

The Care Program

A COMMUNITY APPROACH TO RESPONDING EARLY
TO BREAST AND CERVICAL CANCER



A CASE STUDY MONOGRAPH
of Breast and Cervical Cancer
Education and Screening Programs
in Six Asian American and Pacific
Islander Communities



AAPCHO

ASSOCIATION OF ASIAN PACIFIC COMMUNITY HEALTH ORGANIZATIONS



The Care Monograph is a compilation of case studies highlighting the work of six community health centers across the country to implement breast and cervical cancer education and screening programs for Asian American and Pacific Islander (AAPI) women. The goal of this monograph is to highlight both strategies used by these community-based organizations to educate and screen women about breast and cervical cancer, as well as challenges encountered by each organization. The models in this document are not meant to be viewed as a set of prescribed "solutions." Rather, we hope that readers working with similar communities will gain ideas which they may be able to tailor and apply to their own work.

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Introduction



Breast and cervical cancer in Asian American and Pacific Islander women

National statistics show that breast cancer is the most common cancer among women in the United States, and the number one cause of death for Asian American and Pacific Islander (AAPI) women. An estimated 192,200 new cases of invasive breast cancer and 51,600 cases of invasive cervical cancer are diagnosed each year.ⁱ

Aggregated rates for breast and cervical cancer, however, mask the differences among racial and ethnic groups, especially among AAPI women. Research shows that breast and cervical cancer has had a startling impact in many AAPI communities. For example:

- Breast cancer is the most common cancer among Chinese (55.0/100,000), Filipino (73.1/100,000), Native Hawaiian (105.6/100,000), Japanese (82.3/100,000), and Korean (28.5/100,000) women.ⁱⁱ
- Native Hawaiian women have the second highest breast cancer mortality rates in the country.ⁱⁱⁱ
- 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.^{iv}

Unfortunately, AAPI women also have the lowest breast and cervical cancer screening rates in the United States. For example:

- Only 58.4 percent of Asian and Pacific Islander adult women in the U.S. have had a pap test within the past 2 years, the lowest rate of screening among all racial/ethnic groups.^v

ⁱ American Cancer Society. *Breast Cancer Facts and Figures*, 2001-2002. 2001.

ⁱⁱ National Cancer Institute, SEER Program. *Racial/Ethnic Patterns of Cancer in the United States*. 1992.

ⁱⁱⁱ Ibid. ^{iv} Ibid.

^v CDC Behavioral Risk Factor Surveillance System, 1994. *CA – A Cancer Journal for Clinicians*. 1996;48:1.



- A survey of American Samoan women revealed that only 46% had a Pap smear within the past 3 years.^{vi}
- Studies done in California found that 48% of Vietnamese and 68% of Chinese women over 40 have never had a mammogram.^{vii}

Low screening rates in AAPI communities are particularly alarming given that Asian Americans who immigrated to the US at least a decade ago have a breast cancer risk that is 80% higher than that of new immigrants.^{viii} Also, between 1980 and 1993, the number of cancer deaths for AAPI women increased by 240%, which is the highest increase out of all ethnic and racial groups in the United States.^{ix}



The CARE Program

The Community Approach to Responding Early (CARE) Program was launched in 1997 by the Association of Asian Pacific Community Health Organizations (AAPCHO) with funding by the Centers for Disease Control and Prevention. The long term goal of the program was to lower breast and cervical cancer (BCC) mortality rates among Asian American and Pacific Islander (AAPI) women by building the capacity of community health centers (CHCs) that serve them.

Between 1999 and 2001, six community health centers across the country partnered with AAPCHO to carry out the CARE Program in the following AAPI communities:

- Asian Pacific Health Care Venture, Inc. (Los Angeles, CA) – Thai
- Family Health Center (Worcester, MA) – Cambodian
- Kalihi-Palama Health Center (Honolulu, HI) – Filipino
- 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

Each of these centers has a long history of providing culturally and linguistically appropriate care to lower income and uninsured members of their communities.

^{vi} Mishra SI, Luce-Aoelua PH, Hubbel FA. Predictors of papanicolaou smear use among American Samoan women. *Journal of General Internal Medicine*. 2001;16:320-324.

^{vii} Jenkins C and Kagawa-Singer M. Cancer. In: Zane N, Takeuchi D, and Young K, eds. *Confronting Critical Health Issues of Asian and Pacific Islander Americans*. Thousand Oaks, CA: Sage Publications; 1994:105-147.

^{viii} Ziegler RG, Hoover RN, Pike MC, et al. Migration patterns and breast cancer risk in Asian-American women. *Journal of the National Cancer Institute*. 1993;85:1819-1827.

^{ix} Wingo PA, Ries LA, Rosenberg HM, Miller DS, and Edwards, BK. Cancer incidence and mortality, 1973-1995: A report card for the US. *Cancer*. 1998;82:1197-1207.





CARE Partners at the orientation meeting in San Francisco, CA, May 2000.

For the CARE program, each CARE partner worked to strengthen their health center's breast and cervical cancer resources and programs in eight different capacity areas. These areas included: (1) community needs assessments, (2) education within the center and larger community, (3) coalitions, advisory committees, and partnerships, (4) provider networks and screening, (5) funding, (6) staffing, (7) organizational support, and (8) evaluation.

Each center carried out different activities tailored to their own organization and community in each of these eight areas. In many cases, all six sites conducted activities that shared a similar purpose (e.g. education of women, better tracking of screening, etc.), although the specific strategies each used to achieve their goals differed. For example, all health centers educated women on breast and cervical cancer, although some educated women within groups while others educated them individually. Some held their education sessions in churches whereas others spoke to women in their homes. Likewise, each center formed partnerships, although some focused on partnerships with businesses in the community, others with the media, and yet others with established coalitions.

In addition to unique capacity building activities, all six health centers surveyed at least 75 women ages 40 or older in their communities on their breast and cervical cancer screening knowledge, attitudes, and practices. These surveys were conducted in the appropriate language (English, Khmer, Ilocano, Tagalog, Cantonese, Samoan, or Thai) with a convenient sample of women. All six health centers also kept track of the number of women being screened at their health centers throughout the CARE Program for evaluation purposes and addressed the capacity of their data systems to do so in an easy yet accurate manner.



Cultural Tailoring

The AAPI community is very diverse, consisting of over fifty ethnicities, one hundred languages and dialects, and a collection of histories and experiences both inside and outside of the United States. AAPIs are also a rapidly growing population in the United States. Between 1990 and 2000 the Asian population in the US increased by 48%, and the Native Hawaiian and Pacific Islander populations increased by 9%.^x

Since AAPIs are such a diverse population, those involved with the CARE Program strongly felt that one model of breast and cervical cancer promotion would not work across all ethnic groups. Respecting the cultural diversity among the six AAPI groups and community health centers was a key component to effectively promoting breast and cervical health.

With their expertise and experience, the CARE staff at each site used culturally and linguistically appropriate methods to encourage women in each of their communities to get screened for breast and cervical cancer.

Cultural tailoring included a range of strategies from offering interpretation services to much more subtle methods of using staff, messages, approaches, tones, mannerisms, and places that are considered appropriate in each community.

For example, staff at Waianae Coast Comprehensive Health Center working with Native Hawaiian women helped put women at ease by spending 5-10 minutes introducing themselves and "talking story" about who they are related to and who they know in the community. Establishing a personal connection as a community member was a successful way of establishing trust in the Native Hawaiian community. Trust was also an important aspect to effective education in the Chinese community as well. Women told staff at South Cove Community Health Center that they felt more comfortable having a health professional (in their case, a nurse) speak with them individually. The nurse helped build trust by expressing concern for the woman and her family's health.

^x United States Census Bureau. Available at <http://www.census.gov>. Accessed 2001.



Although they had some unique differences, women of different AAPI ethnic groups all shared many common barriers. These included language barriers, lack of knowledge about breast and cervical cancer; unfamiliarity with Western medicine, cultural modesty or taboos regarding talking about certain parts of the body; lack of insurance or under-insured, lack of time due to child care responsibilities for children or grandchildren, and lack of transportation. When possible, health center staff addressed these barriers in culturally appropriate ways. This included providing translators (for both on- and off-site appointments) and understanding the use of traditional Asian and Pacific Islander medicine and healing practices. The success of the centers' programs can be largely attributed to their cultural tailoring efforts.



