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Community capacity for cancer control collaboration: Weaving an islander network for cancer awareness, research and training for Pacific Islanders in Southern California

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Abstract

Background—Addressing cancer health disparities constitutes a national priority in this country, with funding for Pacific Islander efforts initiated seven years ago by the National Cancer Institute. In 2005, the *Weaving an Islander Network for Cancer Awareness, Research and Training* (WINCART) was launched in Southern California by a collaboration of community and university organizations to build upon past efforts to decrease cancer health disparities for Chamorros, Native Hawaiians, Marshallese, Samoans and Tongans.

Methods—To assess community organizational capacity to participate in collaborative cancer control for Pacific Islanders, a SWOT (Strengths, Weaknesses, Opportunities, and Threats) analysis was undertaken. Two staff members per community organization (CBO) performed the SWOT analyses, with grids analyzed for commonalities and differences between all organizations.

Results—Staff informants provided many examples of what they perceived as organizational strengths and weaknesses with regards to promoting cancer control for their respective Pacific Islander populations. CBO strengths included strong leadership and extensive community experience. Challenges included limited resources, lack of staff skills in some areas, and difficulty recruiting volunteers. In addition, many external opportunities and threats to cancer control promotion were identified.

Conclusion—Results from the SWOT analyses have been used to identify topics for community organizational trainings and supports within WINCART, with the goals of increasing their participation in the development and implementation of collaborative, community-university driven efforts to decrease cancer disparities for Pacific Islanders in Southern California.

Author's Key Words

cancer control; organizational capacity; Pacific Islanders; community capacity

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Introduction

The previous five papers in this Supplement presented research findings from the Pacific Islander Cancer Control Network, one of 18 Special Populations Networks sponsored by the National Cancer Institute (NCI) to address cancer-related health disparities. This report describes “*Weaving an Islander Network for Cancer Awareness, Research and Training* (WINCART), one of 25 NCI Community-Network Programs that are continuing these efforts. The paper begins with a discussion of the need for such programs followed by a description of WINCART and a summary of accomplishments during the first two years.

California is second only to Hawai'i in the number of Pacific Islanders (221,458) in the U.S., and existing studies highlight their unique cancer health disparities. Compared to African Americans, American Indians, Hispanic/Latinos, and Whites, Pacific Islanders in California possess the highest age adjusted cancer mortality rates for lung cancer (71.8 per 100,000), second highest for breast cancer (33.4 per 100,000) and third highest for prostate cancer (27.2 per 100,000, although this rate is unreliable due to the low number of cases) [1]. Cancer detection rates in aggregate are low: 19.2% of Pacific Islander women ages 40 and older in Southern California reported never having had a mammogram compared to 11.1% of non-Pacific Islanders and 18.9% of Pacific Islander women 18 and older were more likely to report never having had a Pap test in comparison to 7.6% of non-Pacific Islanders. The same is true for selected Pacific Islander ethnic groups: for Chamorros, only 37% had ever performed a breast self-exam (BSE) and 77% have ever received a mammogram [2]; for Tongans, only 40% had ever performed BSE, 26% had ever received clinical breast exam (CBE), and 25% had ever obtained a mammogram [3].

To address health disparities in ethnic/racial and other unique populations, researchers and advocates are increasingly turning to Community-Based Participatory Research (CBPR) as the mechanism to address both the medical factors as well as the underlying sociocultural and environmental causes [4]. CBPR brings together community members and university researchers in a collaborative process that stress at least six key principles: it is participatory, it is cooperative (involving equal contribution among members), it emphasizes co-learning, it involves systems development and community capacity building, it is empowering, and it balances research with action [5]. According to Wallerstein (2006), CBPR processes assume improved interventions due to community's unique knowledge of etiology and appropriate change strategies, as well as increased capacities and empowerment in communities leading to greater control over positive health outcomes. Such principles and assumptions underlie the multi-year cancer early detection efforts funded by the Centers for Disease Control and Prevention's REACH 2010 initiative, as well as the National Cancer Institute's Community Network Programs effort [6–8].

The strength and potential of CBPR, however, depends upon the capacities of communities to participate as equal partners in all aspects of research and program planning and implementation activities. The purpose of this paper is to describe the formation of a CBPR network for Pacific Islander cancer control in Southern California, and to share information on the community capacities to participate in education, research, and infrastructure development across the network.

