INCREASING ORGANIZATIONAL CAPACITY FOR BREAST AND CERVICAL CANCER SCREENING OF AAPI WOMEN

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> Abstract: AAPI women have low breast and cervical cancer (BCC) screening rates compared to other ethnic groups. However, there is a lack of culturally tailored programs designed to promote screening practices within AAPI communities. The CARE Program sought to reduce BCC morbidity and mortality rates among AAPI women by building the capacity of community health centers to deliver effective and culturally/linguistically appropriate screening programs in six different AAPI communities. This paper will (1) provide an overview of CARE's theoretical approach, (2) highlight cultural tailoring strategies of BCC screening programs for the different ethnic groups, (3) present selected program results, and (4) discuss limitations and recommendations.

ccording to the National Report Card on Cancer by the American Cancer Society, the National Cancer Institute, and the Centers for Disease Control, there was a downward trend in cancer incidence and mortality between 1990 and 1995 for all cancers combined in all groups. But for Asian American and Pacific Islander (AAPI) women, cancer incidence remained level while death rates increased for all major cancers (Wingo, Ries, Rosenberg, Miller, & Edwards, 1998). As an aggregate group, AAPI women are the only racial group to have exhibited an overall increase in cancer mortality rates for all sites combined (except lung) between 1990 and 1999 (Edwards et al., 2002). Breast cancer is the number one site for cancer mortality for AAPI women, and certain AAPI subgroups have the highest rates of cervical cancer in the U.S.

However, AAPI women have the lowest rates of breast and cervical cancer screening (Pap test, mammography, and clinical breast examination) among any other U.S. racial and ethnic populations (Kagawa-Singer & Pourat, 2000). For example, in Hawaii, 22% of Filipino women have never had a professional breast exam compared to the state average of 10.8% and the national average of 11.2% (Hawaii Breast and Cervical Cancer Control Program, 1998). A survey of American Samoan women found that only 46% had a Pap smear within the past 3 years (Mishra, Luce, & Hubbel, 2001).

The low screening rates in the AAPI community are particularly alarming when one considers that Asian Americans who immigrated to the United States at least a decade ago have a breast cancer risk that is 80 percent higher than that of new immigrants (Ziegler et al., 1993). Although breast cancer rates are lower among aggregated Asian American women (13 deaths for every 100,000 women compared to 27 deaths for every 100,000 women of all ethnicities), it is important to remember that AAPIs are younger than most other ethnic groups. The majority of AAPI women have not reached the age (>40) when most breast cancers occur. Moreover, aggregation of AAPI groups results in lower incidence and mortality rates of breast and cervical cancer and masks those AAPI subgroups that have risks similar to white American women. In fact, a recent study which disaggregated data by ethnicity as well as by generation in the United States found that Japanese American women have the fastest rising breast cancer incidence rates of all women residing in Los Angeles County, suggesting that Japanese American breast cancer rates may have already surpassed rates for non-Hispanic white women (Deapen, Liu, Perkins, Bernstein, & Ross, 2002).

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Aggregated rates also hide the fact that some first generation immigrants may return to their homelands to either seek treatment or die, or that ethnic physicians may attribute the cause of death to something other than cancer to reduce the stigma of the family. In actuality, incidence and mortality rates are relatively high for some AAPI groups. For example:

- Breast cancer is the leading cause of death for Filipino American women (California Department of Health Services, 1996) and for AAPI women overall (American Cancer Society, 2001).
- Native Hawaiian women have the second highest breast cancer mortality rates in the country, largely due to the fact that a greater percentage of these cancers are diagnosed at later stages (Miller et al., 1996).
- Vietnamese women have the highest rate of cervical cancer of any ethnic group in this country, five times higher than the rate among white women (Miller et al., 1996).

The low rates of breast and cervical cancer screening among AAPI communities are indicative of cultural, linguistic, and socioeconomic barriers to health care. These barriers for AAPI women include lack of culturally appropriate services in the community, language-specific providers, cultural taboos, and lack of adequate medical insurance or financial resources. Despite the fact that AAPIs are the fastest growing minority in the U.S., most agencies lack the healthcare infrastructures capable of providing culturally appropriate services.