Conclusion

The case studies that follow were each written by partnering staff at the health centers. They highlight strategies that were used and recommendations for those working with similar communities and programs. Although all of the health centers' breast and cervical cancer programs were designed to educate women about cancer issues and have them come in for screening and follow-up services, no one program worked for all communities. Breast and cervical cancer programs must be culturally tailored, linguistically appropriate, and match the capacity of the organization and community itself to be most effective in impacting the health and well being of our communities.





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unity Case Studies

The case studies that follow highlight strategies used by the different health centers and share their recommendations. Each case study was written by partnering staff at the health centers. Although all the health centers' breast and cervical cancer programs were designed to educate women about the issue and have them come in for screening and follow-up services, no one program worked for all communities. Breast and cervical cancer programs must be culturally tailored, linguistically appropriate, and match the capacity of the organization and community itself to be most effective.



Asian Pacific Health Care Venture, Inc.

By Yunkyung Kim

Background on APHCV

Founded in 1986, Asian Pacific Health Care Venture, Inc. (APHCV) is a non-profit community health center whose mission is to plan, provide, promote, and coordinate accessible, affordable, culturally competent, and effective health care services, and to provide programs of economic development for the benefit of low-income Asian & Pacific Islander (API) communities. In 1997, APHCV began providing direct clinical and health education services in the Hollywood, Silver Lake, Westlake, and Echo Park areas of Los Angeles where poverty and uninsured rates of APIs are high. APHCV provides primary health care services, including prenatal, pediatric, adolescent, adult, and geriatric care, family planning, and HIV



Conducting outreach at a community health fair.

testing and counseling, and women's health services. APHCV provides linguistically and culturally appropriate clinic care and community outreach through its bilingual and bicultural staff in five API languages – Thai, Vietnamese, Khmer (Cambodian), Tagalog (Filipino), and Japanese, in addition to Spanish.

APHCV has long been committed to promoting preventive healthcare access, particularly breast and cervical cancer screening among API women. In the past, women received their clinical breast exams at APHCV and were then referred off-site for mammography and diagnostic services. Two (2) location options for mammography were: 1) Queen of Angels hospital, located within a few blocks of APHCV; 2) Thai Health And Information Services (THAIS), Inc., which has a mobile mammography unit one Saturday per month at its Koreatown site. APHCV now offers mammograms through a mobile mammography unit (details below). Women who require diagnostic services have several locations to choose from in the LA area, depending on their insurance status and qualifications.



BCC and Thai women

For the CARE Program, APHCV proposed to work with Thai women. Los Angeles has a large Thai population, and APHCV is conveniently located next to Thai Town, where most Thai businesses are located. Very little research has been conducted on the general health status of Thai-American women living in the United States; thus, there is little to no data regarding their breast and cervical cancer risk and screening behaviors. However, studies conducted in Thailand show that breast cancer is the second leading cause of cancer deaths among women.¹ Moreover, there is a high prevalence of late stage diagnoses of breast cancer, indicating a lack of regular screening behavior. Cervical cancer accounts for about 13.9% of all cancer incidences in Thailand. One of the barriers to getting screened is that Thai women are often not aware that they are at increased risk of cervical cancer if their husbands or partners are not monogamous. A study conducted in Thailand indicates that Thai women are largely unsure about the cause of cervical cancer, and that most women wait until symptoms develop before seeking treatment, which is often too late.



Barriers to Screening

There are several barriers preventing Thai women from receiving breast and cervical cancer (BCC) services, a major one being language and cultural competence since there

¹ Thongsuksai P, Chongsuvivatwong V, Sriplung H. Delay in breast cancer care: A study in Thai women. *Medical Care*. 2000;38(1):108-114.



A woman being screened on-site with a mobile mammography unit.

are few medical providers who speak Thai and are familiar with the culture. Additional barriers include lack of medical insurance and lack of awareness of the importance of preventive screenings. This is compounded by the fact that outreach can be difficult because the Thai community is geographically dispersed throughout Los Angeles County.

APHCV conducted an in-language focus group with women to discuss

their thoughts on BCC screening. The cultural barriers identified by the participants included: equating cancer with death, fears of screening outweighing benefits to screening, lack of time, gender of provider, and fear of pain. Although nearly all of the focus group participants had at least one pap smear or mammogram, only one participant was getting annual exams.



Project Summary / Accomplishments


The CARE Program allowed APHCV to develop a multifaceted BCC service program as well as develop a plan for future BCC services. Some major activities and accomplishments are highlighted below.

Case management: Through the CARE Program, APHCV began building centralized case management specific to BCC services. Case Manager Nongyao Varanond coordinated follow up of all abnormal pap results with various providers and coordinated off-site referrals for screening and diagnostic mammography. For any off-site referrals, APHCV ensured that a Thai translator accompanied each woman to her appointment. APHCV collected data about its services and the services of THAIs, Inc. & Queen of Angels through both of these activities (case management and off-site referrals). We felt that referring women to off-site facilities with a translator addressed many barriers, however

we were surprised to discover that it wasn't enough. Referrals to these sites provided a new set of challenges. THAI Inc. proved difficult because of the limited number of available appointments. Although Queen of Angels was in close proximity to APHCV, referrals to this facility were time consuming. Not only did the women find the hospital difficult to navigate, but appointments (even with an APHCV translator), often took an average of three (3) hours. This process highly discouraged women from rescreenings and follow-ups. On average, 50% of the women referred to THAIS, Inc. or Queen of Angels did not make their appointments.

On-site mammography: In response to the overall dissatisfaction women had with off-site mammograms, in June 2001 APHCV began collaborating with the Women's Health Clinic for use of its on-site mobile mammography unit. The screening sessions have increased from one (1) 4-hour session per month, to three (3) sessions per month with an average of 30 women being seen per session. Not only is the new location more convenient for the women, it also saves time for our translators and case manager since they are no longer required to travel with the women to off-site referrals.

Community Outreach: For the community outreach, Ms. Suthada Toppel, Thai Outreach Worker, visited locations where Thai women were likely to be found, such as Thai grocery stores, beauty and nail parlors, restaurants, and temples.



Since the Thai community in LA is dispersed, it is more effective to do outreach around business areas such as Thai Town rather than individual homes.

Suthada talked to women about BCC in these settings, which were non-threatening and informal. Developing relationships with the Thai business owners proved extremely important to Suthada's efforts to reach Thai women and disseminate health-related information. For example, Suthada was allowed to stand by the cashier and talk to women as they bought their groceries. The store owners also referred many clients to speak to her as well. Thai beauty and nail salon owners often let Suthada know when they expected a large number of clients and allowed her to sit in the salon and talk to the women as they waited or had their hair and nails done. She used Thai brochures, flipcharts, and a breast model to conduct her outreach. Stickers with Thai translations

were placed over all presentation materials that were developed in English. After the education, the women were encouraged to make appointments at APHCV. These outreach encounters were very personal and therefore much more effective than the education booths that have been used to conduct health-related outreach at large community events in the past. In general, the women have been interested in the education that they receive and thankful that Suthada was there to provide it. When approaching the women, it was important to be respectful of her culture and tradition.




For example, during Thai holidays it is not good to discuss issues that are considered "bad", like cancer. Instead it is better to talk about what an individual can do to maintain good health.

Women also should be treated differently according to age. When talking with older women, it is very important to show them respect and first develop a trusting relationship before talking about BCC. This includes a meeting with them to talk about other non-health related issues, such as about their lives, work, etc. For the Thai community, professional status of health workers such as doctors or nurses does not make a difference. They always prefer to get a second opinion on education provided and diagnoses made on various health issues. For newer immigrants, general health issues are not a priority, until they become more settled and established here.

Media outreach: Media outreach to the Thai community was difficult to get going at first, but was definitely worth the work, since in the end it led to greater awareness about APHCV's BCC program and other services. There are numerous Thai media outlets in Los Angeles including magazines, newspapers, and radio. APHCV started its media campaign with an "open house" to introduce the Thai media and the Thai Consul General to APHCV's services, including BCC services. Although the event resulted in general media coverage on APHCV, it did not result in any stories on the CARE Program or our BCC services. Though APHCV developed a press release on its BCC program for this event, the media stated that the press release would have been more effective if it had been translated into Thai.

Another strategy APHCV used to promote CARE through the media was to buy ad space in Thai newspapers that were open to running BCC articles. The Thai media has slowly shown more interest in writing health articles and now calls the clinic for interviews and photo opportunities whenever APHCV has a BCC activity.



We feel that our progress with the media is due primarily to the relationships we've built with various reporters over time.

