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Human Papilloma Virus and Cervical Cancer Education Needs among HIV-Positive Haitian Women in Miami

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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 human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) in South Florida. Using community-based participatory research methods, we conducted a pilot study to examine human papilloma virus (HPV)/cervical cancer knowledge and identify intervention preferences among HIV positive Haitian women.

Methods: Community health workers conducted three focus groups with 21 HIV-positive Haitian women. All sessions were conducted in Haitian Kreyol, digitally recorded, and subsequently 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 that stigma by providers impacted negatively the care they received and that 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 participated in research previously, 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.

Nearly 80 million Americans are infected with human papilloma virus (HPV) and 14 million new infections occur annually (Centers for Disease Control and Prevention [CDC], 2014). Although most HPV infections do not cause cancer, nearly all cervical cancers are caused by high-risk or oncogenic HPV (Schiffman, Castle, Jeronimo, Rodriguez, & Wacholder, 2007). In Miami, Black women are more likely to be diagnosed with cervical cancer than any other female demographic group (Florida Cancer Data System [FDCS], 2004). This disparity is most prominent among Haitian immigrant women, who represent the largest Black ethnic subgroup in South Florida (FDCS, 2004; Sohmer, 2005). Although 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, 2012; Franco, Duarte-Franco, & Ferenczy, 2001). Haitian women in Miami are less likely than non-Haitians to receive routine Pap smears (Kobetz et al., 2009a). As a result, they suffer from disproportionate cervical cancer incidence and mortality.

Multiple factors contribute to this disparity, including lack of insurance, limited access to health care, low education level, limited English proficiency, and immigration and citizenship issues, as well as cultural barriers (Kobetz et al., 2009a; CDC, 2013; Saint-Jean & Crandall, 2005; Lillie-Blanton & Hudman, 2001;

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Guendelman, Scauffler, & Pearl, 2001; Flores, Abreu, Olivar, & Kastner, 1998; Henry Kaiser Family Foundation, 2000). In addition, this disparity may be exaggerated for Haitian women with human immunodeficiency virus (HIV) infection. Research shows that people living with HIV experience higher rates of HPV infection (Konopnick, De Wit, & Clumeck, 2013; National Cancer Institute, 2012).

In South Florida, Haitians account for one of the largest populations in South Florida diagnosed with HIV/acquired immunodeficiency syndrome (AIDS; Florida Department 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, Nguyen, Kiem, Deeb, & Jayaweera, 2012). Because of 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., 2009a; Saint-Jean et al., 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, and 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, Schulz, Parker, & Becker, 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 *Patne' en Aksyon* (Partners in Action), which has been described previously (Barbee et al., 2010; Kobetz et al., 2009b). 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 workers (CHWs) would be the study personnel primarily responsible for recruiting study participants and collecting data. 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, Lassi, Pariyo, & Huicho, 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 *Patne' 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 important, we 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's institutional review board (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. After obtaining IRB approval from the University of Miami, 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 flyers 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 8-week period by CHWs in a classroom located at Jackson Memorial Hospital, South Florida's public safety-net hospital. A semistructured 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 to 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 recorded digitally, 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's principal investigator to ensure study fidelity and to offer