One Size Does Not Fit All: Differences in HPV Knowledge between Haitian and African American Women

Erin Kobetz1,2,3, Angela Dunn Mendoza2,3, Janelle Menard3, Lila Finney Rutten5, Joshua Diem6, Betsy Barton3, Julie Kornfeld3,7, and Nathalie McKenzie4

Abstract

Background: Historically, all black persons, regardless of ancestry or country of origin, have been categorized as one group for cancer research and control efforts. This practice likely masks variability in exposure to determinants of disease, as well as in risk of cancer incidence and mortality. The current study examines potential differences in knowledge of human papilloma virus (HPV) between Haitian women living in Little Haiti, Miami, Florida, and a national sample of predominately African American women.

Methods: Data for Haitian women were collected in 2007 as part of an ongoing community-based participatory research initiative in Little Haiti. For purposes of comparison, we used data from a largely African American subsample of the 2007 Health Information National Trends Survey (HINTS). These data sources used identical items to assess HPV knowledge, providing a unique opportunity to examine how this outcome may vary between two very distinct populations who are often grouped together for research and disease surveillance.

Results: Relative to the HINTS sample, Haitian women were far less likely to have heard about HPV.

Conclusions: Study data highlight important differences in Haitian and African American women’s knowledge of HPV, a known determinant of cervical cancer risk. Such findings suggest that continuing to classify persons of similar phenotype but different cultural backgrounds and lifetime exposures as one group may preclude opportunity to understand, as well as attenuate, health disparity.

Introduction

In the United States, black women experience an increased risk of developing, and dying from, cervical cancer (1). In South Florida, this disparity is most prominent within the Haitian community, which represents just one of the many diverse black ethnic groups in this region. Between 2000 and 2004, the most recently available data, the incidence of cervical cancer in Little Haiti, the predominantly Haitian neighborhood in Miami, Florida, was estimated to be 38/100,000 (2). This rate is more than four times higher than that reported for black women in the Miami metropolitan area (9/100,000; ref. 2).

Previous research has not examined in great detail whether similar heterogeneity also exists in the distribution of known risk factors for disease. With increasing multiculturalism in the United States, it becomes necessary to evaluate how such factors, particularly those that are amenable to intervention, vary between women of similar phenotype but different nationality or ethnic background. By grouping all black persons into a single category for research purposes, we limit our ability to understand the causes of health disparities, as well as to appropriately target efforts for change.

Accordingly, the current article examines potential differences in knowledge of human papilloma virus (HPV), the principal cause of cervical cancer (3), between Haitian women residing in Little Haiti and a population-based sample of predominately African American women. Although knowledge alone does not determine disease risk, it is a construct recognized by most public health frameworks as essential to the adoption and/or maintenance of health-promoting behaviors, such as routine Pap smear screening, the best method available for cervical cancer prevention (4, 5).
Materials and Methods

Haitian Sample

The data reported for Haitian women living in Little Haiti were collected as part of an ongoing community-based participatory research (CBPR) initiative in the neighborhood, known as Patien en Aksjon (Partners in Action; ref. 6). Community health workers (CHW), who are of Haitian descent and speak English and Haitian Kreyol fluently, recruited potential participants and collected study data in Little Haiti. The CHWs were trained to conduct research using a standardized training manual and also completed an online certification program (CTI) for conducting human subjects research before initiating any study-related activities.

The CHWs recruited women primarily through the extensive network of the community-based organization where they were formally employed, and by canvassing community venues across Little Haiti to identify women meeting study eligibility criteria (e.g., Haitian descent, 21 years of age or older, and no prior history of cervical cancer). The CHWs approached all women who seemed to meet such criteria, told them about the study, and then gauged their level of interest in participating. For women who were interested and eligible, the CHWs scheduled an appointment to conduct the in-depth interview. Interviews took place wherever the participant felt most comfortable, usually at her home, and was conducted in English or Haitian Kreyol, according to her preference.

Between September 2007 and March 2008, the CHWs approached 362 women, with 297 agreeing to participate (82.0%). Of the 297 women, 290 were eligible (97.6%) and 250 (86.2%) completed the in-depth interview as planned. The small percentage of women (7%) who ultimately declined to participate after expressing initial interest in the study primarily did so for fear that signing the informed consent documents could compromise their own or their family members’ immigration status.

On average, the in-depth interview took 1 hour to complete. Where possible, survey items were derived from previously validated instruments and questionnaires. The HPV knowledge questions, in particular, were taken from the Health Information National Trends Survey (HINTS), conducted by the National Cancer Institute on a biennial basis, with the intent of better understanding cancer information needs and experiences in the United States (7). For inclusion in the study in Little Haiti, the HINTS HPV survey items were translated and back-translated from English to Haitian Kreyol. All study participants opted to complete the interview in Kreyol, given their limited proficiency in English.

