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Developing Strategies for Reducing Cancer Disparities via Cross-Institutional Collaboration: Outreach Efforts for the Partnership Between the Ponce School of Medicine and the Moffitt Cancer Center

Clement K. Gwede, PhD, MPH, RN^{1,2}, Eida Castro, PsyD³, Thomas H. Brandon, PhD^{1,2}, Jessica McIntyre, BS¹, Cathy D. Meade, PhD, RN, FAAN^{1,2}, Teresita Munoz-Antonia, PhD^{1,2}, Vani N. Simmons, PhD^{1,2}, Susan T. Vadaparampil, PhD^{1,2}, Julio Jimenez, MD³, and Gwendolyn P. Quinn, PhD^{1,2}

¹H. Lee Moffitt Cancer Center & Research Institute, Tampa, FL

²University of South Florida, Tampa, FL

³Ponce School of Medicine, Ponce, Puerto Rico

Abstract

The disproportionate burden of cancer among U.S. Hispanics is well documented. Historically, epidemiologic data on U.S. Hispanics and cancer have aggregated all Hispanics as one homogeneous group without appreciating the diversity of this population with regard to nativity (nationality/geographic origin). The authors report on the initial efforts of a collaborative academic institutional partnership between a minority-serving institution and a National Cancer Institute–designated cancer center to address cancer health disparities in two Hispanic communities in Puerto Rico and Florida. This article outlines the joint Outreach Program’s initial collaborative strategies and activities in community outreach, cancer education, and research that mutually benefit both the Ponce (Puerto Rico) and Tampa (Florida) Hispanic communities. This partnership program used innovative multipronged community-engagement strategies in the two communities to reduce cancer health disparities. Specific projects and lessons learned from three outreach/cancer education projects and two pilot research projects are discussed. The challenges of balancing service and research agendas in communities with disparate levels of resources and infrastructure are summarized to inform future initiatives in this partnership, as well as serve as an example for similar minority-serving institution/cancer center partnerships to reduce cancer health disparities.

Keywords

cancer health disparities; academic partnerships; Hispanics; immigrant health; community partnerships; community outreach

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The disproportionate burden of cancer among U.S. Hispanics compared with other racial-ethnic groups is well documented (American Cancer Society [ACS], 2009a, 2009b; Carozza & Howe, 2006). One approach to addressing cancer health disparities is through collaborative community–academic partnerships that include outreach programs to reach and engage underserved communities (Gwede et al., 2010; Meade, Menard, Luque, Martinez-Tyson, & Gwede, 2009; Valente, Fujimoto, Palmer, & Tanjasiri, 2010). This article outlines the Ponce School of Medicine (PSM)–Moffitt Cancer Center (MCC) Partnership’s Outreach Program and its initial collaborative strategies and activities in community outreach, cancer education, and research that mutually benefit both the Ponce,

Puerto Rico (PR), and Tampa, Florida (FL) Hispanic communities to reduce cancer health disparities. Specific barriers and facilitators are discussed to inform future initiatives in this partnership, as well as serve as an example for similar partnerships to reduce cancer health disparities. As such, to build relevant and effective community–academic partnerships, an understanding of the population demographics and cancer burden is needed to ignite ideas that can benefit from such collaborations.

BACKGROUND

Approximately 45.5 million Hispanics (or 15% of the total population) lived in the United States in 2007 and 60% of them were born in the United States, whereas the other 40% were foreign born (ACS, 2009b). The majority of U.S. Hispanics have origins from Mexico, Puerto Rico, and Cuba. Historically, epidemiologic data on U.S. Hispanics and cancer have not appreciated the diversity of this population with regard to nativity (nationality/geographic origin), making it difficult to compare cancer incidence and mortality data for U.S. Hispanic subpopulations with their counterparts in their native countries of origin. In a recent report, Pinheiro et al. (2009) showed substantial variability in cancer rates among Hispanic subpopulations with all-cancer incidence rates for Puerto Ricans, Mexicans, and Cubans in FL at least 40% higher compared with their counterparts in their native countries of origin. This was mainly evident for the most common cancers, including breast, colorectal, lung, and prostate. The noted variability requires that each Hispanic subgroup receive adequate research attention. Additionally, it is important to consider diversity and cultural and behavioral factors that influence access and use of established cancer screenings and related modalities among Hispanic populations in their homeland and in the United States (Vadaparampil et al., 2010). These considerations drive the research and outreach reported in this article with the focus on Puerto Ricans residing in either PR or FL.

