

Contextualizing the Survivorship Experiences of Haitian Immigrant Women With Breast Cancer: Opportunities for Health Promotion

Erin Kobetz, PhD, MPH, Janelle Menard, PhD, MPH, Noella Dietz, PhD, Gabrielle Hazan, BA, Hosanna Soler-Vila, PhD, Suzanne Lechner, PhD, Joshua Diem, PhD, and Pascale Auguste, RN

Widespread adoption of mammography and increased treatment efficacy has reduced morbidity and mortality from breast cancer significantly among women in the United States (Lewis et al., 2010). However, that decline has not been equitable across different ethnic groups. Foreign-born minorities continue to be affected disproportionately by adverse disease outcomes, in part because of advanced stage of disease at diagnosis (Gany, Shah, & Changrani, 2006; Saint-Jean & Crandall, 2005). In the United States, recent immigrants and ethnic minorities tend to be diagnosed with late-stage (stages III and IV) breast cancer, for which the prognosis for survival is poor (Echeverria & Carrasquillo, 2006; Kobetz et al., 2010; Summers, Saltzstein, Blair, Tsukamoto, & Sadler, 2010).

A growing body of research has documented the implications of late-stage diagnosis and breast cancer survivorship among ethnically diverse women (Ashing-Giwa, Padilla, Bohórquez, Tejero, & Garcia, 2006; Chung, Cimprich, Janz, & Mills-Wisneski, 2009; Gibson & Hendricks, 2006). However, Haitian immigrants, who are among one of the fastest growing Black ethnic groups in the United States (Gany, Trinh-Shevrin, & Aragones, 2008), are a notable omission from the literature. The current study aimed to fill that gap. The current article will describe data from a series of focus groups conducted with Haitian immigrant women breast cancer survivors to document the unique barriers they face in managing their disease and to understand the impact of such barriers on their survivorship experiences.

Methods

Community-Based Participatory Research

The current study was conducted as part of an ongoing community-based participatory research (CBPR) initiative in Little Haiti, a community in Miami, FL. CBPR is a research methodology, increasingly popular

Purpose/Objectives: To examine challenges faced by Haitian immigrant women managing a breast cancer diagnosis.

Research Approach: Trained community health workers conducted focus groups with Haitian women who were breast cancer survivors. A grounded theory approach guided analysis of transcripts.

Setting: A large community-based organization in Miami, FL.

Participants: 18 women took part in three focus groups. Participants were 40 years or older, were ethnically Haitian, and had been diagnosed with breast cancer 6–12 months prior to the study.

Methodologic Approach: Data were collected as part of an ongoing community-based participatory research initiative in Little Haiti, the largest enclave of Haitian settlement in Miami, FL. Community health workers, integral to the initiative, recruited participants through their extensive social networks and community contacts.

Main Research Variables: Screening knowledge, illness beliefs, social and economic consequences of a breast cancer diagnosis, and advice for breast health education.

Findings: Emergent themes suggest that Haitian breast cancer survivors face multiple challenges, including misperceptions about screening guidelines, disease etiology, and risk; a reduced capacity to earn a living because of physical debility; and diminished social support.

Conclusions: Future research must continue to examine the impact of breast cancer on Haitian immigrant women and identify key strategies, such as community outreach and support programs, to improve their quality of life.

Interpretation: Nurses can play an essential role in such strategies by providing culturally relevant clinical care and partnering with community stakeholders to define the scope and focus of public health intervention.

in nursing, public health, and medicine, that invites community participation throughout the research process, from study conceptualization to dissemination of findings (Israel et al., 2003). Accordingly, CBPR reflects, and often is grounded in, community members' socio-cultural orientation to health and disease prevention,

their language preferences, and their literacy levels. That helps dissuade community suspicion about the intent of inquiry, prevalent in Little Haiti and other underserved communities, which are marked by health disparity and largely disenfranchised from the formal healthcare system.

Partners in Action

In Little Haiti, CBPR efforts are governed by a campus-community partnership known as *Patnè en Aksyon* (Partners in Action). The partnership involves active participation of community leaders from Little Haiti and an interdisciplinary team of investigators from a large university in the Miami metropolitan area. As is consistent with the tenets of CBPR, community leaders primarily are responsible for defining the focus of research and identifying culturally appropriate recruitment strategies and methods of data collection. The academic partners, in turn, write the majority of grant applications, and obtain institutional review board (IRB) approval from their university for funded projects. Community and academic partners contribute collectively to study implementation and dissemination of findings.