PROGRAM DESCRIPTION AND THEORETICAL RATIONALE

With the diversity that exists among AAPI populations, there is a need for nationally proven strategies which can identify and address varied, culturally specific health care needs. The CARE Program (a Community Approach to Responding Early) is the first nationwide model that provides culturally appropriate intervention strategies to promote breast and cervical cancer early detection and screening in a variety of Asian American and Pacific Islander populations.

The CARE Program was based on a four-year cooperative agreement between the Association of Asian and Pacific Community Health Organizations (AAPCHO) and the Centers for Disease Control and Prevention (CDC) from 1997-2001. Based in Oakland, California, AAPCHO is a national association advocating for the health needs of medically underserved Asians and Pacific Islanders. The overall goal of the CARE program was to reduce breast and cervical cancer morbidity and mortality rates among AAPI women by improving the capacity of community-based health centers (CHCs) that serve these women to deliver effective, culturally and linguistically appropriate breast and cervical cancer screening programs. Providing culturally-tailored intervention programs will increase the number of women who practice regular breast and cervical cancer screening through breast-self examinations, clinical breast examinations, mammograms, Pap tests, and pelvic examinations.

The CARE Program was piloted for 1.5 years at six community health centers across the three states of California, Massachusetts, and Hawaii. Each CHC focused on serving a specific AAPI community for the CARE Program:

- Asian Pacific Health Care Venture, Inc. (Los Angeles, CA) – Thai
- Family Health Center (Worcester, MA) Cambodian
- Kalihi-Palama Health Center (Honolulu, HI) Filipina
- Kokua Kalihi Valley Comprehensive Family Services (Honolulu, HI) Samoan
- South Cove Community Health Center (Quincy, MA) – Chinese
- Waianae Coast Comprehensive Health Center (Waianae, HI) – Native Hawaiian.

These six CHCs represented not only ethnic and geographical diversity, but also differed in their stages of organizational capacity and readiness to provide comprehensive breast and cervical cancer screening programs to their particular communities of focus.

Each participating CHC was selected for the CARE program because they already had a strong reputation for serving their respective communities and providing culturally competent care. They specialized in providing quality care to low-income, uninsured, or underinsured members of their communities. Each CHC, however, was at a different starting point and varied in their resources and experiences in providing breast and cervical cancer care. AAPCHO sought to partner with these CHCs to build on their strengths and to document the efforts and strategies required to improve their capacity to address breast and cervical cancer screening needs of their respective communities.

The CARE program was grounded on theoretical concepts and proven models that have been tested among AAPI communities or in breast and cervical cancer screening programs nationwide. The CARE model is based on the belief that breast and cervical cancer screening programs should move beyond focusing on the behavior of individual women alone to consider women in the contexts of their larger communities and the organizations that serve them. Practically speaking, this means using an ecological approach that targets change at multiple levels (e.g. individual, provider, organizational, community, policy) when developing programs and services (Richard, Potvin, Kishchuk, & Green, 1996). AAPCHO and its partners used an ecological approach to breast and cervical cancer control, with AAPCHO focusing at the organizational level. By building the capacity of community health centers already working in AAPI communities through infrastructure and program development, the centers would then be better able to plan, implement, and evaluate effective breast and cervical cancer screening services that incorporate the other contextual ecological factors (community, policy, etc.).

Using this ecological framework, an underlying premise of the CARE model was that individual women were not the only ones who varied in their readiness to participate in breast and cervical cancer screening programs. Organizations providing cancer screening programs also varied in their readiness to implement comprehensive services to women in the community. CARE's model of organizational change applied Prochaska and DiClemente's Transtheoretical Model (Prochaska, DiClemente, & Norcross, 1992) of behavior change to organizations and places them along the same continuum of 5 stages as follows:

- Precontemplation An organization that does not have breast or cervical cancer education and screening programs, and has not yet begun to think about developing any programs.
- Contemplation An organization that is considering implementing breast and cervical cancer education and screening programs, but has not committed or taken any steps yet.
- Preparation An organization that has made initial efforts to plan and prepare for programs and services, but has not yet instituted community-wide efforts.
- Action An organization that is conducting programs, offering services, and incorporating policy changes in order to assist women to seek breast and cervical cancer screening, including the process of overseeing and evaluating program efforts.
- Maintenance An organization that has a history of education, screening, and rescreening in their prioritized populations. Addressing program in-

novation, funding, and institutionalization for long-term survival ensures that the health promoting behavior continues on a regular basis.

