

Patnè en Aksyon: Addressing Cancer Disparities in Little Haiti Through Research and Social Action

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Haitian women living in Miami, Florida, experience an increased risk of developing and dying from cervical cancer compared with women in other racial/ethnic minority and immigrant groups in the area. In response to this disparity, academic investigators from a local university-based cancer center and community leaders from Little Haiti, the predominately Haitian neighborhood in Miami, created Patnè en Aksyon (Partners in Action), a campus-community partnership. We describe the partnership's effort to document the prevalence of lifetime and routine Papanicolaou test use using community-based participatory research methods. Community health workers indigenous to the area recruited participants from various community venues throughout Little Haiti and administered informal, brief interviews to assess their screening practices. The results indicate that Haitian women are underscreened and underscore the importance of community involvement in study implementation. *Am J Public Health*. 2009;99:1163–1165. doi:10.2105/AJPH.2008.142794.

IN MIAMI, FLORIDA, HAITIAN women experience an increased risk of developing and dying from cervical cancer compared with other racial/ethnic minorities and immigrant groups in Miami.¹ The underutilization of routine Papanicolaou test screening likely accounts, in large part, for this disparity.^{2,3} However, previous research has not successfully examined the Papanicolaou test screening behaviors of this population because of the prevalent distrust of health research in Little Haiti.⁴

To overcome such barriers, academic investigators from the University of Miami and community leaders from Little Haiti

created Patnè en Aksyon (Partners in Action), a campus–community partnership. This partnership was formed in late 2004 through the collective efforts of university investigators and directors of Haitian community-based organizations (CBOs) who had worked together previously to address cancer disparities in Little Haiti. The CBO directors enumerated a list of other community leaders, including pastors, traditional healers, and activists, and approached those individuals to solicit their participation. Interested persons were invited to an inaugural meeting in which we collaboratively decided upon the group's scientific focus—to understand why Haitian women are disproportionately diagnosed with late-stage breast and cervical cancers.

The partnership employs the methods of community-based participatory research (CBPR), which invites community participation throughout the research process.⁵ The design of all partnership research initiatives, including the study described here, reflects the collective input of academic and community partners.⁶ We sought to document the prevalence of lifetime and routine Papanicolaou test use

among ethnically Haitian women living in Little Haiti. The majority of Little Haiti residents were born in Haiti and emigrated more recently than did Haitians residing in other communities in South Florida.⁷

METHODS

We selected our study methods based on community leaders' historical insight regarding previous failed research attempts and a shared desire to build local capacity to support future research and intervention. Community leaders advocated for the use of community health workers (CHWs) to collect study data, and helped identify women of Haitian descent who spoke English and Haitian Kreyol fluently to hire for these positions. In September 2007, we trained three women using a standardized training manual, developed by one of the academic partners, which provided intensive training in participant recruitment, interviewing techniques, and data management.

Community leaders also encouraged use of rapid assessment surveys, which are short interviews (5–10 minutes), typically administered in community

KEY FINDINGS

- Compared with other racial/ethnic minorities and immigrant groups in Miami, Florida, Haitian women experience an increased risk of developing and dying from cervical cancer.
- Patne en Akyson (Partners in Action), a campus-community partnership, aims to address this disparity through community-based participatory research and intervention.
- Towards this end, the partnership conducted 1000 rapid assessment surveys to document the crude prevalence of lifetime and routine Papanicolaou (Pap) smear screening among Haitian women living in Little Haiti, the predominately Haitian neighborhood in Miami.
- Study findings suggest that Haitian women in this neighborhood undergo screening at far less frequent intervals than do other minority women in the Miami metropolitan area and more-acculturated Haitian women living elsewhere in the United States.
- Future research must identify barriers to routine Pap smear use and utilize culturally relevant, community-based strategies for change.

venues that enable a crude assessment of a community's health behavior practices. Rapid assessment surveys were initially developed by the US Department of Health and Human Services to examine the HIV-associated risk behaviors in US cities disproportionately affected by AIDS-related mortality.⁸ However, this methodology has since been adapted for use in non-HIV studies.⁹ Their brevity and informal delivery make them ideal for collecting data in communities such as Little Haiti in which there are literacy issues and cultural taboos against revealing health information over the phone or in writing. Patne en Akyson's academic and community partners worked together to develop the questions that composed the rapid assessment survey, giving equal privilege to different perspectives about what information was essential for improving cancer outcomes in Little Haiti.