Management Information System: APHCV also discovered that our Management Information System (MIS) was inadequate in helping us gather necessary data for program and service evaluation. Throughout the project we struggled to obtain relatively simple data, such as the number of Thai women over 40 years old who were seen in the clinic. The only way to obtain this data was to manually review all 1200 encounter forms each month. Because of these problems, APHCV invested in a MIS upgrade that allows us to retrieve more pertinent information.



The CARE Program really highlighted many MIS problems that were previously overlooked.

Community Linkages / Partnerships: APHCV has continued to build the community linkages and partnerships crucial to any health program. The health center is still active in Partnered for Progress, the local Breast Cancer Early Detection Program (BCEDP) coalition, especially in the Asian and Pacific Islander Taskforce. APHCV also partnered with the Asian American Network for Cancer Awareness Research and Training (AANCART), and partnered with UCLA to co-sponsor the first and second annual symposia on cancer among APIs. Lastly, APHCV has partnered with the Los Angeles Department of Health Services (DHS) Office of Women's Health in their Cervical Cancer Initiative.



Next Steps

The CARE Program has provided APHCV with critical capacity to continue its BCC services, and has taught us valuable lessons that we can apply to other programs. APHCV is committed to continuing and improving its BCC services to all of our clients. In addition, we are taking the following steps to continue the work started in the CARE Program:

Improved data collection and use to effectively monitor BCC services and conduct quality improvement. One of the key lessons learned through the CARE Program was that APHCV lacks reliable data. The lack of good data not only hindered our ability to monitor and evaluate our progress, but it also directly affected the timeliness and effectiveness of our follow up and case management. As previously mentioned, APHCV's recent MIS upgrade will play a key role in our continued Quality Improvement to ensure that all women, including Thai women, receive the appropriate BCC screening. In addition, APHCV recently conducted a MIS evaluation through an outside evaluator; the findings of which will help us develop an APHCV MIS Strategic Plan that addresses many of our identified demographic data needs.

Improved case management to reduce the number of women who fall between the cracks at both the screening and diagnostic stages. APHCV is exploring ways to tighten our case management in a way that is operationally feasible. The Health Education Department Manager, the Adult & Senior Services Manager, the Women's Health Nurse Practitioner, as well as CARE Program staff, will be involved in this effort. We would most like to hire a Thai-speaking Case Manager (as 49% of our clients are Thai speaking) dedicated solely to providing BCC management. This Case Manager would schedule all the BCC services, process all lab results with the appropriate providers, schedule and follow up with rescreenings and diagnostic services, and case manage all diagnosed patients. The Case Manager would work with the APHCV Support Service Liaisons to provide services for non-Thai and English speaking patients. APHCV has submitted several proposals to fund a Case Manager, which are currently pending.

APHCV is committed to continuing BCC education in the community. Although this activity is no longer funded, we have integrated the BCC information/outreach into our existing outreach and education efforts. APHCV also submitted several proposals to conduct small in-depth group discussions to help reduce the fear many women have of BCC screening procedures and empower them to openly discuss their health concerns.





Recommendations

- **Conduct outreach and education at Thai businesses or restaurants** — Since the Thai community is geographically dispersed throughout Los Angeles County, it is important to conduct outreach in locations frequented by Thai women during the day — i.e., Thai markets, restaurants, and salons. Finding women here is more effective than finding out where they live and going to their homes.
- **Educate women about the importance of rescreenings** — Once women are screened, it is important to follow up with them to make sure that they are getting rescreened annually — a lot of times they aren't. Education should include encouraging the women to make it a habit to return to their providers for a rescreening each year.
- **Media outreach** — Find out what the most popular ethnic media outlets are, and update them on your health center's activities and programs, regardless of whether they are developing stories on related topics. Developing a relationship with the press is beneficial, since over time your efforts may lead to your center receiving media coverage.
- **Monitor off-site referral visits** — Follow through to check on things such as waiting time, presence of a translator, if necessary, and no-shows.
- **Medical Information Systems** — Prior to implementation of your intervention, assess the agency's capability to generate desired information for monitoring your program. Such data is essential for quality improvement efforts.



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Family Health Center of Worcester, Inc.

By Oanh Nguyen and Varat Pech

Overview of Family Health Center and Community

The Family Health Center of Worcester, Inc. (also known as FHC) has provided comprehensive, family oriented primary care and support services to Worcester's underserved populations for nearly 30 years from its 26 Queen Street facility, which lies in the heart of the community it serves. Our mission is to improve the health and well being of traditionally underserved and culturally diverse people in the Greater Worcester area. In an effort to make health care more accessible to the community,

 FHC developed a "one-stop" model of service delivery that aims to eliminate many of the barriers often faced by our patients.

Recognizing the diversity of our patients' ethnicities and the language barriers they face, we have developed specialized outreach programs in many languages, such as English, Spanish, Russian, Cambodian, Albanian and Vietnamese. The total number of unduplicated patients seen annually at FHC is about 17,555.

FHC provides a wide range of programs and services, including: comprehensive primary care services, dental, urgent care, laboratory, radiology, and the Southeast Asian Health Program. There are also specialty areas of service for women, men, maternal and child

health, teens, HIV, chronic disease management, tuberculosis, homeless families, nutrition education, social services, mental health and substance abuse, school-based health, smoking prevention and cessation, and literacy.



Southeast Asian Health Program

FHC began the Southeast Asian Health Program (SEAHP) in response to the increasing Southeast Asian populations in Worcester, MA. SEAHP's goal is to reduce the burden of diseases that have a high prevalence in our communities through health education and screening for detection. These diseases include tuberculosis, hepatitis B, smoking related diseases, diabetes, and breast and cervical cancer. This program, funded in part by the Office of Minority Health, began in the spring of 1991. Initially, SEAHP consisted of only Vietnamese staff members but soon after, Cambodian health educators were recruited as well. These health educators were trained to educate and serve the Cambodian, Vietnamese and Laotian communities. Ever since the program started, SEAHP has served about 3,000 patients within the three communities. SEAHP has developed a video on breast cancer early detection and produced health brochures on Mammogram, Pap Test and Breast Self Exam in Vietnamese and Khmer.

As part of the CARE program, FHC worked with Cambodian women who are 18 years and older. Cambodians began immigrating to the United States in significant numbers in



Varat Pech, Cambodian health educator, conducting "home visits".



the early 1980's, fleeing the genocide of the Khmer Rouge regime (1975-1979) and the Vietnamese supported government that unseated the Khmer Rouge. By the mid-1980's, many Cambodians settled in Lowell, MA (45 minutes south of Worcester), drawn by available factory jobs and affordable rents. Lowell now has the second largest Cambodian community in the U.S.



Home Visits and Education Parties

Our Cambodian Health Educator, Varat Pech, who is part of the Worcester Cambodian community, administered the CARE community needs assessment survey to women in their homes (i.e., through "home visits") to ask the women about their knowledge, attitudes, and behaviors around breast and cervical cancer. In addition, she educated the women on breast and cervical cancer through both home visits and several focus groups held at the FHC. Varat was able to recruit women from the Cambodian community through a volunteer at FHC, a well-known community leader who helps organize Cambodian festivals. The community leader, along with friends and co-workers, was helpful in referring new Cambodian residents and patients to Varat.

Based on her own experience, Varat did not expect the women to like the education curriculum that was planned because she thought they might view these activities as time consuming.

Home visits were very new to the Cambodian communities, and getting the appointments were quite challenging because the Cambodian women felt extremely uncomfortable about inviting a stranger to their home and discussing these private health issues.

At first many of these women were not interested in attending health education groups or visiting the doctor because culturally they thought that if they don't talk about a disease then it won't come to them.





Teaching women using breast models.

In order to address this barrier, Varat knew that the older women must be approached with more care, politeness and respect. One of the many cultural traditions Varat followed included the traditional greeting of placing one's palms together in front as in prayer and stating the appropriate greeting. Varat was also cautious of not sitting with her legs crossed, since it is viewed as disrespectful. Education to older women was not rushed, but taken at a more relaxed pace. On the other hand, younger Cambodian women were sometimes more educated, and

more readily accepted the education. Those who had previous health-related issues were more receptive to receiving the information. Some of the Cambodian women reached through this project had experienced health conditions but didn't know how or where to go for help. As immigrant women, they were very isolated from the mainstream health care in this country, and the health information provided by Varat was much appreciated.

