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Creating Community–Academic Partnerships for Cancer Disparities Research and Health Promotion

Cathy D. Meade, PhD, RN, FAAN [Senior Member],

Moffitt Cancer Center and Professor at the University of South Florida in Tampa, Florida

Janelle M. Menard, PhD, MPH [Postdoctoral Fellow],

University of Miami in Tampa, Florida

John S. Luque, PhD, MPH [Postdoctoral Fellow],

H. Lee Moffitt Cancer Center & Research Institute, Tampa, Florida

Dinorah Martinez-Tyson, PhD, MPH [Research Assistant Professor], and

Louis de la Parte Florida Mental Health Institute, University of South Florida, Tampa, Florida

Clement K. Gwede, PhD, MPH, RN [Assistant Member]

Moffitt Cancer Center and Assistant Professor at the University of South Florida in Tampa, Florida

Abstract

To effectively attenuate cancer disparities in multiethnic, medically underserved populations, interventions must be developed collaboratively through solid community–academic partnerships and driven by community-based participatory research (CBPR). The Tampa Bay Community Cancer Network (TBCCN) has been created to identify and implement interventions to address local cancer disparities in partnership with community-based nonprofit organizations, faith-based groups, community health centers, local media, and adult literacy and education organizations. TBCCN activities and research efforts are geared toward addressing critical information and access issues related to cancer control and prevention in diverse communities in the Tampa Bay area. Such efforts include cross-cultural health promotion, screening, and awareness activities in addition to applied research projects that are rooted in communities and guided by CBPR methods. This article describes these activities as examples of partnership building to positively affect cancer disparities, promote community health, and set the stage for community-based research partnerships.

Keywords

cancer disparities; CBPR; literacy; immigrant health; community partnerships; health promotion; Latina; African American; Haitian

Cancer disparities have become part of the larger public health and clinical dialogue about health disparities in the United States due to persistent inequities experienced by marginalized groups. Medically underserved groups continue to die more than those with insurance and often have difficulty navigating through the medical care system, thereby decreasing the likelihood of favorable outcomes (Baquet, Hammond, Commiskey, Brooks, & Mullins, 2002; Chu et al., 2008; Institute of Medicine, 1999; McDonald, 2001; Winer et al., 2008). The Tampa Bay region of west-central Florida epitomizes this challenge.

Although Florida residents experience similar illness burden and mortality as the general U.S. population, two important features distinguish the state: the demographic composition and the state economy. Together, these features give rise to a unique set of considerations for public health professionals who want to address health disparities.

Florida's large population is diverse with regard to age, ethnicity, and immigration. The state's sizeable tourism and agricultural industries employ many immigrants in nonbenefited, low-wage positions (e.g., citrus farms, hotel housekeeping, food preparation). These characteristics also combine to shape the population's general literacy level, English-language proficiency, and employment opportunities, which in turn are key determinants that affect health status and access to health care. These factors and the state's cancer profile, which illustrates disparities across ethnicity and income, serve to inform our health promotion efforts. Moreover, forming partnerships with communities are critical for effecting positive social changes to address health and health policy (Koné et al., 2000; Minkler, Blackwell, Thompson, & Tamir, 2003; Minkler & Wallerstein, 2003).

In response to these circumstances that are playing out in our local environment, we formed the Tampa Bay Community Cancer Network (TBCCN), a Community Network Program funded by the National Cancer Institute (U01 CA114627) to address critical access, prevention, and control issues that affect medically underserved, low-literacy, and low-income populations in the Tampa Bay area. Our population focus includes residents of urban and rural medically underserved areas (MUAs) in three west-central Florida counties that are in close proximity to the cancer center. Our community partners are located in and/or serve populations residing in the designated MUAs. In keeping with the core principles of CBPR, we used a participatory process in the creation of the TBCCN as described elsewhere (Gwede et al., 2009). This article describes how a community-academic partner network has informed and fueled a number of outreach and research initiatives for addressing cancer disparities based on the principles of CBPR.