Community health workers (CHWs) also play a central role in many of *Patnè en Aksyon's* research efforts. In the current study, CHWs primarily were responsible for recruiting study participants and collecting data. The CHWs were women of Haitian descent who spoke English and Haitian *Kreyol* fluently and were knowledgeable about community norms and cultural mores. They were employed formally by a large community-based organization whose leadership is active in *Patnè en Aksyon* and is well respected throughout Little Haiti. The affiliation between the CHWs and the organization was, in many ways, critical to the study's success. By providing the study a "community home," the authors did not encounter many barriers to implementation and, perhaps more importantly, were able to build organizational capacity to support future research and intervention.

The CHWs were trained to participate in research using a standardized manual, created by one of the academic partners, that provides didactic instruction on 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. The current study was vetted and approved by the university IRB prior to implementation.

Participant Recruitment and Data Collection

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, including flea markets, health clinics, and laundromats, to identify women meeting study eligibility criteria. Women were eligible to participate if they self-identified as Haitian and had a breast cancer diagnosis in the past 6–12 months. The focus groups were held at the organization's offices over a period of three months. Three groups were conducted, each with about six women, for a total of 18 participants.

One CHW moderated all three focus groups using a semistructured guide developed collaboratively by *Patnè en Aksyon's* academic and community partners. The guide was designed to generate discussion on five specific domains of interest: (a) screening knowledge, (b) breast cancer etiology and health locus of control beliefs, (c) availability of a social support network, (d) effects of a breast cancer diagnosis, and (e) survivors' advice for effective breast health educational outreach. The CHW obtained informed consent from each participant prior to initiating group discussion. Groups were conducted in Haitian *Kreyol*, digitally recorded, and later interpreted and transcribed into English by the CHW. On average, each group lasted two hours. As compensation for their time and contribution to the research, all participants were given a \$25 gift card.

Data Analysis

Two researchers independently reviewed the focus group transcriptions for recurrent themes in responses, following a grounded theory approach. Grounded theory is an inductive, qualitative analytical method applied to textual data that allows for a systematic assessment of salient themes that naturally emerge from the data (Corbin & Strauss, 2007). Such themes collectively depict a theory or framework for understanding a particular research question or questions. The researchers used open coding to assign in vivo codes to emergent themes and subthemes, which consist of words and phrases from participants' discourse to more precisely capture theme meaning (Bernard, 2006). Throughout the coding process, researchers also recorded personal observations about linkages between emergent themes. The researchers discussed any points of difference in coding results and came to a consensus.

Findings

Participant Demographics

All participants were immigrant women of Haitian descent, aged 40 years or older, and diagnosed with breast cancer in the year prior to the study. The authors intentionally did not collect detailed sociodemographic data, given residents' aversion to research and their perception that such information could be used to compromise their personal or family members' immigration status. Although data from the 2000 U.S. Census reflect a

general undercount, trends reveal that Haitians residing in Miami-Dade County, and Little Haiti in particular, are at an economic and social disadvantage compared to other ethnic groups (Saint-Jean & Crandall, 2005). Haitians are employed disproportionately in low-wage occupations, and the poverty rate for Haitians is 30%, almost double the overall county rate of 18% (Sohmer, Jackson, Katz, & Warren, 2005). Among Haitian adults aged 25 years and older, 53% have not completed a high school education (Sohmer et al., 2005). Therefore, based on participants' residence in Little Haiti, the majority of respondents probably live at or below the federal poverty line, have limited formal education and proficiency in English, and experience restricted access to the formal healthcare system (Saint-Jean & Crandall, 2005).

Screening Knowledge

As previously mentioned, the focus group questions addressed five primary domains, or categories of interest. The authors first sought to understand survivors' opinions and knowledge of early detection methods for breast cancer. Participants from all three focus groups named biomedical means of early detection, specifically mammography, breast self-examination, and breast ultrasound; however, women's knowledge of recommended screening guidelines varied widely. Concerning age at which screening should begin, responses varied from 20s to 40s, and screening frequency varied from every six months to annually.

Breast Cancer Etiology and Health Locus of Control Beliefs

The women's discourse revealed an understanding of disease etiology that reflected a combination of biomedical and ethnomedical models of illness. The most commonly named causes for breast cancer included family history, abortions, estrogen from birth control pills, breast trauma, environmental chemicals, radiation exposure from mammograms, stress, depression, bad luck, and poor diet. Importantly, women's assessments of what constituted a poor diet were not consistent with traditional health promotion definitions; that is, for participants in this group, having a poor diet specifically meant eating canned and other processed foods, because they believed chemical additives and food preservatives in these could cause cancer. As one participant explained, "At home, all the foods are natural. Here they are in cans, it is those can foods."

Women's etiologic beliefs did not change from pre- to postdiagnosis, and many women perceived that their diagnosis and survival ultimately were determined by God. Some participants implied that they were skeptical of their physician's treatment recommendations, given that their recovery, or lack thereof, was divine will. To illustrate, one participant related,

Some people do everything right, they eat right, they exercise and the cancer still comes on them, so you cannot tell me you have control. Even when you take care of the first cancer, it can come back. So the control is God.

