

Health Policy & Health Services Research

**Funded by the
California Breast Cancer
Research Program**



CALIFORNIA
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Health Policy and Health Services Research

The **California Breast Cancer Research Program** (CBCRP) has placed research on health policy and health services delivery as one of our highest priorities. Gathering information that will be important for policy makers at the national, state, and local level is vital if research findings are to result in action and change.

Investigators can apply for grants in any of CBCRP's 16 awards, which range from small exploratory awards through several career awards to large grants with no dollar cap.

This booklet contains abstracts, presented as examples of the range of research, of all Health Policy and Health Services projects that CBCRP has funded to date. Some of these projects are complete, others are in progress, and others are just underway.

We are eager to increase our funding of research that explores the organizational and sociopolitical context of breast cancer prevention, detection and treatment, that develops strategies to serve women most effectively, and reflects the issues faced by the state's geographically and ethnically diverse population.

For more information about the CBCRP's Health Policy and Health Services priority issue, please contact:

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For information about the entire CBCRP portfolio, please visit our Web site:
www.cbcrp.org

Health Policy

Exploring either public policy change or health outcomes with regard to breast cancer treatment, prevention, earlier detection, and racial/ethnic differences in breast cancer. Topics of special interest include:

- ◆ Research and formulation of public policy alternatives contributing to breast cancer prevention, e.g., precautionary principle strategies, biomonitoring, and phase-out of persistent bioaccumulative toxins
- ◆ Methods to improve health care outcomes, especially through public health policy initiatives
- ◆ Economic aspects of breast cancer care, including increased efficiency and cost-benefit ratios
- ◆ Impact of direct consumer marketing of genetic testing, imaging techniques, and therapies
- ◆ Quality of care including adherence to state-of-the-art and standard of care guidelines for diagnosis, treatment, and rehabilitation
- ◆ Studies of public (i.e., the lay public and policy-makers) perceptions of breast cancer, the burden of breast cancer in California, and priorities for research

Health Services

Any research dealing with the development of public policy strategies to most effectively deliver services to women.

Topics of special interest include preventing breast cancer and eliminating the barriers to service delivery. Some examples:

- Reducing inequities in access to prevention, detection (*excluding screening mammography*), treatment, and survivorship services for underserved populations
- Outcomes, quality of care, costs, and quality of life in health service delivery systems, including organizational models of service, networking, supportive care, support groups, feminist models of health care, and/or multi-specialty access
- Methods to reduce costs and/or increase patient-physician cooperation, and develop, implement, and evaluate new practices/policies
- Development of better self-reporting patient satisfaction and quality assessment tools covering the entire process of diagnosis, treatment, and rehabilitation

Award Types

The CBCRP funds Health Services and Health Policy research in the following Award Types:

Collaboration Awards:

- Scientific Perspective Research Collaboration (SPRC) Exploratory and Full
- Translational Research Collaboration (TRC) Pilot and Full
- Community Research Collaboration (CRC) Pilot and Full
- Joining Forces Conference

Investigator-initiated, Major Research Projects:

- RFA (Request for Applications)

Innovative Awards:

- IDEA (Innovative Developmental and Exploratory Award)
- STEP (A more advanced IDEA award)

Career Development Awards:

- Dissertation
- Postdoctoral Fellowship
- New Investigator
- Mentored Scholar
- Career Enrichment
- Training Program

For more information about the CBCRP's award types, please visit our Web site: www.cbcrp.org

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The Cost of Breast Cancer in California

Wendy Max, Ph.D., University of California, San Francisco

Breast cancer is a disease that affects a large number of women of all ages, from young mothers to retired grandmothers. The resulting economic burden of the disease is huge, and includes dollars spent to diagnose and treat women, the value of time lost from productive activities by those living with the disease, and the value of the lives lost prematurely. Estimates of the cost of the illness have proven to be valuable for decision makers in comparing alternative treatments and service delivery systems, determining what groups of people should be targeted to receive improved access to care, and determining program budgets. Advocates have found the estimates helpful in persuading others to focus on this costly disease. However, current estimates of the cost of breast cancer in California are unavailable at the state level. This study will develop estimates of these costs using econometric models and approaches that utilize the best available data.