After conducting several health education visits within the participants' homes, the trust between the women and Varat grew. This is important to note because once that trust was established, the women were more open to learning about health issues. They enjoyed the activities not only because they were educational, but because they pertained to them as well.

Some of the barriers to education and screening that we noticed were the weather and transportation. In-home education sessions held during the winter were often postponed due to the snow. Many older women had no means of transportation to the screening sessions and depended on a family member to offer them rides. One cultural barrier preventing women from getting screened was that some women felt screening was unnecessary because they hadn't been sexually active since their spouses were killed in Cambodia during the Khmer Rouge between 1975-79. Varat tried to address this issue by informing them that older women can encounter problems, regardless of whether they are sexually active or not.


Several women finally agreed to go to FHC for their first doctor visits, but once they were onsite they were uncomfortable talking about their personal health issues. One of the biggest challenges between the health providers and the participants was communication, since the women were either not fluent in English or did not speak English at all. Also, these women were not accustomed to exposing their bodies and answering personal questions that were posed by strangers (especially male physicians). However, after at least three visits, the patients became more comfortable with the physicians and were able to discuss health and family issues with them more freely.



Just as Varat was required to build a trusting relationship with the women to conduct her home visits, the provider had to develop this same trust.

It was important that both the provider and women showed respect and understanding for one another. As their translator, Varat helped bridge the cultural and language gap between the women and the providers. Through Varat's work, the women were very receptive and wanted to learn more about any health-related issues sponsored by FHC.

For the CARE program we also developed and started trying a new "group health education party" outreach model. Group education parties were held on the weekends, since most women work during the week. The parties took place in both Worcester and in Lowell. Each group met monthly, with new and repeat visitors. There were usually about ten participants, who were mostly patients from the health center. Individuals referred from friends and relatives also attended.



In these education groups, Varat discussed topics that included breast and cervical cancer screening, women's health issues, cardiovascular disease and the importance of nutrition and exercise.

Small incentive gifts were offered, such as healthy snacks, drinks, and small appreciation gifts (i.e. soaps or candles). In order to address the transportation barrier, participants volunteered to give each other rides to the party.

The education tools FHC used included breast and cervical cancer videos (for new patients), brochures in Khmer, and breast and reproductive health models. Videos were an effective form of education, especially since most of the women were from rural villages, had less schooling, and therefore did not read or write Khmer. At first the women were uncomfortable with the breast models, but over time their interest grew. They particularly enjoyed the female reproductive system model since they'd never really seen what it looked like before.

Through both the home visits and health education parties, Varat worked closely with 130 women age 18 years and older, many of whom were mothers and daughters in the same family. Surprisingly, some of the women's husbands showed an interest in what their wives were learning, and wanted copies of the videos to send to their families in Cambodia!

Varat has enjoyed working with these women and hopes to expand the circle of trust and services in the Cambodian communities. Through the study, she noticed that many Cambodian women were unaware of their health status and did not know what to do in case of illness. It is unfortunate that some of these women have not sought medical care in nearly ten years. Varat is pleased that through the CARE Program, the women are now in a better position to take control of their own health as well as their family's health.

They now know where to go for help when they need it, whereas in the past, the women would only seek medical care through their traditional Khmer physician. Instead of only using herbal medicine to cure diseases, the women now have the option of going to a health care provider to obtain modern medical treatment such as surgery, physiotherapy, radiology and laboratory services, etc.



Future Plans for the Project

Though the CARE Program is concluding, Varat plans to continue the health education parties and keep in close contact with these women. She has come a long way toward building a trusting relationship with them and wants to continue building the special link between the Cambodian communities and FHC. She continues to conduct home visits on a regular basis, which includes both education and reminders for rescreenings. FHC's long-term goal is to train these women to become community outreach experts. Varat



would also be delighted to extend her work to other Cambodian communities in Massachusetts beyond Worcester that have not been included in this program.



Recommendations

- **Trust** — Educating the women to take control of their health begins by building a trusting relationship. It will often take a few visits for the health educator to convince the woman to see the provider, and then a few more visits with the provider before she feels comfortable.
- **Home visits** — Home visits were a successful strategy because the health educator was able to visit the woman in a place that was non-threatening. Many women preferred to learn about health issues in a familiar environment, such as the home, rather than go to a hospital and learn about these issues through a health system that was unfamiliar to them.
- **Visual health education tools** — Most of the women came from rural areas in Cambodia where there were no schools, and so they did not have the opportunity to learn written Khmer. Visual health education materials (i.e. videos) are more efficient to use.
- **Work with community leaders** — Work with someone who is well respected and trusted in the community. They can be a valuable resource in referring you to any new community members.



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Kokua Kalihi Valley Comprehensive Family Services

By Merina Sapolu



Organizational Background

Kokua Kalihi Valley Comprehensive Family Services was formed in 1972 as a non-profit corporation by the Kalihi Valley Community. "Kokua" means help in Hawaiian. Housed in the pastor's office of the Kalihi Baptist Church, the organization started with a coordinator and four outreach workers who combed the valley, connecting residents in need of health care services. Today the center consists of over 70 staff members who offer services in 12 languages and from five locations, three of which are in public housing areas. Our services include dental, medical, prenatal, family planning, nutrition, WIC, immunizations, STD/HIV testing and services, mental health, health education, social services, transportation, translation, outreach, professional education, youth services, and community advocacy.



Young and older women working together sharing thoughts on women's health.

Community Served

Kalihi Valley is a residential community within the city and county of Honolulu and is home to 28,228 residents. Kalihi Valley and its neighboring areas are home to the largest percentage of immigrants and refugees in the state of Hawaii. According to the 1990 U.S. Census, 23% of Kokua Kalihi Valley's (KKV) clients live below the federal poverty level. Eighty-nine percent of Kalihi Valley residents are of Asian or



Pacific Islander ancestry, with the main ethnicities being Filipino, Japanese, Samoan, Native Hawaiian, and Chinese. Samoans account for 12% of Kalihi Valley residents and over 45% of the 4,000 residents of Kalihi Valley public housing; statewide they represent only 1.3% of the population. These figures show that Kalihi Valley and its surrounding areas have one of the largest concentrations of ethnic Samoans in the state. Although there isn't a great deal of data on Samoan Americans, data from the Hawaii Tumor Registry suggested that breast and cervical cancer are the first and third most common cancer among Samoan women.¹



Outreach to Churches

Samoan churches are the center of most activities in the Samoan communities, and historically KKV has had a close relationship with local churches. In fact, four members of the original planning committee and first board of directors of KKV were from local churches, and each played a key role in KKV's development. With this in mind,

we decided to focus on partnering with churches in the area to bring awareness and education about breast and cervical cancer to its female members.

As in any Asian/Pacific Islander community we were aware of the barriers we needed to overcome, including: language, culture, indifference, fear of the big "C" (cancer), the belief that they are too old for any screening, transportation, not wanting to see a male provider, fear of being questioned about immigration status, and lack of time.

Approaching the churches

Each Samoan church represents a distinct community. Samoan health educators from KKV began by visiting church ministers and their wives to introduce the CARE Program and to schedule educational presentations. Our first presentation was before a gathering of approximately 200 Samoan women. After we presented to the group, we sat at an

¹ Mishra, S, Luce-Aoelua, P, Wilkens, L. Cancer among American-Samoans: Site-specific incidence in California and Hawaii. *International Journal of Epidemiology*. 1996;25:713-721.

information table outside of the church to answer any questions the women might have on breast and cervical cancer. We anticipated that with KKV's good relationship with the churches, outreach and education would be easy. The response however was far from what we expected, since very few women approached the table. There was little interest in our table; in fact the attitude of most women was that of indifference. However, when women were asked if they knew someone who had died from breast or cervical cancer, many women said that they did. We weren't taken seriously, which was their way of denying the issue.

After brainstorming and considering other ways to approach the women, we decided to go back and speak to the church's youth groups. Our hope was to educate the youth about the importance of breast and cervical screening, and have them encourage their mothers and wives to see their providers and get screened. The youth had a positive response to us, and we began to rethink the strategy we had tried in the adult group. Instead of having a large group educational presentation on breast and cervical cancer, we decided to have small group discussions of 7-10 women on women's health issues. The women felt that the issue of breast and cervical cancer was too sensitive to discuss in front of others, especially within the church. We also learned that we had to find different ways of describing reproductive organs. The women suggested that we use the term "forbidden parts" rather than "vagina" or "cervix".