From October 2007 to January 2008, the CHWs approached nearly 1000 Haitian women in various community venues across Little Haiti, including laundromats, health clinics, and churches. Participation was limited to women of Haitian descent, 40 years and older, who did not have a previous history of cancer. Our age range was 40 years and older because of our concurrent focus on mammography screening, which is generally recommended for women starting at age 40 years. Of the 1000 women approached, 940 agreed to participate.

In the rapid assessment survey, the CHWs asked participants a series of questions about their mammography and Papanicolaou test screening behaviors as well as their preferences for obtaining

health information (Box 1). We focus here solely on participants' responses to the questions about their Papanicolaou test screening behaviors.

RESULTS

Of the 940 participants, 67% reported having had at least one Papanicolaou test in their life. Of those with a history of screening (n = 630), only 44% reported having a least one Papanicolaou test in the past three years as recommended by national guidelines. There is not a direct comparison for our data, although in relation to national averages and data collected with more-acculturated Haitian women, the women in our sample appear to be underscreened.^{10,11} The reasons, which may explain this disparity, remain unanswered by our data.

We intentionally did not collect detailed sociodemographic data as part of our rapid assessment survey, because of residents' perceptions that such information could be used to compromise their immigration status. However, we can assume based on their residence in Little Haiti that the majority of respondents were living at or below the federal poverty line, had limited formal education, and had restricted access to the formal health care system.⁷ Data for the seven census tracts that compose Little Haiti reveal an average median household income of \$18 339 and show that more than half (58%) of the residents did not graduate high school.¹² Little Haiti also falls within federally designated Medically Underserved Population and Health Provider Shortage Areas.¹³ Access to care in this

neighborhood is further complicated by residents' lack of insurance, questionable immigration status, and limited proficiency in English.^{14,15}

DISCUSSION

Our rapid assessment survey data, although limited in scope, provide preliminary insight into the Papanicolaou test screening practices of Haitian women living in Little Haiti. Such data are important for a number of reasons, but most notably because they offer insight into the reasons Haitian women residing in this area experience an increased risk of developing and dying from cervical cancer. Patne en Akyson is now conducting additional research to identify barriers to cervical screening in Little Haiti. As was true for our rapid assessment survey, the approach employed in this follow-up study reflects the pairing of academic and local knowledge. It is only through the mutual exchange of ideas that we can successfully overcome multiple challenges—such as language differences and historical distrust of outsiders—that contribute to existing inequities in Little Haiti and compromise the promise of future intervention. ■

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Contributors

E. Kobetz did the majority of the writing and editing and was responsible for the final draft. J. Menard contributed significantly to the writing and editing of the article. B. Barton drafted much of the description of Patnè en Aksyon and provided editorial assistance. L. Pierre and P. D. Auguste drafted the sections characterizing Little Haiti and the challenges faced by many recent Haitian immigrants. J. Diem contributed to writing about community-based participatory research and was the primary editor of the article.

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Human Participant Protection

This study was approved by the University of Miami's institutional review board.

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RAPID ASSESSMENT SURVEY QUESTIONS

- Are you Haitian?
- Were you born in Haiti?
- If no, where were you born?
- Have you ever had a mammogram?
- Have you had at least 1 mammogram in the past 2 years?
- About how many mammograms have you had in your life?
- Has a doctor or nurse examined your breasts in the last year?
- Have you ever had a Pap smear?
- Have you had at least 1 Pap smear in the past 3 years?
- About how many Pap smears have you had in your life?
- How would you rate your health?
- Do you have a place where you go for regular health care?
- What type of place is it?
- Who do you talk to if you have questions or concerns about your health?
- Who would you talk to if you had questions or concerns about cancer?
- Generally, where do you go for health information?
- Where would you go for information about cancer?

Source. Partners in Action Rapid Assessment Survey Data, 2007.