BACKGROUND

We ascribe to a socioecologic framework, which posits that health and illness are inextricably tied to the dynamics of multiple levels of influence situated in a social context (Sallis & Owen, 1997). Levels of influence are composed of internal and external factors, which interact to shape individual behaviors and a community's health profile. Such factors include cultural beliefs, educational attainment, employment and economic opportunities, and social and health policies. Within this perspective, disease disparities may be understood as the complex interplay of factors and end products of cumulative exposures that are both social and environmental in form. As Krieger (2005) notes, "We take it as a basic fact that we all live and act in bodies that literally embody biologically, across the lifecourse—our societal and ecological context" (p. 8). This embodiment of lifetime exposures holds for both infectious and chronic disease, including cancer.

Although major advancements have been realized concerning early detection for cancer, these advancements disproportionately benefit demographic groups with greater resources, including higher education and literacy and access to health care services (Freeman, 2004; Ward et al., 2004). Therefore, innovative health-promoting strategies that foster community capacity are essential to address the complex conditions that create health disparities.

Strategies

Many of TBCCN's health-promoting strategies are based on the expressed needs of community partners who need outreach and services in their respective communities. Therefore, community engagement that emphasizes service is at the heart of our network.

For example, health promotion activities range in scale from small to large events (e.g., 20 to 1,000 attendees) and include health fairs, cultural events, education at multilingual clinics, and cancer awareness classes. In addition, mobile mammography and linkages to follow-up care is provided at many outreach events. Bilingual (English–Spanish, and English–Haitian Creole) outreach workers and staff members considerably facilitate outreach efforts and rapport development with community members. All of these activities have been critical to establish the foundation for solid relationships and cultivation of partnership trust and rapport among community partners.

Importantly, from these partnerships, we have been able to foster research collaborations that benefit community constituents and move forward the research dialogue on cancer disparities. The concept of research is often not well received by community members, as it may be associated with historical abuses, especially among marginalized populations (Giuliano et al., 2000; Robinson & Trochim, 2007). As such, genuine, reciprocal research partnerships must be cultivated to advance social and public health research on cancer disparities. This often requires flexibility in research designs, implementation plans, and clear definition of expected outcomes. In short, community partners must be part of the dialogue about the risks and benefits of research projects and share in the power of the research relationship (Lesser & Oscós-Sánchez, 2007; Scarinci, Johnson, Hardy, Marron, & Partridge, 2009). The following sections describe the development and implementation of several TBCCN health promotion initiatives (two outreach and two research) that were fueled by community–academic partnerships. Common to all the projects is the involvement of community partners for shaping and directing the beneficial outcomes for their community.

Outreach Project 1: Campamento Alegria—Empowering Latina cancer survivors through education, support, and networking—Campamento Alegria is a community-based initiative that offers Latinas diagnosed with cancer a positive and memorable experience through a variety of culturally and linguistically relevant educational, social, and recreational activities. This initiative stems directly from a TBCCN partnership with a local nonprofit organization serving Latina cancer survivors, and its primary objective is empowerment of survivors through education and information. The program emerged in response to an identified community need and serves as a model program that can be replicated by others interested in reaching Latina cancer survivors through innovative approaches (Martinez, Aguado Loi, Martinez, Flores, & Meade, 2008).

To date, oncology camps have largely been conducted in English, which limits full participation of primarily Spanish-speaking survivors. This program is unique in that it is culturally and linguistically tailored to meet the needs of Latina cancer survivors, closing communication and information gaps to this population. To our knowledge, there are no comparable programs in our community that fit this niche and address Latina cancer survivorship issues using this approach.

This free, 3-day camp is planned and implemented by community volunteers under the direction of the Latinas Unidas por un Nuevo Amanecer, a breast cancer support group. The relaxed setting allows participants to easily share their experiences and to connect with other women facing similar life challenges. Camp activities are strategically designed to strengthen survivors' ability to cope as they face cancer treatment and survivorship issues. All sessions and activities are conducted in Spanish. Educational activities cover topics such as clinical trials, nutrition, stress management, sexuality and intimacy, and meditation. Other recreational and rejuvenating activities include exercise, canoeing, communal meals, massage, and other activities donated by local salons.