African American Sample

To our knowledge, HINTS is the only publicly available dataset that includes questions about HPV knowledge. HINTS 2007 used mixed-mode, dual-frame design for participant recruitment. One frame was a list-assisted, random digit dial computer-assisted telephone interview, wherein one adult from each household was selected for an interview. The second frame was a relatively comprehensive national listing of addresses available from the United States Postal Service for the purpose of administering a mail survey. Both the random digit dial and mail survey were conducted from January through late April 2008. The overall response rates were 24.2% for the random digit dial household screen and 40% for the mailed survey. Further details on the HINTS sample and sampling design are published elsewhere (8). For the current study, we restricted our analyses to the subsample of self-reported, non-Hispanic black HINTS respondents (n = 470). Despite obvious differences in methods of sampling and data collection between the two studies, the overlap in question content provides a point of comparison to examine potential variability in knowledge of HPV among African American and Haitian women, who are otherwise routinely homogenized into one ethnic group for public health research purposes.

Measures

Primary Variables of Interest. HINTS and Little Haiti respondents alike were first asked whether they had ever heard of HPV. Participants who responded “yes” to this question were then asked three additional questions about the virus and its association with cervical cancer. These questions assessed whether a woman could correctly identify that HPV (a) causes cervical cancer, (b) is a sexually transmitted infection, and (c) will often go away on its own without treatment. For the purpose of analyses, we coded a “don’t know” response as conceptually equivalent to “no.” Missing data were excluded from analyses.

Other Variables of Interest. In addition to HPV knowledge, we also examined the sociodemographic composition of the Little Haiti and HINTS study samples. For both datasets, we collapsed continuous variables into categories to facilitate comparison between the two samples. Variables of interest included age (18-25 years versus 26 years and older), annual family income (less than or equal to $35,000, $35,000 or more), educational attainment (less than high school versus high school degree or greater), employment status (employed versus unemployed), health insurance coverage (yes versus no), and years lived in the United States (less than 5 years versus 5 or more years). In most instances, we dichotomized such variables using their median. Annual family income was the only exception to this rule. We created the categories for this variable using $35,000 as the point of demarcation, as this was one of the few places of overlap in the way the two studies organized this variable.

Data Analysis

For the Little Haiti sample, analyses were conducted using SPSS version 16. HINTS data were analyzed using SAS-callable SUDAAN version 9.0, which accounted for
the study’s complex survey design and also enabled appropriate calculation of SEs and 95% confidence intervals. For the HINTS analyses, we employed the jackknife variance estimation technique because it is compatible with the sample design and weighting procedures for HINTS. Frequencies for the variables of interest were generated independently for each study sample. Given the variability in the two studies’ design and methods of data collection, we were unable to test whether observed differences between such variables were, in fact, statistically significant.

**Results**

Table 1 characterizes the samples in terms of their sociodemographic composition. Women in our sample ranged in age from 18 to 75 years. As shown in the table, Haitian women residing in Little Haiti tend to have lived in the United States for less time, have a lower annual income, have completed fewer years of formal schooling, and are less likely to possess health insurance than their HINTS counterparts. Approximately a quarter (25%) of the participants from Little Haiti had lived in the United States for less than 5 years, whereas only a nominal percent (0.2%) of the HINTS sample had been in the United States for such a limited duration. The majority of Haitian women (95.6%) in our sample had an annual family income less than $35,000, and nearly half (49.2%) reported less than high school as the highest level of schooling achieved, compared with 60% and 20% of the HINTS sample, respectively. Eighty-five percent of the Haitian women did not have any form of health insurance coverage relative to only 21% of HINTS respondents, despite the slightly higher unemployment within the primarily African American HINTS subsample (39.2% versus 47.6%).

Table 1 also relays the proportion of the two samples that had ever heard of HPV. Knowledge of HPV was much higher (70.2%) among the HINTS sample than the Haitian sample (22%). Haitian women were also less likely to be adequately informed about HPV than their HINTS counterparts, although detailed knowledge about the virus was not particularly high in either sample (Table 2). Haitian women were less likely than their HINTS counterparts to identify HPV as a common sexually transmitted infection (8% versus 75%) and to consider HPV the principal cause of cervical cancer (18% versus 54%).