AAPCHO defined elements that characterize each level of organizational stages of change by using ideas commonly found in articles on community development, organizational capacity, and health management (Goodman et al., 1998). Based on this literature and experience of CARE's advisory committee members, eight categories were identified as essential for an organization to build their capacity to deliver effective breast and cervical cancer screening programs. These eight components were:

- **Funding and resources**
- Organizational support
- □ Staffing
- Coalition, advisory committee, or partnership building
- Organizational ability to assess community needs
- Community education through outreach and inreach
- Provider networks, screening, and treatment capability along the cancer care continuum
- **D** Evaluation

Partnering CHCs were placed in stages of readiness for BCC screening in all eight capacity areas using a self-assessment checklist of organizational capacity developed for the program. This checklist included specific criteria for each of the eight components. For example, criteria under the "Evaluation" component probed whether or not the organization had identified evaluation objectives and methods, developed an evaluation plan, conducted evaluation activities, and were using evaluation results to inform their BCC screening programs and services. Some criteria were considered "primary" and used to stage an organization, while other criteria were considered "secondary" and used for program planning, but not staging purposes. Staging of each CHC for the eight components of organizational capacity was then averaged together to determine an overall stage of organizational capacity at the start of the program. These starting stages represented an "average" level for centers over all 8 components of organizational capacity, although centers could be at different stages for each component as see in Table 1.

Center	Readiness Stage
Asian Pacific Health Care Venture (APHCV)	Contemplation
Family Health Center (FHC)	Preparation
Kalihi Palama Health Center (KPHC)	Contemplation
Kokua Kalihi Valley Comprehensive Health Services (KKV)	Contemplation
South Cove Community Health Center (SCCHC)	Contemplation
Waianae Coast Comprehensive Health Center (WCCHC)	Preparation

Table 1. Stages of Readiness for Community-Based Health Centers.

The goals and activities that partnering CHCs worked on for the CARE program were based on specific workplans in each of the eight components of organizational capacity. For example, each CHC developed activities that would help them increase funding and resources for breast and cervical cancer screening. How each CHC decided to do so, however, was based on their current capacity and stage of readiness in the area. For example, organizations with little resources to conduct screening might elect to work on investigating funding possibilities, establishing relationships with potential funders, and drafting a development plan. Organizations that already have funding for screening, however, might elect to work on maintaining that funding while seeking additional resources for other cancer support services.

Using CARE's framework of assessing and developing organizational capacity for BCC screening programs, partnering CHCs developed and carried out workplans tailored to improve their capacity to screen AAPI women in ways that matched their own strengths and areas of need. Just as each health center varied in its level of capacity, however, each AAPI community being served by them presented with different demographics, cultures, histories, environments, resources, and needs. No one approach to reaching AAPI women would work with such diversity; different cultural tailoring strategies that addressed the specific ecological resources and barriers experienced by each community were needed.

Each CHC worked in conjunction with their communities to develop breast and cervical cancer education programs that are similar in function, but culturally tailored in form. The CARE Program used a framework called "Form and Function" developed by Marjorie Kagawa-Singer, Ph.D., to better understand how the six partnering CHCs culturally tailored their breast and cervical cancer screening programs. This framework holds that although cancer screening programs for diverse groups of women may attempt to implement activities that accomplish the same "function" (e.g. educate women about cancer or reduce their barriers to getting screened), the specific "forms" or ways in which these functions are best achieved will be unique for different communities. For example, in regards to education, some women may prefer to be educated one-on-one by medical providers in a clinical setting, while others prefer informal talking groups that occur in the community. Still others may best relate to learning about the issue through the media.