The ministers took it upon themselves to announce when small group discussions were being held. From then on, the turnout for our sessions improved, for not only did women get involved, but men did too. The group discussion topics ranged from reproductive



A group at church discussing breast and cervical cancer.

health to breast and cervical cancer early detection and screenings. At these sessions, refreshments were contributed by everyone in a potluck style. The churches also provided food as well. Sharing food during these sessions is important, because it is valued by Samoan culture.

Home health parties

In addition to the discussion groups at local churches, we also looked for ways to reach church members outside KKV's service area. We used the approach of "Taking the message home" by having Home Health Parties. We began by asking our longtime health center clients if they could host these parties in their homes and invite their friends and relatives. The discussion groups, which consisted of 8 to 12 women, started off with "talk story", which is a way for us to all break the ice and become more comfortable and trusting of one another. Samoan talk story usually includes questions such as, "How long has it been since you visited home?" or "Which village are you from?"

The health education and discussion focused on participants learning how to take care of one's self before taking care of one's family because these women prioritize the needs of their loved ones above their own. Because it was often difficult for the women to come out right away and share their experiences, we helped facilitate the discussion through an activity called "Carouse!". The activity involved writing health-related questions (in Samoan and English) on newsprint and posting those questions on the wall. Participants then split up into small groups and wrote their answers on the newsprint. Every 2 minutes, each group rotated to a different newsprint, so by the end of the activity, everyone had responded to each question. At the end of the exercise the papers were collected and we discussed each question and comment. Through the discussion the women were able to share their experiences, which helped women learn more about their health and it debunked myths surrounding breast and cervical cancer. We also used visual educational materials, such as breast and cervix models and flipcharts. Written materials were not used because of the lack of Samoan-language health education materials, and because of the low English literacy rate among the women.

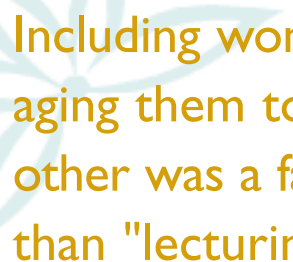
At the end of each session, each woman wrote a note listing three "promises" to herself, describing actions she wanted to take as a result of participating in the session. This was their way to commit to what they have learned. Some examples of the promises women made include: "I promise I will go for a Pap smear test" or "I promise to tell a friend about this presentation." These notes were then sealed in self-addressed envelopes and collected by the health educators. After three months, the notes were mailed back to the women. We then followed-up with the women by telephone to see how many of



the promises were kept. We found that about 50% of the women fulfilled two out of three promises, and 20% of the women fulfilled one out of three.

One common barrier that came up was that women sometimes felt that nothing should be done about cancer: "If it is God's will, so be it." To this, I replied that "God helps those who help themselves." The women enjoyed sharing their experiences during these group meetings. One participant said, "This is very educational, I'm glad I came." Another one commented, "We should do it for the next generation."

The Women's Home Health Parties were a successful partnership between KKV and the community, partly because the neutral and intimate environment and smaller groups put the women at ease. As time passes, the women are much more open to discuss their experiences and ask questions.



Including women in health discussions and encouraging them to share their experiences with each other was a far more effective method of education than "lecturing" them.

We have been very successful in continuing our educational discussion groups, especially since moving into our new facility in the summer of 2001. Our health center has a "greeter" that meets both new and old clients at the door and conducts in-reach, informing them of services, such as our breast and cervical cancer program. Since we are in a new neighborhood, she has been able to recruit many new patients to these groups. She is utilized by our clients as a counselor and outreach worker. She is also "Nana" to many of them, which means grandma or elder auntie. In addition to the health center greeter, our outreach workers have also been going door-to-door in the neighborhood, as well as to nearby bus stops, to educate and recruit more women to the program.



More Community Outreach

In addition to conducting church outreach and small discussion groups, we have also taken our message to the radio. One of our local Samoan radio programs is run by a Samoan woman of royal heritage. People trust and believe what she has to say, and she

is viewed as a role model. Our outreach worker has gone on the air to talk about women's health issues and share her own experiences with breast and cervical cancer screening, emphasizing to women that it is important to live a healthy life and to be screened. She urges the women to take charge of their lives first so they can be there for their families later. These radio talks are conducted monthly, and have been well received by the community.

During the CARE Program, we also learned that some private physicians out in our community were not recommending breast and cervical cancer screenings for their female patients. The physicians did not give specific reasons why they didn't recommend these screenings, but when asked they said that if a woman does not ask for a screening, they don't bring it up either. With respect to pap smears, many of the providers were unable to do this procedure because they lacked the appropriate supplies. We also realized that some physicians refused to refer patients for screenings because the procedure had to occur off-site, and because the physician was afraid of losing their patients to another provider. When we first approached these physicians and asked them to encourage their female patients to get screened, they were resistant. However, when we threatened to expose their practices on the local Samoan radio show, they became more agreeable. The situation has improved, especially because of increased television and newspaper coverage stressing the importance of breast and cervical cancer screening.

These were some of the ways we reach out to our community through the CARE program. When we were unsuccessful with an approach, we went back and re-evaluated that approach and tailored it to fit and work in the community we were serving. It is also important to remember that what works for one community may not work for another, because of cultural differences, age, gender, immigration status, etc.



Recommendations for Education and Outreach

- Conduct outreach in locations where your community centrally gathers.
- Do not conduct outreach education as experts but as individuals willing to share and learn from the community. Samoan women want people who are experts in their fields, but they do not appreciate people talking down to them. So for those who go in to do educational presentations, do it in a sharing, talk story way.
- It is always good to have some idea about the group before the presentation, including their mood, experiences, and interests, so you know in what direction to take the discussion in. Include positive and negative testimonies from Samoan



women who have had screenings for breast and cervical cancers. This makes the education much more powerful and easier for the women to relate to.

- In Samoan culture, humor plays a critical part in discussing some of these sensitive issues — It helps to put the women more at ease and allows them to talk more freely.
- The language you use (i.e. medical terminology) during each discussion depends on the immigration status and years of formal education of the group. Overall, the message should be simple and clear.
- Promote active participation from the group members during a presentation. Not only does it keep the participants' attention and ensure that each individual takes part in the discussion, but it also helps ensure that participants can relate to the information that is discussed.
- Women can be persuaded when you discuss what's at stake.
- Partner with others who are reaching the community successfully.
- Be flexible — Have a variety of different ways of reaching your community; if one way does not work try another.



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Kalihi-Palama Health Center

By Andrea Macabeo and Doris Segal-Matsunaga

Overview of Kalihi-Palama Health Center & Community

Kalihi-Palama Health Center (KPHC) is a community health center located in urban Honolulu, Hawaii. KPHC serves Kalihi-Palama, a low-income, inner city community and a designated medical and dental Health Professional Shortage Area (HPSA). Within the densely populated district of over 47,000 residents are 7 public housing projects and a blend of apartments, single family/extended family homes, emergency shelters, industrial facilities, and small businesses.

KPHC's mission has always been to deliver health services to those who face barriers to health care, such as low income, lack of health insurance, unfamiliarity with Western



In order to make health education party participants feel more comfortable, CARE staff intermingled with them informally.

medical practices, and little spoken English. Eighty-percent of KPHC patients are Asians or Pacific Islanders; 80% live at or below the poverty level. Many are immigrants or refugees, and more than a third of our adult patients require an interpreter. Filipino patients are the largest single ethnic group served by KPHC. Of the 11,000 patients served by the clinic in the year 2000, 23% were Filipino. Over half of these patients had no health insurance.

History and Mission

In 1975, the Reverend Richard Wong and other concerned citizens recognized the urgent need for medical services for Kalihi-Palama residents and others who faced access barriers to health care. Hale Ho'ola Hou (House of Life) was founded that year at Kaumakapili Church to provide primary medical services to the poor, elderly, homeless, and newly arrived immigrants.

Since its inception, KPHC has expanded its services to fill the growing need for affordable, quality health care. The health center now offers comprehensive services, including adult and pediatric primary care, prenatal, midwifery, dental, optometry and behavioral health services, health education and WIC programs. Included in this care are clinical breast exams and pap tests.