This project will provide several measures of the economic cost of breast cancer in California. Annual costs will include dollars spent on health care services, the value of lost productivity resulting from time lost for those living with cancer, and the value of lost productivity resulting from premature death from the disease. We will also estimate the lifetime cost of breast cancer over the course of the disease for older women on Medicare and look at how it varies by age and stage at diagnosis and by the type of treatment initially received.

We will estimate the cost of breast cancer using large datasets available from the state and federal government. Annual health care costs will be estimated by adding up the dollars spent for women with a primary diagnosis of breast cancer. We will also include the additional costs for women with other diagnoses but who have a secondary diagnosis of breast cancer. Hospital costs can be estimated in considerable detail, and the other types of costs are built upon these. Lost productivity costs will be estimated by valuing the

time lost as a result of breast cancer at market wages and an imputed value for household production. Lifetime costs are estimated by comparing the total lifetime Medicare expenditures for women with and without breast cancer assuming they are the same in every other way. The difference between these costs is the lifetime cost of breast cancer.

The project will provide the first detailed estimates of the cost of breast cancer at the state level that have been made in over 17 years. Annual cost estimates will be available by age and race/ethnicity, allowing for comparisons among various subgroups of the population. The study will also provide California-specific estimates of lifetime costs of the disease, with separate estimates for women who receive different initial treatments. These data will permit policymakers and advocates to provide economic input to a number of activities and programs that focus on breast cancer.

**Initial
Abstract,
RFA (2003)**

African American Women and Breast Cancer: What Works?

Carol Somkin, Ph.D, Kaiser Foundation Research Institute

Priscilla Banks, African American Advisory Committee on Cancer

African Americans, while diagnosed less frequently with breast cancer than whites, continue to have a greater proportion of women diagnosed with late stage disease and greater mortality from breast cancer. The proposed research focuses on low-income African Americans who do not have health insurance and who are especially at risk for the development of late stage disease. Many of the factors hypothesized to account for the high breast cancer mortality among African American women, such as lack of insurance, lower rates of screening, delayed follow-up and/or treatment, lower quality and/or less aggressive treatment can be viewed generally as access barriers.

While uninsured women have initial access to breast-related services through the state and federal BCEDP/BCCCP programs, there is evidence that compared to other ethnic groups African American women are not utilizing them to the same extent. In a qualitative study, whose goal is to generate hypotheses, we will examine in depth the possible effects of secondary access factors (organizational and communication barriers and facilitators) on the use of breast-related services by low-income, uninsured, African American women. Our focus will be on discovering what it is about the health care settings and interactions with providers and staff that promotes or inhibits the experience of culturally sensitive care for African American women.

We will use qualitative methods (observation and open-ended interviews) to examine the often subtle access barriers that may inhibit low-income, uninsured, African American women from obtaining timely breast-related services and explore factors that may alleviate these barriers. We will conduct observations in clinics to identify features of culturally appropriate settings from an African American perspective. We will also conduct 80 exploratory interviews with low-income, uninsured, African American women who do and do not obtain care along the continuum from no screening to screening, repeat screening, follow-up of a breast abnormality, and detection of breast cancer.

This pilot study uses an innovative approach to the study of cultural competence. It will be conducted by a diverse community group of African Americans who will be involved in all aspects of the project, in collaboration with two traditional researchers. This collaboration will ensure that the findings will be both relevant to the African American community and scientifically sound. We will explore issues of cultural sensitivity in patient-provider/staff communications and the physical and social environment of the health care settings in which the communications take place. This will enable us to develop testable hypotheses not only about each of these areas separately but also about their interrelationships.