Evaluation of the CARE Program sought to determine the program's proximal effects on capacity building and stages of change for community health centers. Distal outcomes included: (1) sustainable and continued progress for each CHC along the stages of organizational capacity; (2) increased and sustained screening for breast and cervical cancer among AAPI women in the target populations at the six CHCs (or linkage to others who would provide such screening); (3) identification of breast and cervical cancer outreach and inreach educational programs that are culturally and linguistically appropriate; and (4) clarification of the elements needed to connect the services required in the continuum of care for diagnosis and treatment of breast and cervical cancer. Data collection methods included: (1) community needs assessment surveys to determine women's current screening knowledge and practices, (2) qualitative reporting on workplan activities and cultural tailoring strategies through Monthly Log Reports and Quarterly Reports, (3) tracking of BCC screening through Monthly Screening Logs, (4) self-assessment of organizational capacity through use of an Organizational Stages of Change Checklist, and (5) site visits to assess organizational capacity and community context first hand.

SELECTED PROGRAM RESULTS

ORGANIZATIONAL CAPACITY BUILDING

CARE's evaluation results found that all six health centers successfully improved their organizational capacity to provide breast and cervical cancer programs and services to their communities of focus during the 1.5 year pilot implementation period. Five of the six sites were able to move at least one organizational stage of change beyond their baseline as assessed by one overall score on CARE's evaluation checklist. In fact, five sites were able to move two stages forward from their baseline (APHCV from Contemplation to Action; FHC from Preparation to Maintenance; KKV from Contemplation to Action; KPHC from Contemplation to Action; SCCHC from Contemplation to Action). Although WCCHC's assessed stage of overall organizational capacity remained within the same stage throughout the pilot period, the health center advanced a stage along several of the individual components, including staffing, community outreach, provider networks and screening, and evaluation. These results suggest that pilot sites were able to build their infrastructure and programs for breast and cervical cancer screening during the pilot period. Due to the short time period of our pilot period, however, the program was not able to evaluate the relationship between increased organizational capacity and screening rates.

CULTURAL TAILORING APPROACHES TO EDUCATION AND OUTREACH ACTIVI-TIES

As part of the CARE Program, all six partnering CHCs conducted community needs assessments and provided education for AAPI women in their communities. Using Kagawa-Singer's Form and Function framework, analysis was done on effective strategies used by sites to culturally tailor their BCC education programs to the communities of focus. Following are some examples of common Functions of education programs and the specific Forms they took within the different communities. Exactly how education was carried out was informed by the health centers' past experience working in the community, needs assessments of community women, and close partnerships with community members.

Presentation style: All six sites had the following presentation styles in common: showing and expressing respect, especially with older women, using a conversation style rather than a formal one, and exuding a caring attitude when talking to the women. All sites expressed the importance of relationship building with the women, reporting that it is the only way to gain the women's trust and have them open up to discuss sensitive and private health issues, including breast and cervical cancer. How trust was established, however, varied from community to community. In Native Hawaiian communities in Waianae, for example, trust was established by using a Native Hawaiian health educator who was a member of the community herself. She in turn established immediate rapport with women by using a style that reflected the culture, values, and history of Native Hawaiian communities. She spent time "talking story," talking about who she knew and who she was related to in the community. She also spoke in "pidgin English" (a combination of Hawaiian, English, and other languages that reflects Hawaiian history) and addressed older patients as "Auntie" instead of "Mrs.," which was appropriate given her own cultural background. In the Cambodian community at Worcester, trust was established by visiting and talking with women a couple of times before breast and cervical cancer was discussed. Education to older women in particular needed to be taken at a relaxed pace and not rushed. The health educator also adhered to cultural traditions by greeting women by placing her palms together in front of her body while giving her verbal greeting, and by not sitting with her legs crossed, which can be viewed as disrespectful.