History of BCC programs (pre-CARE)

“While breast cancer incidence is highest among Caucasian and Hawaiian women, breast cancer mortality has been relatively higher in Hawaiian and Filipino women, which is in part a result of later stage of disease at diagnosis.”¹

Since 1998, KPHC has collaborated with the Hawaii Breast and Cervical Cancer Control Project (BCCCP) by recruiting Filipino and Hawaiian patients for free mammograms and follow-up provided by a local hospital, St. Francis Medical Center. The Hawaii BCCCP works with Filipino and Hawaiian women because they have the highest breast and cervical cancer mortality ratios. Five-year survival rates for both diseases are worse for Hawaiians, followed by Filipinos. According to the 1998 State Behavioral Risk Factor Survey, 22% of Filipino women and 13% of Hawaiian women have never had a professional breast exam compared to the state average of 10.8% and the national average of 11.2%. In addition, 7.5% of Filipino women never had a pap smear compared to the 4.8% state average and 5.4% national average.

¹ State Plan of the Hawaii Breast and Cervical Cancer Control Program. January 1998.

Despite the availability of BCCCP funded free breast and cervical cancer screening, these services continue to be underutilized by Filipino and other eligible women over 50. The primary barrier to screening is the lack of bi-lingual, bi-cultural staff assigned to recruitment. Other barriers, identified via focus groups, key informant interviews, and by KPHC and St. Francis health workers, include: language barriers, lack of time due to multiple jobs, lack of family members or friends to accompany them to services, anxiety surrounding diagnostic screening results, and lack of transportation to and from clinic sites. This reflects both limited transportation options and a strong desire to have a family member accompany the patient to a provider for language, cultural and moral support. In many of Hawaii's Filipino families, especially those recently immigrated, family members work at multiple low-paying service sector jobs and cannot afford to accompany relatives to non-urgent medical visits.



CARE Program Planning: The Role of Filipino Culture and Values

To plan an effective program, it was essential to become knowledgeable about Filipino culture and values.

The historical, social, and cultural aspects of life in the Philippines and among Filipinos in Hawaii became the foundation of this program.

The strategies developed to recruit and educate Filipino women incorporated key cultural values and customs, which are described in the sections on implementation and recommendations.



CARE Program Implementation


"Filipinas believe that the best person to "educate" them would be another Filipina. They would have instant credibility and would be best at understanding the concerns of other Filipinas." ⁱⁱ

ⁱ Hawaii Breast and Cervical Cancer Control Program. *Focus Group Summary Report*. August 1997.



In an attempt to reduce the breast and cervical cancer mortality rates of Filipino women, KPHC implemented a unique educational approach that involved hosting monthly Women's Health Education Parties and Group Clinics. The purpose of the program was to recruit Filipino women to participate in the CARE needs assessment survey and to conduct culturally tailored health education regarding breast and cervical cancer control.

This program was developed with the assistance of an in-house Filipino Advisory Committee that consisted of medical assistants, health educators, a nutritionist, and a nurse. The Advisory Committee recommended incorporating cultural values into recruitment methods, the curriculum and the style of interaction with participants. For example, the education sessions were designed to have a social, party-like atmosphere, creating a familiar environment which allowed participants to get to know the project staff and each other in a non-threatening, "non-medical" setting. To establish rapport and trust, our staff interacted with participants in a "karinosa" (caring and friendly) manner.



To accommodate the different languages and dialects spoken by our clients, the educational parties were conducted in "Itaglish", a word KPHC staff coined to describe the process of combining and switching back and forth between Ilocano, Tagalog, and English during the session.



The Women's Health Education Parties

The Women's Health Education Parties, consisting of 10 to 15 participants, were approximately 2 to 2 1/2 hours long and held at various venues in the community including KPHC, local churches, and local agencies. At the beginning of the Party, an icebreaker was used to get to know the participants. Three questions were asked: (1) What part of the Philippines are you from? (2) How long have you lived in the US? (3) How many children and grandchildren do you have? These questions allowed KPHC staff to get to know the participants and to find common ground between them.



Marissa Dela Cruz and Jeanette Montenegro address health education party participants.

Following this introduction, participants were asked to complete the CARE survey, which was offered in two different languages, Tagalog and English, and a Philippine dialect, Ilocano. Bilingual and bicultural Filipina staff provided assistance for women who had difficulty in completing the survey. The second hour of the Party was dedicated to providing participants with information

regarding the "Truth about Breast and Cervical Cancer". Women were taught about early detection, including clinical breast exams, mammograms, pap tests, and breast self-exams. This portion was conducted in a culturally appropriate "talk story" (sharing of stories) manner to create a more comfortable and supportive environment. And of course, as in all Filipino gatherings, a merienda (light meal) was provided at the end. All participants that attended the Party received a ten-dollar drug store gift certificate.

The health education party participants were recruited via a number of different strategies, including: (1) Filipina bilingual recruiters (KPHC Medical Assistants) inviting women from the KPHC clinic waiting room, (2) Referrals from KPHC and community medical providers, (3) Social networks, and (4) Personalized invitations sent out to Filipino women over age 40 listed in the KPHC patient database, and followed up by a call from one of our staff. These personalized invitations added a Filipino twist by translating our CARE program slogan into Tagalog, the national language of the Philippines.

To ensure that all women, despite financial barriers, have access to screening, KPHC partnered with St. Francis Hospital and the Hawaii BCCCP to provide free screening to eligible women (ages 50-64, uninsured or underinsured) in a Group Clinic format. Clinical breast exams, mammograms, and pap tests were provided to all eligible participants from the Women's Health Education Parties via the BCCCP program. Transportation to and from KPHC was provided by the St. Francis BCCCP Program. KPHC staff provided technical assistance in filling out forms, translating information, and providing moral support to participants. In addition, to ease patients' anxiety and at times long wait periods, refreshments and a Filipino video were provided. All participants

received a free tote bag that contained a message translated in Tagalog: "Kalihi-Palama Health Center: Pangalagaan ang kalusugan ng mga kababaihan" which translates to "Kalihi-Palama Health Center: Taking Care of Women's Health."



Recommendations for Community and Patient Recruitment

"Look through the local Philippine Newspapers and look at the calendar of events. Take some money out of your budget and attend these events so that you can be visible within the community. That is the best way to reach them (Filipino women)."

— Minerva Falcon, Former Philippine Consulate General of Hawaii

"You may feel you are wasting time talking about other people and sundry matters, but to a Filipino, cultivating a friend, establishing a valuable contact, and developing personal rapport are what make business wheels run." ⁱⁱⁱ

- **Be visible:** Take the time to network within the Filipino American community. Introduce yourself and your program to community leaders and health care providers. Attend community events and social gatherings in order to heighten awareness of your program and establish yourself as the "person" behind the project.
- **Access community resources and social networks:** Identify, involve and motivate possible groups associated with the population you want to work with (ie: Philippine Medical Association, Philippine Nurses Association). Utilize health care providers, community contacts, front line staff workers with access to ethnic community contacts and social networks, and past program participants to recruit clients.
- **Offer incentives for recruiters:** Recruiters are likely to be busy health workers or community residents who are volunteering extra time because they believe in the goals of the program and/or have a reciprocal relationship with the program staff. Possible "appreciation" incentives include lunches, gift certificates, recognition, social support, etc.



Recommendations for Educational Sessions

"Filipinos have a tendency to relate to persons rather than to agencies or institutions. For example, Filipino clients prefer to go to a clinic or hospital where they know at least some staff members." ^{iv}

ⁱⁱⁱ Roces, A, Roces G. *Culture Shock! Philippines. A Guide to Customs and Etiquette*. Portland, OR: Graphic Arts Center Publishing Company; 1992.

^{iv} Tompar-Tiu, A, Sustento-Seneriches, J. *Depression and Other Mental Health Issues: The Filipino American Experience*. San Francisco, CA: Jossey-Bass Publishers; 1995.



- **Provide refreshments:** Traditionally, when visiting Filipinos in their homes, guests are always served something to eat and drink. In order to create a comfortable environment, serving refreshments is a must.
- **Conduct sessions in a group setting:** Learning in a group setting gives women an opportunity to share their experiences and support with one another.
- **Create a warm and friendly environment:** Creating a safe and warm environment will make it easier for women to share their experiences and provides another opportunity to establish rapport with your clients.
- **Establish rapport and trust:** As mentioned in the quote above, Filipinos tend to relate to persons rather than to agencies or institutions. By establishing rapport and trust with the community and your clients, they will be more receptive to your program.



Future Plans for the Project

Kalihi-Palama Health Center plans to continue CARE activities. Recently, KPHC received a 2-year grant from the Office of Minority Health to promote early detection of breast and cervical cancer among Filipino Women. We will continue to conduct culturally appropriate women's health education parties and clinics and write and disseminate a program guide entitled "A Breast and Cervical Cancer Education Model for Filipino Women" which documents the process, findings and curriculum of this project.