Ponce School of Medicine–Moffitt Cancer Center Partnership

The geographic proximity and large Hispanic populations in FL and PR have driven the formation of an academic partnership between PSM and MCC under the umbrella of the National Cancer Institute's (NCI) Cooperative Planning Grant for Comprehensive Minority Institution/Cancer Center Partnership (MI/CCP) program to facilitate initial stages of planning for a comprehensive partnership. As such, the PSM–MCC Partnership is an NCI-funded cooperative planning agreement to build and strengthen the relationship and joint infrastructure between the institutions aimed at understanding the reasons behind the significant cancer disparities and address this issue among Hispanic populations in Ponce (Southern PR) and in Tampa, FL, through trans-disciplinary basic research, cancer education and training, outreach, and tissue procurement. The partnership's Outreach Program consists of investigators from both institutions with expertise in psychology, psychiatry, public health, health education, social marketing, community engagement, and health disparities research.

The goal of the Outreach Program is to develop new community partnerships and strengthen existing community outreach programs for cancer prevention and control for Puerto Ricans living in PR and FL drawing from community-based participatory research (CBPR; Minkler & Wallerstein, 2008) and social marketing (SM; Lefebvre & Flora, 1988) approaches as guiding frameworks. Coordinated communications and interactions between the teams at both institutions have been central to cultivating and sustaining the Outreach Program. This is achieved through monthly telephone conference calls and quarterly face-to-face reciprocal site visits/ retreats that help reinforce the common goals and strengthen the trust and commitment among the collaborators.

APPROACH/STRATEGIES

Guiding Frameworks for Community-Based Outreach and Research

Our blended approach to community-based outreach and research was partially informed by lessons from community-based prevention marketing, a synergistic approach that combines CBPR and SM concepts to address public health problems (Bryant et al., 2007; Sharpe et al., 2010). CBPR emphasizes the key concept that improvements in public health are most successful when community members are equitably involved in the full spectrum of action: from problem definition, to intervention, to evaluation, and when interventions address an array of social and economic factors to improve the health of the community (Israel, Schulz, Parker, & Becker, 1998; Minkler & Wallerstein, 2008). SM has been successfully used with Hispanic communities to affect health conditions (Thackeray & Neiger, 2003; Wechsler, Basch, Zybert, & Shea, 1998). Unlike commercial marketing, which attempts to persuade consumers to buy a product or service that has already been developed, in SM the behavior or service is adapted to reduce barriers and highlight benefits as seen by the consumer. SM consists of five steps (see Figure 1), including planning, message and materials development, pretesting, implementation, and evaluation (Lefebvre & Flora, 1988). In this context, the synergistic application of CBPR and SM frameworks (see Figure 1) guided the process of community participation in planning and implementation of outreach and research projects described below and empowered both Hispanic communities by integrating community member knowledge and feedback. In the subsequent sections, we summarize each outreach and pilot research project, and the key elements of each activity are also summarized in Table 1. All projects received institutional review board approval.

Outreach Projects in Tampa, FL, and Ponce, PR

Outreach Project 1: *Latinos y el Cáncer*/"Latinos and Cancer" (Tampa, FL) and *Hablemos de Cáncer*/"Let's Talk About Cancer" (Ponce, PR)—Guided by a CBPR framework, community outreach and educational symposia served as a pivotal foundation for the PSM–MCC Partnership's Outreach Program. The first *Latinos y el Cáncer* educational symposium took place in 2006 in preparation for formalization of the PSM–MCC Partnership. The goal was to provide cancer education in Spanish to the Tampa Bay Hispanic community and provide access to MCC facilities and services. With integrated involvement of community advisors, short presentations on cancer and its prevention, clinical trials, and nutrition were followed by smaller breakout sessions where participants had the opportunity to ask questions of experts in different subspecialties. This event was extremely successful with more than 250 participants and highly positive comments and evaluations. Under the PSM–MCC Partnership umbrella, these free community events were replicated in Ponce (*Hablemos de Cáncer*) and are now conducted biannually at each site, in alternating years to allow for joint planning and participation by collaborators from both institutions.