Methods

In 2004, community-based organizations (all serving different Pacific Islander populations) and university researchers convened many planning meetings to develop a new network to address the many unique and enduring cancer health disparities for Pacific Islanders in Southern California. We named ourselves the “*Weaving an Islander Network for Cancer*

Awareness, Research and Training,” with the overarching goal to reduce cancer-related mortality and morbidity through the promotion of education, training and research among at least five Pacific Islander populations (Chamorros, Marshallese, Native Hawaiians, Samoans, and Tongans) in five counties of Southern California (Los Angeles, Orange, Riverside, San Bernardino, and San Diego). Of primary concern for the network are the improvement of, and access to, and utilization of, effective cancer prevention (e.g., nutrition, physical activity, and tobacco use) and control (e.g., early detection) interventions among these Pacific Islander groups. Founding organizational members included nine CBOs and researchers from five universities, with three specific structures developed for facilitating collaboration between community and university members. The first, the Community Advisory Board (CAB), is comprised of representatives from all nine CBOs with the role of guiding the development of the major educational, training and research developments. Fourteen researchers from five universities serve on the Scientific Advisory Board (SAB) with the focus on helping to provide technical assistance and training to the communities, and develop and review CBPR proposals. Lastly, the Steering Committee is comprised of one representative each from the CAB and SAB, along with six other staff and the NCI Program Officer who manage the operations of the overall network. Please refer to our recent publication for a more complete description of the historical development and current structure of WINCART, along with our first year accomplishments [9].

WINCART was initiated in May of 2005 with funding from the National Cancer Institute’s Center to Reduce Cancer Health Disparities as one of 25 Community-Network Programs nationwide. The first year of funding was devoted to infrastructure development of the network, and WINCART’s CBO partners participated in an assessment of their capacities for participating in network-wide efforts to promote cancer education, training and research. The SWOT strategic planning tool was used to assist CBOs in identifying their own unique situations and environments, and involve evaluating four main elements: Strengths, which are the organizational characteristics that can help achieve a desired outcome; Weaknesses, which are organizational characteristics that may be harmful to achieving the outcome; Opportunities, or the helpful conditions outside of the organization to achieving the outcome; and Threats, which are the harmful conditions outside of the organization to achieving the outcome. While this planning tool originated for for-profit organizations, it has been used successfully by non-profit groups to assist in decision-making towards health and other goals [10].

The aim of WINCART’s CBO SWOT analysis was to identify the internal and external factors that may be important to achieving the network’s goal of increased cancer education, training and research within each of the participating Pacific Islander ethnic communities. A meeting was established with each organization, including the WINCART program staff and other organizational leaders (such as the health supervisor, if applicable, and the Executive Director). Each organization was provided with a SWOT grid and a general set of questions regarding the organizations capacity in the four areas of assessment. Meetings were about two to three hours long and entailed discussions of the four assessment areas. WINCART program staff recorded comments and categorized responses in the four assessment areas as defined by the organizational staff and management representative. Eight of the nine CBOs completed a SWOT analysis. The ninth CBO is the overall community liaison and participated in data collection in the SWOT analysis.

After the data was collected for each SWOT analysis, the information was entered into a word processing file for each individual CBO. These files were shared back with the SWOT participants to ensure accuracy and completeness. Once finalized, they were then distributed back to each CBO for their use in community-specific planning. These files were also shared with each Steering Committee member in order to help develop network efforts to support CBO educational activities, identify topics for CAB trainings, and plan for future research

development. The remainder of this paper summarizes the SWOT analysis results across all eight CBOs, and shares activities undertaken in the second year to promote continued community capacity building.

Results

The SWOT analyses surfaced the many internal and external factors influencing the capacities of WINCART CBOs to address the cancer education, research and training needs of their Pacific Islander communities. Overwhelmingly, CBO staff shared with pride their perceived strengths in their respective communities for advancing WINCART's goals. First, all eight CBOs felt that they had strong leadership (such as board members, executive directors or managers, and/or staff) within their organizations that supported the WINCART vision, and who could carry out the planning and implementation of community-specific activities to address WINCART's goals. This leadership also possessed the trust of community members that they would work for the betterment of their Pacific Islander populations, although each organization differed in the subgroups (e.g., youth vs. elderly) with which they felt that they had built such trusting ties. All eight CBOs had established relatively long histories of service to their communities, which ranged from 4 to 33 years. In six of these groups, health education and referrals were priority services, while in two groups health was seen as an equal service to other social and cultural programming. Lastly, all organizations also reported strong connections to other organizations and social groups within their own communities, with four also citing strong ties to organizations outside of WINCART's region.