Determinants of Breast Cancer Treatment in the Underserved

Rose Maly, Ph.D., University of California, Los Angeles

Breast cancer is a devastating diagnosis under any circumstances, but it can be especially distressing for low-income, uninsured women without sufficient resources to pay for their care. Twenty-four percent of the California population is medically uninsured, with rates estimated as high as 33% in Los Angeles County. Low-income and less-educated women are more likely to be diagnosed with advanced breast cancer, less likely to receive standard treatment, and less likely to survive five years than breast cancer patients in the general population. Devising interventions to reduce suffering and death in this vulnerable population will require identifying the most changeable predictors of receiving appropriate treatment. For example, psychosocial factors, such as the patient-physician interaction or empowering patients to interact with the health care system, are more likely to be alterable than hospital characteristics. However, little research has been done to examine aspects of patient-physician interactions and treatment decision-making that impede or facilitate obtaining optimal treatment, relative to other determinants of care, especially in low-income and underserved cancer patients.

In a defined population of low-income, underserved breast cancer patients we will examine:

1. What patient- (e.g., transportation, competing life needs) and health care system-level factors (e.g., volume of breast cancer patients treated), determine receipt of appropriate breast cancer treatment?
2. What psychosocial studies of public (i.e., the lay public and policy-makers) perceptions of breast cancer, the burden of breast cancer in California, and priorities for research and informational support do low-income, underserved breast cancer patients receive from cancer care providers and from informal and formal support networks at the time of breast cancer diagnosis and treatment?
3. What interpersonal processes of care, especially in patient-physician interaction, mitigate the impact of patient- and system-level barriers on receipt of appropriate breast cancer care?

We will survey 230 low-income (200% federal poverty level or lower), uninsured, newly diagnosed breast cancer patients in Los Angeles County, as identified by the California Breast Cancer Treatment Fund. Participants will be interviewed six months after breast cancer surgery with regard to difficulties encountered in obtaining medical attention and treatment for their breast cancer, individual psychosocial factors (e.g., their social support, confidence in communicating with physicians), and their interactions with their cancer treatment providers and staff. Participants will then be re-interviewed 18 months after surgery about any subsequent patient-provider interactions, reasons for stopping or not beginning any recommended treatment, and their health-related quality of life. To assess health care system-level factors, all cancer providers and practice characteristics will be assessed via mailed surveys. To assess quality of breast cancer treatment received, all participants' cancer-related medical records will be obtained and abstracted. An advisory committee of breast cancer advocates will provide input into questionnaire development and into translation of the study findings into programmatic changes.

The proposed study will be amongst the first to comprehensively identify the most influential determinants at the patient, patient-physician interaction, and health care system levels of receipt of appropriate breast cancer treatment in low-income, underserved women. In so doing, the study will provide a strong empirical foundation for developing the most effective interventions to facilitate appropriate treatment and reduce suffering and death in this vulnerable population of breast cancer patients.

**Initial
Abstract,
RFA (2001)**

Does a Peer Navigator Improve Quality of Life at Diagnosis?

David Spiegel, M.D., Stanford University
Caroline Bliss-Isberg, Ph.D., WomenCare, Santa Cruz

This study is designed to evaluate the effectiveness of a peer navigator program where a woman newly diagnosed with breast cancer is matched with a trained, volunteer, breast cancer survivor. WomenCARE, a well-established Santa Cruz agency, and the Psychosocial Treatment Lab at Stanford, therefore, ask whether newly diagnosed women will improve their quality of life by participating in a peer navigator program. WomenCARE's Peer Navigator Program provides support, peer modeling, and information for recently diagnosed breast cancer patients. Navigators and Sojourners (newly diagnosed women) are matched on group variables in individual rank order of importance. The pairs stay in close contact for a minimum of three months and up to six months if both agree.