Consistent with CBPR principles for community participation, each event is planned in collaboration with community members while taking into consideration the needs of the specific community, the participants' evaluations, and input from community leaders. Although both events have the same basic organization as the original event, each event is tailored for the local community rather than taking a "one-size-fits-all" approach. For example, in Tampa (*Latinos y el Cáncer* held in 2006, 2008, and 2010) participants have the opportunity to register in the National Marrow Donor Program to become potential bone marrow donors and in Ponce (*Hablemos de Cáncer* in 2008 and 2010) the community has access to cancer screenings (e.g., mammograms, skin cancer screenings) and other health screens (e.g., diabetes, blood pressure). The symposia at both sites are focused on prevention, nutrition, clinical trials, and specific cancer types addressed in breakout

sessions: lung, colon, prostate, breast, and hematological malignancies. However, other topics are event-specific in response to the feedback obtained from the community. For example, during the 2010 *Hablemos de Cáncer* in Ponce, a short talk on spirituality during the breakout sessions was added. Both academic and community speakers are included in these symposia to maximize community participation and community relevance. Community speakers include local community leaders and cancer survivors providing individual testimonies about their disease/survivorship experiences.

Lessons learned: This collaborative approach has worked very well as we continue to experience an increase in attendance at these events. The two Hispanic communities value language-appropriate and culturally relevant cancer education, and their participation and feedback guides the organization of the events. Successful continuation of these activities requires strong institutional commitment for cancer care and related services to support the necessary diagnostic, treatment, and follow-up care if cancer is found. For example, the cancer center (MCC) and PSM have established channels to provide diagnostics, cancer treatment, and follow-up care for uninsured individuals through a variety of funding mechanisms, including county health insurance program, ACS programs, and charity care as indicated. Patient assistance is provided as needed to help each person with timely access to these services.

Outreach Project 2: Community and Cancer: Exploring Needs—Community and Cancer is ongoing facilitation of community focus groups in southern PR area to identify needs and barriers to cancer care and preventive services. During the fall of 2007, eight focus groups were held with cancer patients, survivors, cancer health care providers (HCPs), community leaders, and faith-based organization. The evaluative data from these initial sessions were used to help inform the development of a brief questionnaire (in development) to be used in surveys of community members attending future *Hablemos de Cáncer* symposium in Ponce and the *Latinos y el Cáncer* event in Tampa. Results from the focus groups continue to inform planning as specific topics/themes from the focus groups have been addressed in the educational events. Some themes that have been identified as a source of need are psychological and spiritual support, family/ caregiver support, access to health care services, transportation, cancer prevention education, and financial/ health insurance concerns.

Lessons learned: Community participation and engagement are critical for identifying salient needs of the community even when the agenda is constrained by funding mandates. Initial efforts are underway to translate these findings into community-member–fueled and prioritized projects to address selected needs such as developing a resource directory for cancer survivors in Ponce, PR.

Outreach Project 3: Cultural Communication Workshops: Outreach Events for Physicians and Health Care Providers in Tampa, FL—To assess the perceived cultural competence of healthcare providers, Spanish-only speaking cancer patients from Tampa were surveyed about perceptions of provider attitudes. This survey revealed that more than 90% of patients felt they were perceived as “knowing less” since they did not speak English. Thus, the need to improve cultural communication among providers was identified. The first workshop titled “Communication with Hispanic Cancer Patients: The Cultural Context of Breaking Bad News” was determined by surveying oncologists ($N=72$) at the MCC, asking them to rate their preference for additional training in the nine Agency for Healthcare Research and Quality cultural competency techniques. A total of 66% selected, “I am interested in receiving information on how to communicate difficult issues

such as terminal illness and controversial diagnosis, in a way that is respectful to Hispanic culture.”