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South Cove Community Health Center

By Martha Hackett

The CARE Program was adopted by the South Cove Community Health Center (SCCHC) to increase awareness among Chinese women in Quincy, Massachusetts of the importance of breast and cervical screening, and to increase our understanding of the barriers faced by these women.



Background of South Cove Community Health Center and Chinese Community

The South Cove Community Health Center was started 29 years ago in Boston's Chinatown. It now serves the Asian community of Greater Boston and more than 15 surrounding communities. The comprehensive health center offers internal medicine, OB/GYN, pediatrics, eye, dental, social services and behavioral health (including mental



Irene Li, CARE nurse, at a community health fair.

health, mental retardation, family therapy and an after school program). Last year the health center served its clients through more than 72,000 visits. The various emphases in care we offer reflects the various clients we serve, who are primarily from Chinese, Vietnamese and Khmer communities. The center has conducted breast





Bilingual outreach flyer posted in the community.

and cervical cancer screening through its OB/GYN unit for 25 years. South Cove provides services to uninsured women, through the Massachusetts Department of Public Health's Breast and Cervical Cancer Initiative (BCCI) program (now called the Women's Health Network). In 1995, SCCHC opened a satellite clinic in Quincy, MA to respond to the growing Chinese population in that region. The 2000 U.S. Census shows that in Quincy, out of a total of 88,025 people, there are 13,546 Asians (up from 5,500 in 1990).



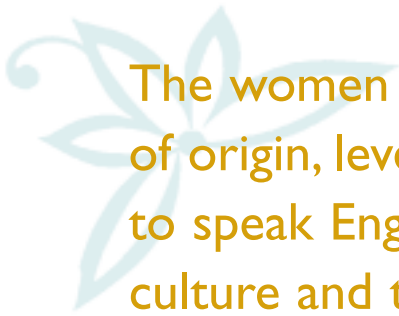
Traditional Asian Beliefs of Health

The relationship between the community and the health center is a complex one. Traditional Asian views about health are grounded in the belief that maintaining balance in your body and in your life keeps you healthy. You achieve balance through healthy behavior, diet, exercise, rest, and good relationships with your family and community. You know you are out of balance or ill when you develop symptoms like pain, dizziness, weakness, abnormal bleeding or insomnia. If an individual has these symptoms he or she is likely to go to an herbalist or to a provider of Western medicine. However, this understanding of health is a barrier to breast and cervical cancer screening, which is based on the principle that screening should occur when you feel healthy and before you have symptoms.



Care Program Planning

Our CARE program was designed to increase the number of women who received breast and cervical cancer education and screenings in the Quincy community. This screening was to take place in a primary care setting so that other health care needs might be addressed in a holistic manner. Some of the women we were trying to reach with these services have been in the United States for 15 to 20 years, others for less than a year.



The women are diverse in many ways: country of origin, level of education, income, work, ability to speak English, acculturation to the dominant culture and their beliefs in the traditional understandings of health and disease, especially cancer and the possibility of cure versus "my fate" or "my bad luck".

Our plan was to reach out to women, bring them in for care and ask them about the barriers that prevented them from being screened, their understanding of breast and cervical cancer, their sources of health information, and how they felt barriers might best be overcome.

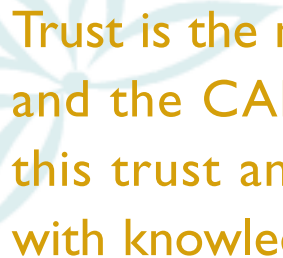


Outreach Activities

We used posters in Chinese and English to advertise our program, and included a telephone number women could call to speak with a bilingual nurse for more information. We also participated in health fairs, participated in a local Chinese cancer support group, and had articles published in the Sampan Chinese/English newspaper. In addition, two staff members were interviewed in Cantonese about breast and cervical cancer issues by a local radio station. However, when we conducted needs assessment interviews, most women told us that the most effective form of outreach was one-on-one — the CARE



nurse speaking with each woman, expressing concern for her and her family's health and explaining the benefits and process of breast and cervical cancer screening.



Trust is the most important aspect of education, and the CARE nurse was able to develop this trust and empower the individual women with knowledge.

Women with more traditional views of health and disease felt that talking about cancer gave the disease power and could bring "bad luck". Therefore any group discussion of screening needs to focus on the issue of staying healthy (the positive) rather than on cancer (the negative). Discussions about cancer should be held with a provider or nurse who has already established a trusting relationship with the patient. This should be done before any discussions about cancer take place. Younger women in the community, some of whom are more educated or acculturated, may not feel as many cultural barriers to breast and cervical cancer screening or to seeking care as older and/or more traditional women.



Two other prominent barriers mentioned by most women were lack of insurance coverage and time.

The first barrier was addressed through the Massachusetts Department of Public Health Women's Health Network, which provides free breast and cervical cancer screening for uninsured, low income women. The barrier of time is just as important. Most of these women work in jobs that do not give them time off, or are responsible for caring for their grandchildren. To as great a degree as possible we have adjusted our screening hours to better meet women's needs. Beyond this, we have encouraged women to realize how important their health is to the well being of their family, making screening for breast and cervical cancer important for their families as well as for themselves and therefore a priority.

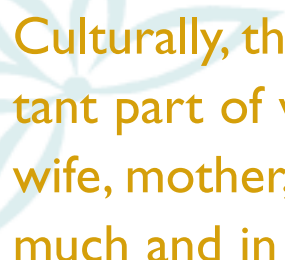


Summary of Work: Meeting Our Objectives

The CARE program reached out to women of Quincy as well as those who visited the Quincy site. Six hundred women received clinical services over a period of one year. In addition, these women received very important health education, including one-on-one counseling sessions that taught women how to do breast self exams, when to seek care for abnormal bleeding, and the importance of regular breast and cervical cancer screening. Women with non-GYN health issues were referred appropriately to other providers, and social service support around issues of lack of health insurance was offered to all women, if necessary.

For the CARE program, we also interviewed 75 Chinese women to assess their understanding of breast and cervical cancer issues and any experience they may have had with previous screenings. From the preliminary results, we learned that many women do not appreciate the concept of screening, and that this barrier must be addressed first.

In addition to the surveys, we conducted a second group of needs assessment interviews with 21 women to ask women the best way to provide education. This technique was chosen instead of a focus group format because we discovered that many women would not come to or would not speak in a public arena on a subject such as cancer. These interviews were with women in their 20's to 70's. The women gave us information on what women know and where they look for health information, how we might best get our message out, and where outreach might be most effective. Most women said they expect to get health information from a community health center provider or private doctor.



Culturally, the Chinese family is the most important part of women's lives. They are seen as a wife, mother, friend, and daughter. They give so much and in turn end up not thinking or caring about themselves.

Again and again the women told us the most effective outreach is one-on-one, by a professional health care staff person who is compassionate, patient, concerned for the woman's well-being and willing to teach and listen to the woman's concerns.

Our Women's Health Network program is ongoing, as is our GYN unit's commitment to reach out to the women in our community and deliver the message that breast and cervical cancer screening is important. The information we gathered from the two sets of interviews conducted for the CARE program will better inform our efforts. We have also developed an evaluation tool to integrate into our ongoing care to continue our assessment of the effectiveness of our efforts.



Recommendations

- Understand and respect the traditional Asian belief of maintaining balance in both health and life.
- Use an educational setting that is culturally appropriate. The Chinese women at SCCHC were more comfortable speaking about cancer confidentially and one-on-one with a health professional instead of in a group of peers, because they believe that talking about it in front of others can give it power.
- Trust: since cancer is a serious disease, an established relationship with a provider such as a physician or nurse is important.



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Waianae Coast Comprehensive Health Center

By Sheila Beckham



Background of WCCHC and the Community

The Waianae Coast Comprehensive Health Center (WCCHC) is a community health center located on the rural Leeward Coast of the island of Oahu. WCCHC is not only the largest employer on the Waianae Coast, but it is the largest employer of Native Hawaiians in the state. The community of 50,000 is comprised primarily of Asian Americans and Pacific Islanders: 50% are Native Hawaiian, and 26% are other Pacific Islander or Asian. Demographics, health status, and socio-economic indicators collected from WCCHC patient visits show that the Waianae Coast is in dire need of health, economic, and social service support. Of the 21,463 patients seen at WCCHC in the



Bobbie Kelii, nurse practitioner, discussing screening with a patient.

year 2000, 69% of the patients were living in poverty, and 66% of the patients were uninsured or receiving Medicaid.