When designing the camp, we formed a planning committee consisting of community members, Latina cancer survivors, TBCCN representatives, and health professionals to guide each step. We also reviewed national programs and spoke with organizations that had implemented similar activities in our community. We were highly successful at recruiting Latina survivors through word of mouth, and we encourage others wanting to reach at-risk groups to forge partnerships that include them as members of the focus population. An important output of this partnership has been the development of a funded research project to create a Spanish-language toolkit for teaching women diagnosed with breast cancer about stress management techniques while undergoing chemotherapy.

Outreach Project 2: Haitian Heritage Festival—The Haitian Heritage Festival is an annual event organized by a partner CBO, the Haitian American Alliance, Inc., directed by Haitian American leaders from our community. Each May, the festival attracts approximately 1,500 people to celebrate heritage and cultural history in recognition of Haitian Flag Day, designated as May 18. The partnership began in 2004, when a need was realized to bring culturally and linguistically relevant health education, promotion, and screening services to the local Haitian community. The CBO coordinates participation and sponsorship of other Haitian nonprofit organizations, musical and cultural performers, and local business owners. Collaborative efforts between the CBO and TBCCN have focused on layering health services onto the festival's cultural activities, including mobile mammography, health promotion, and cancer education in Haitian Creole.

Annual collaboration for this festival begins long before the event, through assistance with planning, seeking external funding support for the festival, and building community networks to bring health education and services to this event that attracts many people who are medically underserved. Importantly, we recognized that cancer disparities and awareness were not the primary health concern for this population. We responded by facilitating relationships with other local health care service providers that could meet community-identified needs centering on health promotion for hypertension, diabetes, and HIV/AIDS education and screening. We added cancer screening and education to these services. For many attendees, this event is the primary or only point of contact with formal health services. This event provides access to education and screenings in a culturally appropriate venue, and provides festival attendees with information about area providers and clinics that offer low- or no-cost health care regardless of immigration status.

Continuous support of this event led to other opportunities for collaborations with the Haitian community, fostering critical trust and rapport with the community that are paramount to sustained partnerships. Examples include successful extramural grants funding a community health worker position for breast and cervical cancer education and awareness promotion, focused education and outreach at local Haitian churches, collaboration for CBPR on colorectal cancer, and adapting the successful Witness Project® (Erwin, Spatz, Stotts, & Hollenberg, 1999) to meet the unique linguistic and cultural needs of the Haitian community. Also, the partnership contributed to defining the need for Research Project 1 (described next).

Research Project 1: Colorectal cancer in ethnic subgroups of U.S. Blacks—

Colorectal cancer (CRC) is the third leading cause of cancer deaths among American men and women, with 49,960 deaths and 148,810 new cases expected in 2008 (American Cancer Society, 2008b). U.S. Blacks have the highest CRC incidence and mortality rate of all groups and these disparities have remained startlingly unchanged over decades (American Cancer Society, 2008a). As a group, U.S. Blacks also demonstrate much lower use of cancer screening and treatment technology, and foreign-born Blacks may have even lower rates of CRC screening. There is now a well-recognized and growing segment of Black immigrants

born in other countries, including the Caribbean, Africa, and South America (American Cancer Society, 2008a). However, the impact of the diversity within the population of U.S Blacks on cancer CRC screening is largely unexplored because Blacks are commonly treated as a homogeneous group, without consideration of possible cultural and behavioral differences associated with national ancestry in the various distinct immigrant communities.