A workshop was planned jointly among PSM–MCC collaborators and community members. The workshop included a didactic lecture from a Hispanic provider addressing culture, terminal illness, and communication strategies; and a discussion session with a panel of interpreters, translators, and bilingual providers from Ponce and Tampa. Fifty-five clinicians, including oncologists, advanced practice nurses, physician assistants, and registered nurses attended. A seven-item pretest was administered prior to the workshop, followed by a three-item posttest. Results indicated that 62% endorsed that the workshop was helpful in developing techniques for communicating bad news to Spanish-speaking patients. At pretest, 25% reported having very little knowledge about the cultural context of breaking bad news to Hispanic patients, yet at posttest 0% reported having very little knowledge. At baseline, 20% of participants felt very comfortable with their cultural communication skills; however, only 3% felt very comfortable after attending the intervention. These data suggest that providers who previously had a high level of comfort based on misperceptions of good cultural communication realized that they needed improvement after attending the workshop and that the workshop was a good tool for improving knowledge.

Lessons learned: Findings demonstrated that a cultural competency training event could attract a significant number of physicians and other HCPs. Moreover, the majority reported that the training was beneficial. More extensive evaluation is needed to determine whether such training produces changes in providers’ actual communication with their patients. Future plans include continuing to offer the workshop annually, incorporating a standardized patient presentation, and encouraging entire clinic teams to attend together (e.g., teams might include nurse, surgeon, nurse practitioner, physician assistant, or social worker).

Research Pilot Projects in Ponce, PR

Research Pilot Project 1: Smoking Relapse-Prevention Education for Pregnant and Postpartum Women—Approximately 42% of Puerto Rican women smoke during their prime childbearing years (Roberts-Clarke, Morokoff, Bane, & Ruggiero, 2002). Hispanic women, however, are more likely to make a quit attempt during pregnancy, creating a “window of opportunity” (Fang et al., 2004) to assist them in remaining abstinent postpartum. Previous research has demonstrated the efficacy and cost-effectiveness of a self-help smoking relapse-prevention booklet series, entitled *Forever Free: A Guide to Preventing Smoking Relapse* (Brandon, Collins, Julian, & Lazev, 2000; Brandon et al., 2004). Recently, a version of the *Forever Free* series tailored to pregnant women, *Forever Free for Baby and Me*, was developed by our research group (Lopez et al., 2008) and showed that effectiveness at extending abstinence, compared with a control condition, was dependent on the level of positive partner support reported at baseline (Brandon et al., 2010). To expand the availability of low-cost intervention to the largest ethnic minority group in the United States, we undertook the effort to transcreate this booklet series into Spanish (*Libres Para Siempre Por Mi Bebé y Por Mí*, LSBM) using a multistage qualitative approach with mainland U.S. Hispanic women (Simmons et al., 2010).

Following the development of LSBM, we identified the goal of expanding dissemination efforts and assessing the cultural acceptability of the LSBM series in PR specifically using the outreach infrastructure of the PSM–MCC Partnership’s Outreach Program. To date, we have distributed 184 sets of booklets throughout southern PR through partnerships with multiple distribution channels such as health departments, Headstart programs, obstetrics/gynecology clinics and other provider clinics, and community health fairs. We also

conducted qualitative interviews with 19 community-based HCPs to obtain feedback on the booklets and suggestions for culturally appropriate dissemination of the LSBM booklets (Litvin et al., in press).

Results revealed that HCPs were impressed with most aspects of the booklets: content, quality of translation, visual appeal, and cultural acceptability. Nevertheless, HCPs emphasized the importance and value of interpersonal contact as an optimal means for distributing information in Puerto Rican culture. For example, they suggested that the booklets could be distributed following *charlas* (health-related themed presentations open to the community), a popular medium for providing health education in PR.

Lessons learned: The data from this pilot study suggest the need for evidence-based smoking cessation and relapse-prevention interventions to be made available to smokers living in PR. Although our booklets have been found to be culturally acceptable, a novel finding of our formative work in Ponce was the need to consider culturally specific dissemination strategies guided by CBPR and SM frameworks. Future directions include testing the efficacy of the LSBM booklets and evaluating various modalities of dissemination (including *charlas*) to determine their acceptability and effectiveness in a larger population of Hispanic smokers in PR.