Availability of a Social Support Network

Women's experiences varied with regard to social support, although some common threads emerged. Participants commonly indicated that it was very difficult initially to talk about their breast cancer with anyone, but that this difficulty eased with time. Women explained that they confided in people about their diagnosis based on the closeness of their relationships. Women initially spoke only to close friends and some family, often waiting until after treatment had begun or was complete. Women frequently explained that they did not want to tell their own children, partners, or husbands for fear of causing them worry and sadness. One woman explained,

Me, it affected me. With my husband and my kids—my husband, as soon as he found out I had cancer, he left. My kids were scared, [and] they thought I was going to die.

For many women, support for their disease often came after treatment was completed, if at all.

Some participants also described the loss of friends and family because of their diagnosis. A few women said that friends did not want to get physically close to them for fear of catching the disease or because of the belief that cancer survivors were poisonous as a result of receiving chemotherapy. For example, one woman explained,

Illness should be confidential; you are not suppose to talk about your illness to just anybody. Once you talk about your illness, you get a bad feeling, because the person you are telling pulls away from you.

Another said,

Me, my family kind of stayed away from me because many members of my family, they just cannot accept cancer.

Many participants had been told that their cancer was a function of insufficient prayer or turning away from God, and described how such ideas negatively impacted their relationships with family and friends who refused to abandon those beliefs.

Multiple Effects of a Breast Cancer Diagnosis

Beyond the impact on personal relationships, participants described other negative outcomes of their breast cancer diagnosis. Most commonly, women described the economic impact of the disease. Women with health insurance described repeated bouts of treatment

interruption as a result of issues with reimbursement and loopholes in coverage, where the insurance provider could arbitrarily reject provider claims. Others commonly described how treatment regimens and corresponding side effects negatively impinged on their work and subsequent pay. That issue was particularly salient for women employed outside the formal economy (e.g., housekeeping, child care) or for those whose partners or husbands left in response to their cancer diagnosis. Women frequently related an inability to afford prescribed medication, which often was deemed critical to their recovery and disease-free survival. Lastly, women related issues with self-image following surgical treatment. Participants described the difficulty in being comfortable with their appearance following lumpectomy or mastectomy, particularly around their spouse or partner. One participant said,

I have always been open with my disease. But there is one area that I cannot be open. I don't let anybody see [my chest].

Survivors' Advice for Effective Breast Health Educational Outreach

Women acknowledged the inherent challenges in breaking the Haitian community's silence around breast cancer, but thought doing so was important and necessary. Toward that end, they advocated for including Haitian breast cancer survivors in educational outreach to dispel commonly held myths about cancer and the curability of disease. Participants emphasized that such efforts should feature several survivors at once to illustrate that survivorship was not a fluke or one-time thing. Women also suggested using church pastors to facilitate acceptance into the community, and having survivors speak in a group at churches about the importance of early detection and seeking timely biomedical care for breast abnormalities. Participants also strongly suggested the use of local *Kreyol*-language radio and television, given their long-standing use as trusted mediums for information in Little Haiti and in the Haitian community at large.

Discussion

The current article represents one of the first attempts to describe, understand, and contextualize the challenges faced by Haitian breast cancer survivors. Study findings highlight important similarities between the survivorship experience of Haitian immigrant women and other socially marginalized groups. For example, study participants' pluralistic notions of illness causation are consistent with findings reported from work with Haitian women in West Central Florida (Meade, Menard, Thervil, & Rivera, 2009) and other immigrant

groups throughout the United States (Coffman, Shobe, & O'Connell, 2008; Wade, Chao, & Kronenberg, 2007). Similarly, the perception of many women from the sample that their survival was divinely determined resonated with literature from African American survivors (Erwin, Spatz, Stotts, Hollenberg, & Deloney, 1996; Gullatte, Hardin, Kinney, Powe, & Mooney, 2009; Hamilton, Powe, Pollard, Lee, & Felton, 2007).

Haitian breast cancer survivors' financial struggles in the face of overwhelming medical bills also are not unique (Darby, Davis, Likes, & Bell, 2009; Pisu et al., 2010). Women in the sample, like many other medically underserved groups, described the financial toll of treatment costs on their family income, and the difficulty paying for medications, such as tamoxifen, given their other expenses and limited economic resources. However, the current study is unique because of the overwhelming number of women in the sample—and the Haitian immigrant community at large—who are employed in informal economic sector wage positions (e.g., housekeeping, day labor) and for whom missed work translates to lost wages and possible unemployment (Chen, Vanek, & Carr, 2005). Participants poignantly described the inherent difficulty in coordinating work responsibilities with treatment regimens, and how they forced themselves to work through physical discomfort for fear that their employer would replace them with someone healthier. Most of the women in the sample were reliant on their wages to live, let alone cover the cost of breast cancer care, and for a number of women, the issue of job security became even more relevant post-diagnosis when they were abandoned by their husband or partner because of their illness.

