understood the purpose of the test and reported they had the procedure because their doctor instructed them to have it done. *“I take the test every year because I trust my doctor to keep me healthy and he tells me the test will keep me healthy. But I never knew they were testing for a disease or cancer.”* However, none of the women reported receiving any education regarding the procedure or its clinical significance.

Perceived HIV stigma

Women revealed that HIV stigma reduced the likelihood of discussing their health concerns with anyone, including family and friends. All participants agreed with one group member who stated, *“Haitian women, even if they are dying, can’t talk about these issues.”* Participants often noted negative experiences with non-HIV providers and were unaware that it is illegal for healthcare workers to discriminate against people living with HIV. *“We go to the doctors but some of them won’t touch us. There should be laws against that kind of treatment.”*

Health education preferences

Participants acknowledged they would like to receive further education on cervical cancer and HPV. Focus groups, education sessions, and one-to-one conversations in clinic waiting rooms were identified as potentially effective mechanisms to improve such knowledge. Television and radio were also discussed as a valuable way to reach the target population and increase participation in group education activities. To inform Haitian women about specific aspects of HPV and cervical cancer, participants felt that flip-charts filled with educational pictures would be a more effective tool than written materials. These findings are consistent with previous research regarding best methods to improve cervical cancer and HPV knowledge among Haitian females (Kobetz et al 2012).

Our sample noted that limited literacy and health literacy among Haitians made reading text based educational materials challenging for many Haitians and expressed support for the utilization of ethnic media, such as Haitian radio as an effective method of delivering information on cervical cancer to Haitian women. This data supports prior research on Haitians (Kobetz et al 2012) and other minority groups (Cee, et al, 2013; Henderson et al, 2013) regarding efficacious methods for communicating health education. Although all participants reported experience working with an HIV case manager, they did not perceive

case managers as effective health educators. Instead, utilizing community health workers to conduct home visits and small group education sessions were preferred methods of health education. Participants also felt that specific classes on HPV should be available for HIV positive women, especially as it relates to cervical cancer risk.

Participation in research

A general support for participating in research was expressed by most women. Participants felt research participation could yield beneficial information and that it may lead to improved health outcomes. They agreed that research focused on diseases other than HIV was especially important to maintain optimal health among people living with HIV. All reported that they were amenable to further participation in research trials but none had been previously been asked to participate in a research study. They also did not know how to access studies for which they were eligible. Many felt that traditional recruitment strategies, such as fliers and other written materials posted in public places were inappropriate for a population with limited literacy, particularly since Haitian Kreyol is primarily a spoken language rather than written *“We don’t know about research because we don’t read the papers on the walls. If people told us about it we would participate. I speak three languages but I do not read.”*

Discussion

Our primary aims were to identify cervical cancer education needs among HIV positive Haitian women and determine potentially effective methods to improve knowledge among this population. We found that Haitian women living with HIV have a limited understanding of HPV and cervical cancer and want more education on these health issues, especially as they relate to people living with HIV. To our knowledge, this is the first study to assess HPV and cervical cancer knowledge among HIV positive Haitian women and to describe preferred methods of intervention that may lead to improved awareness and screening behaviors.

Although estimates are that one quarter of HIV positive women do not receive an annual pap smear (Oster et al, 2010), all women in our focus groups had undergone annual pap screening. Consistent with the Theory of Planned Behavior (Ajzen, 1991), our participants’ belief that having the procedure done could keep them healthy combined with their desire to comply with the normative expectations of their physicians led to their strong intention to complete the test. Furthermore, given that all the women in our sample were covered by insurance and reported a usual source of care, these structural impediments did not preclude our participants from having the test done. However, the fact they underwent the annual screening without understanding the test’s purpose shows how powerfully such intentions influenced their behaviors. Of note, similar misunderstandings about the Pap test have been reported for other ethnic groups (McCarey et al, 2011).

It is important to highlight that our participants were unique in that they had successfully obtained Ryan White Insurance Coverage, which provided consistent access to comprehensive healthcare, including Pap smears. Many populations at increased risk for cervical cancer may not have continuous healthcare access and improving screening

behaviors among groups without insurance coverage may require more intense educational and clinical interventions.

We also found that HIV stigma persists as a barrier among this population. In the Haitian community in particular, stigmatization of those with HIV comes from its association with homosexual behavior and promiscuity—social taboos in Haiti (Cook-Ross, 2010). In addition, thirty years ago the CDC incorrectly considered Haitian ancestry as a risk factor for HIV transmission which still leads to considerable mistrust of the US health care system by Haitians (Pitchenik et al, 1993). Despite such barriers, all of the women expressed willingness to participate in research and understood the importance of increasing representation of Haitian females in ongoing clinical trials. To ensure this population is adequately represented in ongoing research studies, participants recommended increased utilization of alternative recruitment methods culturally tailored for this population..

Conclusions

Our study offers invaluable insights on health education needs of Haitian HIV positive women and demonstrates the need to develop culturally relevant cervical cancer education and prevention programs targeting this high-risk group. Based on our study findings, we conclude that culturally tailored community based educational interventions are needed to improve cervical cancer knowledge, screening behaviors and representation of HIV positive Haitians in clinical studies. Importantly, we also concur with the national guidelines issued by the Advisory Committee on Immunization Practice, which recommend that immunocompromised persons receive the HPV vaccination through age 26 (CDC, 2014). We are now applying these findings to develop a community health worker intervention addressing the needs of this community in Miami.

Implications for Practice

Our research highlights the critical need for effective HPV and cervical cancer education to be integrated into public health care serving Haitian-Americans and other culturally-distinct populations. Peer education delivered by CHWs was identified as a culturally- acceptable, method of improving disease knowledge among participants in our study. Such findings add to the growing body of evidence supporting the efficacy of CHW interventions and offer a promising supplement to existing public health strategies. For example, in busy clinics that lack the human resources to offer individualized patient education, CHWs may be an effective adjunct for providing preventive education and health system navigation that increases access to, and participation in, screening for cervical cancer and other treatable conditions.

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Table 1

Demographic Variables N = 21

HIV Positive	100%
In US 5 years	90%
Not Married	97%
3 children	82%
Catholic Religion	95%
Employed	67%

Table 2

Key themes and representative quotes from focus groups

Misconceptions about HPV and cervical cancer	<i>"If you have the Cancer, you can not have babies anymore."</i>
Under-education about cervical cancer screening	<i>"I take the test ... because I trust my doctor. But I never knew they were testing for cancer."</i>
Perceived stigma from providers	<i>"We go to the doctors but some of them won't touch us. There should be laws against that kind of treatment."</i>
Research participation limitations	<i>"We don't know about research because we don't read the papers on the walls. If people told us about it we would participate. I speak three languages but I do not read."</i>