Research Pilot Project 2: Social Marketing and Cancer Genetics Among Puerto Rican Women—Individuals who carry mutations in *BRCA1* and *BRCA2* (*BRCA*) genes have lifetime risks of 55% to 85% for developing a primary breast cancer, 40% to 60% for developing a second breast cancer (Ford, Easton, Bishop, Narod, & Goldgar, 1994; Metcalfe et al., 2004; Robson et al., 2005), and 15% to 60% of developing ovarian cancer (Carter, 2001; MacDonald et al., 2002). Recent studies have documented the presence of *BRCA* mutations in Hispanic women (John et al., 2007; Weitzel et al., 2005; Weitzel et al., 2007). However, the majority of participants in previous studies documenting *BRCA* mutation prevalence among Hispanics in the United States have been of Mexican origin (John et al., 2007; Weitzel et al., 2005; Weitzel et al., 2007). To date, there is no information available on these issues for Hispanic women living in PR. Thus, the purpose of the current pilot study was to explore baseline levels of knowledge and interest in genetic testing (GT) among women living in PR.

A cross-sectional design was employed to recruit women in Ponce, PR ($N = 25$), through community-based outreach methods (e.g., attending cancer support groups, partnering with local ACS and community advocates, posting flyers at hospitals). The majority of participants were aged ≥ 31 years (92%), were married (56%), had children (76%), were college educated (40%), and employed (68%). About half of the participants had a personal history (48%), and a third had a family history (32%) of breast cancer. Very few reported a personal history (12%) or family history (8%) of ovarian cancer. With respect to interest in GT, 100% of participants reported they would have *BRCA* GT if it were made available to them. Regarding specific motivators and barriers to GT, the most commonly cited motivation for GT was provider recommendation. The most commonly cited barrier was cost of GT. With respect to knowledge, of the 11 knowledge items related to *BRCA* prevalence, patterns of inheritance, cancer risk, and risk management, the average number of correct responses was 5.00 ($SD = 1.87$).

Lessons learned: Currently, *BRCA* genetic counseling and GT are not readily available in PR. Thus, similar to the United States, research studies may serve as an important way that women initially gain access *BRCA* genetic counseling and GT. Based on our preliminary results, there are key attitudinal, knowledge, and motivational factors that warrant further

consideration in the context of recruitment strategies and protocol development for *BRCA* testing studies in PR (Vadaparampil et al., 2010).

DISCUSSION AND CONCLUSIONS

The PSM–MCC Partnership’s Outreach Program efforts, guided by CBPR and SM as frameworks for community engagement, represent an effective cancer outreach program that is feasible, acceptable, and culturally relevant to Hispanics residing in two separate communities in Ponce (PR) and in Tampa (FL) to reduce cancer health disparities. The specific lessons learned from each formative outreach project and pilot research initiative were discussed earlier. This section summarizes two overarching lessons and opportunities that could have broader implications for other academic and community partnerships for reducing cancer disparities: (a) integrating outreach and research for mutual benefit and (b) working with differential resource availability and infrastructure for cancer prevention in PR and mainland United States.

The Outreach Program at both institutions provided a unique opportunity for integration of community outreach and pilot research activities by providing coordinated cancer education activities that empower community members, as well as implement beneficial pilot research projects. As a result, the “attendant” objective when embarking on each initiative was to ensure that community participation and benefit were paramount considerations. To ensure this, the team at both institutions used existing community partnerships (Gwede et al., 2010; Meade et al., 2010) or convened new community advisory groups (Simmons et al., 2010) to gain community participation. In addition, ensuring that community outreach events yielded evaluative data that informed future research efforts was an important goal for the researchers. Also, researchers sought to ensure that each research project had apparent community benefit, while yielding substantive evaluative and research pilot data to support sustainability and next steps. Community input enhanced the tailoring of each project to ensure responsiveness and more readily address pertinent needs of each community rather than implanting a “one-size-fits-all” solution in both communities. Mutual benefit (Minkler & Wallerstein, 2008) to both communities and academic institutions was an important consideration and served as the platform for integrating outreach and research efforts.