Lessons learned from Hispanic, Asian, and Caribbean immigrant communities regarding cancer rates and screening behaviors suggest that disaggregation may reveal potential CRC screening disparities otherwise concealed by “lumping” foreign-born with native U.S.-born Blacks into one homogenous group (John, Phipps, Davis, & Koo, 2005; Shah, Zhu, & Potter, 2006; Kwong, Chen, Snipes, Bal, & Wright, 2005; Lee-Lin & Menon, 2005; Consedine, Magai, Spiller, Neugut, & Conway, 2004; Garbers & Chiasson, 2006; Magai, Consedine, Conway, Neugut, & Culver, 2004).

In this pilot study (3U01CA114627-03S1 [C.G., Project Leader]), in partnership with the TBCCN, we assessed cultural beliefs, perceptions, and behaviors related to CRC screening in three ethnic subgroups of U.S. Blacks—(a) native U.S.-born, that is, African American; (b) Haitian-born; and (c) born in English-speaking Caribbean countries (Jamaica, Trinidad and Tobago)—residing in Hillsborough County. We also assessed the feasibility of recruitment methods, rates of and reasons for participation, and interest in participation in future studies among these three defined ethnic subgroups.

The project was founded on key tenets of CBPR, where TBCCN community partners including the Haitian American Alliance (previously referenced in Outreach Example 2), a cultural advisory group, and the research team participated collaboratively in defining the need and scope of the project, including designing recruitment strategies and interpreting findings. Cultural advisors were key community leaders representing the three ethnic groups of interest who not only served a critical advisory role in matters of significance and community benefit of the study but also evaluated study materials and provided valuable contributions in the design and implementation as key informants.

A cross-sectional design was used, using sequential mixed qualitative and quantitative research methods. The study recruited 20 men and women (in each ethnic subgroup) from medically underserved areas of Hillsborough County, the main geographic site for TBCCN. Eligible and consenting individuals 50 years or older with no personal diagnosis of any cancer took part in face-to-face qualitative in-depth interviews followed by assessment using a brief quantitative questionnaire read aloud by a trained interviewer.

Several lessons that have implications for both research and practice have emerged. First, cultural advisors proved to be a critical asset to understanding and overcoming study design and recruitment barriers. They served as ambassadors and cultural brokers who facilitated linkage to community events and cultural organizations serving the populations of interest. Second, it became apparent that the population of foreign-born Blacks is geographically dispersed and several recruitment approaches are needed. In addition, reaching individuals 50 years or older proved challenging because the majority of foreign-born immigrants tended to be younger or lived outside the MUAs. Finally, to produce notable impact on cancer health disparities, the lack of readily available, affordable, and accessible colonoscopy CRC screening services must be addressed in future efforts aimed at extending this line of research. A clear implication for practitioners is the need for linkages to colonoscopy screening services. To that end, this pilot project has since led to collaborations with a GIS expert who is assisting TBCCN with mapping cancer screening resources in our community, for example, access points for colonoscopies for medically underserved populations.

Research Project 2: Barbers Against Prostate Cancer (BAPC)—Prostate cancer is the second leading cancer in African American men, with a mortality rate 2.4 times higher and an incidence rate 60% higher than in Whites (American Cancer Society, 2008b). Given the disproportionate incidence and mortality between African Americans and the majority population, cancer education and outreach programs endeavor to reduce these health disparities, which are often explained in relation to multiple factors, such as poor access to health care, lack of follow-up services, late-stage diagnosis, underestimation of risk, and information needs (Jones, Underwood, & Rivers, 2007; Richardson, Webster, & Fields, 2004). Cancer awareness materials such as brochures, booklets, and fact sheets are valuable tools used to disseminate information to the community; however, many materials are not always culturally and literacy appropriate nor easily accessible to all population groups.