Over the past 30 years, WCCHC has expanded its services from one central clinic site to four separate clinics throughout Waianae and its adjacent communities. We provide an array of services that include primary, preventive, and specialty



medicine, twenty-four hour emergency care, lab, x-ray, dentistry, behavioral health, case management, substance abuse treatment, adult day care, integrative/alternative and traditional Hawaiian medicine, nutrition and health education, chronic disease management, and homeless outreach. WCCHC's central site is also home to the Hawaiian medicine center, which utilizes traditional Native Hawaiian healing methods, such as herbs and massage (known as "lomi lomi"). Over half of the Native Hawaiian population at WCCHC relies on traditional healing methods, either alone or in combination with Western medicines. Lifestyle, customs, and cultural values among Filipino, Samoan, Native Hawaiian, and Caucasian residents on the Coast are heavily influenced by traditional Hawaiian practices — resulting in a unique "local flavor:"



History of Breast and Cervical Cancer Programs

Our center became actively involved with breast and cervical cancer issues in the late 1980s due to the high incidence and mortality rates among Native Hawaiian women.

Breast cancer is the most common cancer in Native Hawaiian women, affecting 105.6 out of 100,000 women each year.

They also have the second highest death rates from breast cancer in the country.

Past programs at WCCHC include the Waianae Cancer Research Project, which was funded by a grant from the National Cancer Institute from 1991-1996. This program was designed to test the effectiveness of a community-driven, culturally appropriate approach to breast and cervical cancer screening practices among Native Hawaiian women. Screening education and support was provided by trained lay health workers in a group setting called "kokua groups." Kokua is a traditional Hawaiian value referring to a mutual willingness to help others without expecting anything in return.

WCCHC has obtained additional funding from local sources as well as the Susan G. Komen Foundation to continue our kokua groups, expand our network of lay health trainers, and conduct breast and cervical cancer education within our WIC Program (Women, Infant, and Children) and at local high schools.



Though each of these programs has helped many women overcome their fear of talking about cancer and getting screened, there are still many other women in the community who need to be reached as well as women needing re-screening. There is still a sense of denial about cancer among some women. Since our center already had several years of experience introducing breast and cervical cancer issues to the community prior to CARE, our goal for this project was to build on our previous work and develop a more sustainable program that could be integrated into the primary care clinic setting and could be maintained without large amounts of external funding



Program Implementation and Cultural Tailoring

As a partner in the CARE Program, WCCHC administered community needs assessment surveys to 75 Native Hawaiian women over the age of 40 to learn about their needs, attitudes, and beliefs around breast and cervical cancer.

Although some outreach was done in the community using the kokua group model, we also focused on integrating these activities into the primary care clinic setting through one-on-one education.

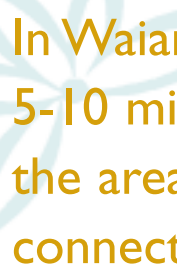


Teo Kuakini using a breast model to teach breast self-exam.

To encourage women to participate in the surveys and education sessions, WCCHC provided "incentives", which included healthy snacks and a \$10 gift certificate to a local drug store. Each of the incentives was well received.

Cultural Tailoring for Native Hawaiian Women

Before conducting education sessions and administering the CARE surveys, it was necessary to build trust between the health educator and the women and to ensure that they were in an environment where they could speak comfortably about breast and cervical cancer. One way we accomplished this was by speaking to the women in "pidgin English". Pidgin English, which is widely used among Hawaii's residents, is a combination of Native Hawaiian and English and reflects the culture and history of Hawaii. The Native Hawaiian health educator also relied on "talk story" to allow the women to get to know each other.




In Waianae, "talking story" involves speaking for 5-10 minutes about who you are related to in the area, and who you know. Everyone's personal connection with the community needs to be established first before talking about other topics, such as health education.

We discovered that patients find it difficult to discuss breast and cervical cancer because they often know someone who died from cancer. Other women were initially shy about discussing breast or cervical anatomy and were hesitant to participate in clinical breast or vaginal exams. By talking story, however, the women were able to talk comfortably, share experiences, and develop trust with one another. The educator also made the women feel more comfortable by using simple, uncomplicated, non-medical terminology to discuss medical procedures and female body parts. Older patients were addressed as "Aunty" instead of "Mrs.", and the educator became a "sistah" to the patient. The health educator had to be a bit more sensitive with younger women less than 40 years old, since they often seemed to be uncomfortable and giggled more during the education sessions. However, by the end of the session the younger women also asked a lot of questions. The health educator also took the opportunity to ask them to share the breast and cervical cancer information with their mothers, which many were eager to do.

Since the health educator was from the Waianae community and was viewed by the women as a community member, not as a health educator, she was much more readily received by the group. This was critical to the success of the program, for if the health educator were a stranger to the community, the group would have been much more hesitant to trust her and she would have had to spend a significant amount of time developing a relationship with the group first. By the end, most of the women agreed to participate in the screening exams after receiving the prevention education. Again, using a talk story approach to find common ground helped make the women feel comfortable.

Kokua Groups

The health educator also organized women into small discussion groups (under the kokua group model) based on women who knew each other through family or friends. The sessions were held in women's homes. During the kokua groups, the CARE surveys were administered and breast and cervical cancer education was provided. The health educator facilitated a discussion among the women to talk about their knowledge about breast and cervical cancer and provided education to encourage them to either get screened or rescreened.



Here, women were able to come together in a comfortable space to talk story about sensitive issues related to breast and cervical health. It was an opportunity for the women to informally learn from their peers and to empower and motivate one another in a non-threatening environment.

One-on-one education

In addition to the kokua groups, the health educator began administering the surveys and providing education with women in clinic waiting rooms. This was done at the main WCCHC site and also at several of WCCHC's satellite clinics. She approached Native Hawaiian women who were waiting for a doctor's appointment for either herself or a family member. This step was not only cost-effective, but it was also a logical progression that allowed WCCHC to move toward its goal of integrating a breast and cervical cancer program into a sustainable program at the clinical services level of the health center.

Partnerships

The health educator also partnered with other community organizations, such as Ke Ola Mamo, to ensure that the CARE survey and education was being administered to women who were not patients of WCCHC. The health educator provided these services to the women that were in Ke Ola Mamo's weight management program. Ke Ola Mamo has also provided resources to support mammograms at WCCHC, some transportation for patients, and case management.

Education materials

Education materials utilized throughout the program included breast and cervical cancer brochures and cards with breast self-exam instructions and screening recommendations on them that can be hung in the shower. The health educator also used breast and female reproductive system models, which were received well by the women, many of whom were viewing these models for the first time. In the kokua groups, a women's health diary was also used so that each participant could write down a specific question for the health educator to answer. The diary gave women who didn't feel comfortable asking her question publicly, the opportunity to do so privately. Educational pamphlets on healthy Native Hawaiian foods that prevent cancer as well as other illnesses were distributed as well.



Integration of Breast and Cervical Cancer Programs

One of the major lessons learned by participating in the CARE Program was that it is necessary to involve all of the various departments and "key players" of the center (e.g., mammography department, information systems, medical providers, medical records, team office managers, and preventive health staff) in the planning, implementation, and evaluation of a multifaceted project such as CARE. This was critical to developing a sustainable program model and integrating the CARE Program into the primary care clinic setting. Although getting each party to participate and work together requires extra time and commitment, comprehensive participation by the various departments is key to institutionalizing breast and cervical cancer services into a health center. One barrier we had this year was an administrative directive requiring providers to focus on increased productivity. This directive has made it difficult to get other providers to participate with programs and grants of any kind. We have made every effort to educate providers and administration on the CARE program and will continue to advocate for culturally relevant interventions. We just have to be patient and work with the constraints, so that once providers increase productivity they'll have more time to participate in programs in the



future. Now that CARE has ended, WCCHC plans to continue the integrated education component within the clinic setting two days per week.



Recommendations

- Establishing trust with the women is key — This includes talking story with them to introduce yourself and your connection to the community. Finding common ground is how trust can begin to be established.
- Make sure your health educator is a member of the community — Being part of the community rather than a health educator is more important to the women. Not only does the educator know the culture and language, but this also ties in with the issue of trust.
- For program integration, get commitment from leadership and all other departments that will participate — even peripherally — in the project prior to implementation.



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The Care Program

A COMMUNITY APPROACH TO RESPONDING EARLY TO BREAST AND
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