Participants repeatedly expressed concern about sharing their diagnosis with family members and friends. Some of those concerns related to the aforementioned issue of partner abandonment, whereas others reflected a desire, common across survivor groups, to protect family, particularly children, from excess worry (Barnes et al., 2000; Hilton & Gustavson, 2002). However, in the current sample, the majority of such concerns were grounded in sociocultural beliefs about cancer, seemingly unique to the Haitian community. Within Little Haiti, the authors found that cancer often is seen as punishment for insufficient prayer or belief in God. The women in the current study shared negative experiences with family members, friends, and coworkers who held such beliefs and were less than sensitive about their illness. Participants also relayed feeling stigmatized by their social networks as a result of widespread fears that cancer is contagious and that adjuvant therapy makes survivors poisonous to the touch. Such stigmatization significantly influenced participants' willingness to disclose their diagnosis, and limited the extent and type of social support available to those who ultimately broke the

silence about their disease. Future research must explore how to address community norms surrounding cancer appropriately to improve survivors' access to necessary support services. Participants suggested that such efforts would benefit significantly from participation of multiple survivors, who could effectively demonstrate that a breast cancer diagnosis is not an unequivocal death sentence.

Participants also advocated for addressing the root causes of cancer disparity that they perceived accounted, in large part, for the challenges they experienced postdiagnosis and also impeded access to routine mammography screening, associated with earlier-stage diagnosis and improved disease outcomes. For example, they suggested efforts to improve health insurance coverage, the number of health providers who speak Haitian *Kreyol*, and immigration policy toward Haitians. They believe—and data uphold this assertion—that the net effect of such barriers is screening and treatment delay, which ultimately also contributes to poorer quality of life and overall survival (Gierisch, Earp, Brewer, & Rimer, 2010; Shen et al., 2005).

Study findings must be interpreted within the context of current health policy, which may now afford better treatment opportunities to medically underserved immigrant women, and in light of other notable limitations. The study was restricted to a small sample of 18 women and cannot be generalized to Haitian breast cancer survivors at large.

Implications for Nursing

The article represents one of the first attempts to describe the breast cancer survivorship experiences of Haitian immigrant women and can inform future research and intervention. Nurses have a unique opportunity to positively contribute to such intervention efforts. They can impact breast cancer survivorship experiences by serving as key educators and advocates

for screening and treatment adherence. Nurses also can assist women with understanding treatment options, navigating patients through the complexities of the healthcare system, and finding community-based resources such as support groups and advocacy organizations. As indicated by the study data, nursing practice must be informed by an understanding of the cultural and structural contexts in which coping with breast cancer unfolds.

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Erin Kobetz, PhD, MPH, is an assistant professor in the Department of Epidemiology and Public Health in the Miller School of Medicine, a member of the Sylvester Comprehensive Cancer Center in the Division of Cancer Prevention and Control, and the director of the Jay Weiss Center for Social Medicine and Health Equity in the Miller School of Medicine, all at the University of Miami in Florida; Janelle Menard, PhD, MPH, is a postdoctoral research associate in the Sylvester Comprehensive Cancer Center in the Division of Cancer Prevention and Control at the University of Miami; Noella Dietz, PhD, is an assistant professor in the Department of Epidemiology and Public Health in the Miller School of Medicine at the University of Miami; Gabrielle Hazan, BA, is a student intern in the Sylvester Comprehensive Cancer Center in the Division of Cancer Prevention and Control at the University of Miami; Hosanna Soler-Vila, PhD, is an assistant professor in the Department of Epidemiology and Public Health in the Miller School of Medicine at the University of Miami; Suzanne Lechner, PhD, is an assistant professor in the Department of Psychiatry and Behavioral Sciences in the Miller School of Medicine at the University of Miami; Joshua Diem, PhD, is a clinical assistant professor in the Department of Teaching and Learning in the School of Education at the University of Miami; and Pascale Auguste, RN, is an outreach coordinator at the Haitian American Association Against Cancer, Inc., in Miami. This research was funded by the American Cancer Society (MRSRG-07-159-01-CPHPS), the Lance Armstrong Foundation, and Susan G. Komen for the Cure (DISP 0708723). Kobetz can be reached at EKobetz@med.miami.edu, with copy to editor at ONFEditor@ons.org. (Submitted September 2010. Accepted for publication October 26, 2010.)

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