This pilot project addresses prostate cancer disparities through the utilization of barbershops. Barbershops, known to attract large numbers of African American men, are more than a place for haircuts and shaves—they are places for men to socialize and fraternize. Such familiar community venues, deemed trustworthy, have a strong potential to address potential barriers to prostate cancer screening, such as distrust of the health care system, issues around masculinity related to aversion for the digital rectal exam, and fatalism concerning cancer in general (Clarke-Tasker & Dutta, 2005; Forrester-Anderson, 2005; Hart & Bowen, 2004). Thus, BAPC (3U01CA114627-03S2 [J.L., Project Leader]), sought to adapt low-literacy prostate cancer education materials, focused on the message of informed decision making, to be used by barbers acting as lay health advisers. The study aims were to (a) assess the feasibility of using barbershops to disseminate relevant prostate cancer health messages and (b) provide training and evaluative workshops to African American barbers to provide them with the skills to deliver health promotion in the community.

Building on existing community linkages, we partnered with the Community Health Advocacy Partnership (CHAP), a community-based nonprofit organization that works to provide advocacy for quality health care for minority, poor, and underserved communities. By partnering with CHAP in the recruitment of barbershops and administration of the training and evaluation, the research team has coalesced around the tenets of CBPR to involve the community in the research project, facilitated by the dissemination of project results through local and national print, Internet and television media (e.g., see Parham, 2009).

The BAPC pilot project uses a mixed methods approach divided into three phases. In Phase I, the primary activities included performing qualitative formative research to customize materials from previously developed prostate cancer print and audiovisual media (Meade, Calvo, Rivera, & Baer, 2003). In addition, eight barbers were recruited for the study to gauge their interest in the project and assess their perceptions regarding the feasibility of the project. In Phase II, we developed a lay health adviser training curriculum for the barber training classes, combining low-literacy-level print materials and multimedia, based on the Project Leader's past curriculum preparation experience with migrant farm workers (Luque et al., 2007). Next, we trained the barbers, evaluated the training program, and collected data on the content of the prostate cancer education topics delivered to the 115 clients by the barbers during the two-month pilot intervention. In Phase III, we assessed the acceptability of the adapted materials and the feasibility of using barbers to disseminate prostate cancer health messages by surveying 40 clients to gauge behavioral intention to discuss prostate cancer screening options with a health care provider after receiving the barber education.

Our pilot study suggests that barbers can be effective communicators about prostate cancer information to encourage men to seek regular preventive health care (full results presented in another article). Key lessons learned reinforce the need to explore promising

communication channels found in community neighborhoods and to engage community members from project inception through to evaluation. Current TBCCN efforts underway entail creation of a barbershop advisory council and maintenance of the prostate cancer information stations in the barbershops.

CONCLUSION AND DISCUSSION

Although the ideas described in this article point to fertile areas for health promotion efforts, the innovative aspect of these projects is the teaming up of community and academic partners to shape outreach and research programs according to community need. Health promotion and research interventions then must be designed with a deep understanding of the social context of peoples' lives, including where cancer prevention "fits in" with regard to daily life priorities, culturally mediated beliefs about etiology, prevention and treatment, economic barriers, and other factors. This means being cognizant of the potential for competing or mismatched goals in a partnership (i.e., research projects vs. services provision) and to learn, from community members themselves, which health concerns and research questions are most important to them, and to respond to these needs as much as possible. This understanding is achieved through realizing that community members are cultural experts—they "know what will work and what will not in their own communities" (Schensul, 1994, p. 1). Interventions and programs created through the use of CBPR are located in the community; therefore, the insider's perspective is a critical element for success.

Improvements in health are most successful when community members are 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 (Baker, Horman, Schonhoff, & Kreuter, 1999; Scarinci et al., 2009). Although the outreach and research examples presented here are from communities that differ ethnically, culturally, and linguistically, they share some commonalities that have important practice implications that are central to the social context of health disparities: social marginalization, low literacy, low English proficiency, discrimination, lack of health insurance or access to health care, and in many cases, linguistic isolation. Our partnerships aim to unpack and make explicit factors contributing to cancer disparities that emerge from solid partnerships built on trust, rapport, and ongoing dialogue and commitment. Furthermore, the development of such partnerships can then be viewed as one of the greatest assets for tackling health inequalities.

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