Delivery Method: All sites except the health center focusing on Filipino women (KPHC) conducted education individually with women. In addition, the majority of CHCs, except the one working with Chinese woman (SCCHC), conducted educational small groups as well (less than 15 people). For the Chinese women in SCCHC's community of Quincy, needs assessment via key informant interviews revealed that it was not culturally appropriate to talk about cancer in a public setting; they found that talking to women one-on-one was the most well received approach. Three out of six sites educated women through ethnic media as well, though the forms differed. APHCV in Los Angeles had access to the local Thai newspapers and their organizational newsletter. In Honolulu, KKV had ongoing access to a monthly Samoan radio show, and SCCHC had one-time access to a local Chinese radio station and two articles published in a local bilingual newspaper.

Location: Community health centers were used by all sites for needs assessment survey administration, health education and outreach activities. Community locations including English-as-a-second-language classes, citizenship classes, health fairs, businesses, and religious-based centers such as churches and temples were also used by most sites to conduct outreach activities. Homes were another venue for KKV, WCCHC, and FHC to the conduct outreach since the setting was more intimate and comfortable. For SCCHC, homes were not culturally appropriate because the more traditional Chinese women in their community believed that it is bad luck to talk of deadly, life-threatening illnesses such as cancer in their home and with those outside the family.

<u>Message Source</u>: Most sites reported that the women felt more comfortable when they received the health message from either a provider or a health educator whom they knew and trusted. When language capacity existed, providers were encouraged to give

Cancer Society or the Breast and Cervical Cancer Control Program for education and outreach activities, while FHC and WCCHC used their own materials, which they had developed prior to the CARE program. After realizing the limited number of breast and cervical cancer materials available in Thai, APHCV decided to develop their own during the course of the project. It was important that culturally appropriate photographs and graphics were used on educational brochures and outreach materials. Anatomical models seemed to work very effectively for all sites. Since this was the first time many women had seen such models, particularly of the female reproductive tract, women found the models to be helpful. Some sites used flipcharts or videotapes when conducting outreach. FHC in particular found videotapes to be useful as an educational tool since many women in their community did not read English or Khmer well. KKV, KPHV and WCCHC used similar discussion techniques called "talk story" (in Native Hawaiian communities) or Kwento/Kwento (in Tagalog) to conduct their group education session.

<u>Traditional Medicine</u>: Most sites mentioned that women often used traditional medicines along with Western medicine for cancer treatment. Whether or not they discussed this with their providers often depended on the level of trust and openness that had developed between them and their providers.

<u>Structural/Logistical Needs</u>: Most sites extended their work hours to either after-hours or on the weekends to accommodate women's schedules. All sites had bicultural, bilingual staff on-site and, if needed, they could also arrange to have outside interpreters come on-site. All sites provided assistance to women for obtaining financial support to be screened.

BREAST AND CERVICAL CANCER SCREENING

While data collection challenges made it difficult to collect screening data (see challenges discussed below), a preliminary assessment was conducted of the impact of the educational programs on screening utilization by looking at the cumulative numbers of total screening exams and the numbers of cancers that were diagnosed. Over the course of one year, a total of 3413 screening exams were done through the CARE program with women ages 40 and older. Of this total number, 977 were clinical breast exams (CBEs), 1350 were mammograms, and 1086 were Pap tests. In addition, a total of 2345 screening exams were done through the CARE program with women age 18-39. Of this total number, 850 were clinical breast exams (CBEs) and 1495 were Pap tests. A total of 19 breast cancers and 8 cervical cancers were diagnosed. Given

the nature of CARE's data collection challenges, these numbers were likely an underestimate of the number of screenings actually conducted.

CHALLENGES AND LIMITATIONS

In general, CARE partners were successful in establishing close community partnerships, developing organizational capacity for breast and cervical cancer screening programs, developing culturally tailored education programs for AAPI women, and getting a significant number of AAPI women screened. However, the program was not without challenges or limitations.

One major barrier that most sites encountered involved data system limitations in tracking breast and cervical cancer screening and referrals. The challenges experienced varied from site to site. For example, some sites were not able to extract ethnicity data on the women being screened from computerized databases, leaving them to collect the information by hand. APHCV detailed this problem in their quarterly report:

"We knew that there were limitations to our system, however, we did not really look closely at it until this project. Part of the cultural competency of an organization is to know who your patient population is, so that services can be tailored appropriate to that population. We know anecdotally from our clinicians and support staff that the majority of our clientele is Thai: however, we cannot substantiate that with numbers. We can only extract language data, not ethnicity, so that our "Thai" data excludes all English speaking Thai clients. The awareness of this issue and the pressure to address it immediately will result in more culturally competent care for our clients through better programs for Thai patients. The data will also help us in seeking funding for this population."