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**Table 1. Characteristics of study samples**

<table>
<thead>
<tr>
<th>Sociodemographic background</th>
<th>Haitian American females*</th>
<th>U.S. non-Hispanic black females (weighted population estimates)†</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yearly income &lt; $35,000</td>
<td>95.6</td>
<td>58.4</td>
</tr>
<tr>
<td>Less than high school graduate</td>
<td>49.2</td>
<td>19.1</td>
</tr>
<tr>
<td>No health care coverage</td>
<td>85.0</td>
<td>21.8</td>
</tr>
<tr>
<td>Unemployed</td>
<td>39.2</td>
<td>47.6</td>
</tr>
<tr>
<td>≤5 y in the United States</td>
<td>24.9</td>
<td>0.2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Screening behavior and HPV knowledge</th>
</tr>
</thead>
<tbody>
<tr>
<td>Told by a doctor that have HPV</td>
</tr>
<tr>
<td>Have heard of HPV</td>
</tr>
</tbody>
</table>

*Patnè en Aksyon 2007, Pap Tes Lakay (Pap Test in the House).
†National Cancer Institute, 2007 Health Information National Trends Survey (HINTS).

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**Table 2. Detailed knowledge of HPV among Haitian and U.S. black females who had previously heard of the virus**

<table>
<thead>
<tr>
<th>Percent correct responses</th>
<th>Haitian American females*</th>
<th>U.S. black females (weighted population estimates)†</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n = 54</td>
<td>n = 325</td>
</tr>
<tr>
<td>Do you think that HPV...</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Causes cervical cancer?</td>
<td>18.3</td>
<td>75.1</td>
</tr>
<tr>
<td>Is a sexually transmitted infection?</td>
<td>18.7</td>
<td>54.2</td>
</tr>
</tbody>
</table>

NOTE: Women who responded “don’t know” were included as incorrect responses; women who refused were excluded from the analysis.

*Patnè en Aksyon 2007, Pap Tes Lakay (Pap Test in the House).
†National Cancer Institute, 2007 Health Information National Trends Survey (HINTS).
Discussion

Haitian women may have lower levels of HPV literacy than their HINTS counterparts for a number of reasons, the most obvious of which is that the majority of Haitian women in our study, and Little Haiti generally, are impoverished and have had limited formal education opportunities. Income and education are well-established determinants of health status and health literacy (9-12). Persons with higher incomes often have greater access to health care services, and, in turn, exposure to health information. With increasing educational experience, individuals tend to have more opportunity to learn about disease processes and have greater self-efficacy to actualize disease prevention.

Study findings may also reflect Haitian women’s limited access to existing health information resources. In Little Haiti, most residents primarily speak Haitian Kreyol and are therefore excluded from otherwise widely available educational materials about HPV. To our knowledge, very few printed resources about HPV are available in Kreyol. Even so, the efficacy of print materials for Haitian women is limited. Kreyol is primarily a spoken language, with a relatively recent standardized orthography, that few people have learned for reading and writing (13). Radio and television programming, which are often the best means of health promotion in the Haitian community, have not been incorporated into HPV educational initiatives despite the increased risk of cervical cancer among this population subgroup (14).

Study Limitations
Study limitations involving the use of the HINTS data set include an overall low response rate (around 20%) and a proportionately small (n = 470) sample size for African American women. The design was also cross-sectional, and, as such, causal relationships between knowledge, awareness, and health behaviors can only be speculated.

The Little Haiti CBPR study was limited due to our reliance on convenience sampling. These sampling methods were guided by the insight of community partners regarding how data could be most successfully obtained, and our understanding of a deep-rooted, historical distrust of outsiders within this community. We also had a small sample size, albeit with a very high participation response rate. Despite such limitations, the information gleaned from the two studies provides a point of comparison to illustrate how meaningful differences in health knowledge are obscured by socially constructed categories of race often used in public health research.

Conclusion
Our study findings resonate with those of other researchers in demonstrating the importance of disaggregating data in otherwise homogenized racial/ethnic categories whenever possible (15, 16). The current classification system, which groups individuals primarily on the basis of phenotype, is problematic and arbitrary because it is based not on biology but on social constructions, which shift over time (17, 18). It fails to capture existing variability in disease risk within ethnically mixed, multicultural populations, such as the United States, and confounds understanding of the actual contribution of “race” to disparity in disease outcomes. Future research should approach ethnic categorizations critically, recognizing the inherent in-group differences that especially are relevant in geographic regions with higher concentrations of immigrants (19). Then, we may be better able to tailor interventions for unique population subgroups, and in doing so, make meaningful progress toward change.

Disclosure of Potential Conflicts of Interest
No potential conflicts of interest were disclosed.

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