Another unique challenge in this partnership was working with differential resource availability and infrastructure for cancer prevention in PR and mainland United States. During the process of problem identification (particularly for Outreach Projects 1 and 2), it was important to realize that community members may bring up many priority “social and general health” needs that are not directly related to cancer and may seem indirectly related to our efforts to address cancer health disparities. Using lessons learned in other academic community partnerships (Gwede et al., 2010) our team was cognizant of additional community concerns while keeping appropriate focus on addressing cancer education, prevention, and care concerns. For example, Outreach Project 1 provided cancer screening resources and cancer survivorship resources in Ponce and Tampa, while recognizing that transportation and languages services were important considerations/barriers to be addressed concurrently. Finally, because the resources for addressing genetic counseling and testing for hereditary breast and ovarian cancer are virtually nonexistent in PR, the Outreach Program closely collaborates with a researcher who is providing genetic counseling and testing services in the context of a research protocol. They have used the data to support grant applications to increase the availability of hereditary breast and ovarian cancer genetic counseling and testing services in PR.

In summary, partnerships between majority- and minority-serving institutions can enhance community outreach and engagement efforts to reduce cancer health disparities when

situated in CBPR and SM frameworks or other appropriate theoretical/conceptual frameworks. Collaborations between academic institutions and community must retain heightened focus on mutual benefit and sustainability. The balance between these two perspectives helps reduce tension between the needs of academic researchers and the importance of empowering communities and enhancing access to services. The lessons and opportunities derived from these initial efforts are demonstrative of the possible achievements to be realized as this partnership achieves sustainability through future larger scale collaborations and enhanced outreach and community-based research infrastructure in both Ponce and Tampa Hispanic communities.

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FIGURE 1.
Five Basic Steps of Social Marketing With Infusion of Community-Based Participatory Research

TABLE 1

Summary of Each Project and Frameworks Applied

Project	Goal/Objective	Audience	Process/Outcomes	Framework(s)	Lessons Learned
<i>Outreach Project 1: Hablamos de Cáncer</i> (Ponce, Puerto Rico) and <i>Latinos y el Cáncer</i> (Tampa, Florida)	Provide community education and awareness, and access to cancer screenings and related services	Cancer survivors and their caregivers or family members, general public	Community feedback fueled the development of Outreach Project 3 Increase in attendance of Hispanics at monolingual (Spanish) events	CBPR	Community is responsive and committed to culturally and linguistically tailored cancer education
<i>Outreach Project 2: Community and Cancer: Exploring Needs</i>	Identify needs, barriers and community priorities	HCPs, survivors, caregivers, clergy	Needs assessment Directory of services for cancer survivors	CBPR	Community-identified needs/barriers Community-fueled solutions outlined
<i>Outreach Project 3: Cultural Communication Workshops: Outreach Events</i>	Develop and implement a cultural competency training for oncologists and other HCPs	Physicians and health care—providing teams	Better-defined audience SM (segmentation) and curriculum; focus on HCP teams rather than physicians alone		Include HCP teams not just physicians Standardized patient approach preferred
<i>Research Pilot Project 1: Smoking Relapse-Prevention Education for Pregnant and Postpartum Women</i>	To expand dissemination efforts of a Spanish smoking relapse-prevention intervention in Puerto Rico and to assess the cultural acceptability of the LSBM series in Puerto Rico.	Smokers living in Puerto Rico ($N=184$) HCPs providing direct care to pregnant patients ($N=19$)	Dissemination of LSBM booklets via community health fairs, Healthy start clinics obstetrics/gynecology clinics Qualitative interviews conducted with HCPs evaluating culturally acceptability of booklets and dissemination strategies	CBPR and SM	Need to consider culturally specific routes for dissemination of health interventions, even within similar ethnic groups
<i>Research Pilot Project 2: Social Marketing and Cancer Genetics among Puerto Rican Women</i>	To identify knowledge and attitudes related to GT for HBOC	Women on Island ($N=25$)	Quantitative and qualitative evaluation of knowledge about HBOC and interest in GT Identified barriers and lack of GT referral resources	CBPR and SM	Significant interest in GT among Puerto Rican women Lack of resources for referrals

NOTE: CBPR = community-based participatory research; SM = social marketing; LSBM = *Libres Para Siempre Por Mi Bebe y Por Mi*; HCP = health care provider; GT = genetic testing; HBOC = hereditary breast and ovarian cancer.