Also, some centers could track certain screening exams more easily than others. For example, in some cases CBEs were only recorded in patients' charts and not coded in computerized databases as mammograms and Pap tests were. Therefore, quick summary reports totaling CBEs could not be generated. Furthermore, each health center had a different referral system for screening exams that could not be done on-site, and some centers had difficulty tracking the women once they were referred for screening off-site.

AAPCHO and the evaluation team provided technical assistance to sites regarding these issues to some extent, but all CARE's partners identified a need for computerized data systems that can be used by their organizations to track screening. Ideally, such systems should be simple to use, inexpensive and compatible with other systems that organizations are already using. Barriers and challenges in data collection were incorporated into sites' workplans so that all sites would have time to focus on developing their screening delivery and tracking services. For example, when APHCV experienced tracking challenges, they decided to make it their goal to improve the health center's Management Information System. APHCV's management committed the organization to a long-term solution that could be easily integrated into the health center's current system and would benefit other programs as well. After researching options, the health center purchased an optional Community Package module for their existing Medical Manager system that allowed them to collect data in the format they needed.

A major limitation of the CARE Program was that it was not possible to sufficiently evaluate the relationship between increased organizational capacity and screening rates during the CARE Program due to the short time period of 1.5 years for program implementation. A year's time is not enough to sufficiently evaluate changes in screening rates.

DISCUSSION

To maximize effectiveness and support sustainability, BCC programs and services need to be looked upon within the context of organizational capacity along the entire continuum of cancer care. Organizational capacity in the areas of funding and resources, organizational support, staffing, partnerships, community needs assessment, community education, provider networks and screening, and evaluation are all needed to bolster efforts to promote screening and the early detection of cancer. Organizations will be at different stages of capacity in terms of these eight components; efforts to build upon strengths and improve capacity in less developed areas will help ensure the effectiveness and sustainability of programmatic and clinical efforts. Often breast and cervical cancer screening programs focus on only a small subset of the organizational capacity components discussed above, usually those that have more tangible outcomes, such as conducting education. Building capacity in areas with less visible results, e.g. garnering organizational support or forming community partnerships, can easily be overlooked or unappreciated, despite their important role at supporting community screening efforts.

One key finding that came out of the CARE program is that for the ethnic communities focused on, trust between women and their providers of care was a critical factor to screening success. The supportive "function" of trust was the same across all 6 sites. However, the specific "form" of how to build trust varied from community to community. Organizations that have not yet established trust and partnerships with their community will need to allow time to build relationships with community members and to conduct thorough needs assessments. This time is especially important to factor into program timelines. Organizations that haven't established trust yet would also benefit from forming inclusive, participatory partnerships with community-based organizations that have already earned the respect of women in the community. However, these factors are often not considered or developed in many BCC approaches. Future efforts should acknowledge this finding and provide organizations the time, funding, and resources needed to develop trust and institute policies around it.

Providing effective, culturally competent breast and cervical cancer programs and services is important to increasing screening and rescreening rates of AAPI women. If adequate time and resources are put into tailoring programs to meet the logistical, linguistic, and cultural needs that are present in communities with women who are underserved, the women can be reached. However, there is no one model that will adequately address the needs of heterogeneous AAPI communities. Programs and services need to be tailored to match both the communities served as well as the organizations serving them. CARE's adapted model of organizational stages of change provides a framework for assessing and building organizational capacity in the area of breast and cervical cancer screening while Kagawa-Singer's Form and Function Framework provides structure to culturally tailoring a BCC program for diverse communities.

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HEALTH EDUCATION RESPONSIBILITY AND COMPETENCY ADDRESSED

Responsibility II - Planning Effective Health Education Programs

Competency D - Design educational programs consistent with specified program objectives.

Subcompetency 3 -Select strategies best suited to implementation of educational objectives in a given setting.