With regards to weaknesses, all eight CBOs identified the lack of resources as one of their foremost challenges. In most cases, such resources were financial: seven out of eight CBOs stated that they did not have enough funding to develop and implement programs to meet the needs of their communities. Those same seven groups also identified a wide range of challenges concerning people, including the perceived lack of staff skills in specific areas (e.g., using computers), the difficulty in recruiting appropriate staff to run programs (e.g., male staff for prostate cancer education), or the unavailability of volunteers (e.g., youth, parents, cancer survivors) to guide such programs. In three cases, weaknesses of the organization to promoting cancer control involved the challenges of addressing all of the cultural characteristics of their Pacific Islander populations. For instance, Pacific Islanders who speak a language other than English are not familiar with medical terminology, and in some cases such terms cannot be translated into their native language. A different example is the difficulty of preserving indigenous Pacific Islander heritage, and the creativity needed to infuse cultural identity issues into health and other programs. Lastly, three organizations talked about the challenges of cancer research, whether it be trying to keep up with the implications of current research for program development in their communities or participating in future research that requires special skills (such as data analysis).

External opportunities for CBOs to promote cancer control included many potential financial and other resources. For instance, CBO staff believed that funders were paying special attention to their unique needs, and were willing to explore the development of creative education, research or training activities (such as a health pipeline program to encourage Pacific Islander high school students to go to college to pursue health-related degrees). Six of the eight CBOs also discussed increasing opportunities to collaborate with interested researchers, such as those serving on WINCART's SAB, and to gain visibility by presenting at national conferences (such as the American Public Health Association). Three CBOs added that they were excited about the possibilities of working with more Pacific Islander students from the academic institutions of SAB members, as well as clinicians at hospitals who want to learn more about how to work with Pacific Islander communities (e.g., to address concerns regarding involvement in clinical trials). Despite these opportunities, however, CBOs shared several threats to cancer control

among Pacific Islanders, including continued federal cuts to health research and service budgets, the high cost of living for community members in Southern California, and the resulting difficulties in making health a priority over other competing concerns of their populations.

Discussion

While capacities for communities to participate in CBPR efforts to address cancer and other health disparities are increasing, we must pay attention to the unique capacities of individual community organizations to participate fully in such a paradigm. WINCART has embodied CBPR principles from its inception, and since receiving NCI funding in 2005 has concentrated on understanding and promoting capacity building within each of its CBO partners. The SWOT analyses by these partners provided clear indications to WINCART's steering committee as to needs for increasing staff skills, particularly through trainings on research development, organizational management, and program planning and evaluation. Since completion of these SWOT analyses, WINCART has held two network-wide events: the first of which was a report-back to all WINCART members on the first year successes and second year plans, and the second a retreat among community partners to foster closer bonds that can build upon their unique strengths to aide each other with advice, support, and even cross-training.

Despite the internal weaknesses and external threats to their work, community partners contributed to a successful second year for WINCART. The partners held over 223 events to educate 27,886 individuals, with topics ranging from tobacco cessation, breast, cervical, colon, prostate, lung, liver, skin, testicular, esophageal, naso-pharyngeal cancers, lymphoma, nutrition/diet, physical activity, diabetes, obesity and general health. All education included information to beneficial screening methods and early detection, often linking individuals to health services facilities. The partners also successfully leveraged their NCI funds to obtain an additional \$334,238 in grants for cancer control in their communities. With regards to research, a total of six grant proposals were submitted to NCI and other funders, involving topics ranging from cancer epidemiology, physical activity and nutrition assessment, to cancer survivorship (two of which were spearheaded by Pacific Islander junior researchers, and one by a Pacific Islander community partner). Over the course of the next three years, WINCART hopes to continue promoting community capacity building to address cancer education, research and training, with the long term goal of impacting the factors influencing cancer disparity among our many Pacific Islander populations.

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