This proposal originated in Santa Cruz County. The peer-matched patient navigator concept emanated from the personal experiences of women participating in support groups at WomenCARE and two community-based, patient-focused collaborative meetings. Women across the spectrum of socio-economic, cultural, educational, and ethnic differences expressed the same level of need for mentors. These breast cancer survivors brought their ideas and enthusiasm to the scientists at Stanford. Thus, the study speaks directly to the CBCRP belief that communities should be active participants in research about themselves. The research team was awarded a CBCRP Pilot Grant in July 2000. Together they gathered and analyzed preliminary process data in preparation for a randomized trial. A community-wide network, including key media sources, has begun to disseminate preliminary findings. This network of agencies and doctors is poised to assure widespread dissemination of future findings as they become available.

The major hypothesis of the study is that quality of life at diagnosis and in early treatment is enhanced by the presence of a peer navigator. The notion of a patient navigator is not unique, and there are widespread peer assistance programs throughout the state. However, we believe that this proposal is unique in its quest to study long-term, criteria-matched navigation by peers.

The methodology for this proposal is a randomized trial to test the effectiveness of a peer navigator intervention. An experimental group of at least 70 newly diagnosed women will receive a one-time consultation with a cancer professional. The newly diagnosed women will then be matched according to specified criteria with peer navigators who will provide support for a minimum of three months and up to six months. A control group will receive a one-time consultation with a cancer professional. Standardized quality of life assessments will be administered to both groups at 3, 6, and 12 months. The results of these assessments will demonstrate whether peer intervention results in improving quality of life, self-efficacy, doctor-patient communication, and post-traumatic growth while reducing depression and trauma. Since Navigators are also assessed, the impact of providing peer support will also be measured.

If this project ultimately demonstrates that Peer Navigation is effective in improving a newly diagnosed woman's quality of life, it could provide the impetus for improving the quality of similar programs, stimulate the formation of more programs, and provide evidence to support health policy changes, leading to the establishment of peer navigation programs throughout California as a common component of standard treatment process. All women who participate in the study will benefit from receiving more and better-organized information than they would ordinarily receive.

(Note: This is a continuation of the 2000 CRC Pilot Award.)

For a progress update, please visit CBCRP's Web site at www.cbcrp.org/research/.

Geographic Variation in Breast Cancer Stage at Diagnosis

Pamela Davidson, Ph.D., University of California, Los Angeles

Breast cancer stage at diagnosis (BCSAD) is generally reported in 3 progressive stages:

1. Localized tumors are malignant and invasive but confined to the organ of origin
2. Regional neoplasms have extended beyond the organ of origin into surrounding tissues, involve regional lymph nodes, or both
3. Tumors have spread to remote parts of the body from the primary site

An earlier, more localized BCSAD is highly desirable because it is directly related to survival and mortality, but previous research has shown that the percentages of breast cancer patients with a localized tumor at diagnosis ranged from 40% to 71% in California counties. The individual level patient characteristics (e.g., age, race/ethnicity, health insurance status) associated with BCSAD have been investigated. This pioneering research will focus on the community level factors (health policy and financing, health care delivery system, and community risk factors) associated with better or worse BCSAD that have not been investigated previously.

Data obtained from this study will be used to address two central research questions:

1. How do county-level differences in health policy and financing, local health care delivery systems, and community risk factors influence BCSAD?
2. What are the implications for developing effective community level policies, programs, and health services to improve this cancer outcome?

The research team will obtain county level data from multiple data sources including:

1. Information on female breast cancer patients obtained from the California Cancer Registry
2. A variety of other data sources to obtain information on health policy and financing, health care delivery system, and community risk factors
3. Information obtained from the California Health Interview Survey (CHIS), focusing on access to health insurance and health care, including cancer-related questions developed by the National Cancer Institute.

Data will be analyzed to compare county level differences in BCSAD and the individual and community level determinants. Two members of the project Advisory Board are founders of community based organizations, providing breast cancer consumer education and advocacy programs. Advisory Board members will provide ongoing consultation and advice regarding implications for supporting breast cancer patients and reducing the impact of breast cancer in California.

No studies in cancer health services research have investigated the effects of community level determinants of cancer outcomes in a comprehensive way. However, as information systems and data analysis methods become more sophisticated, researchers are beginning to develop the capacity to obtain and analyze data from a variety of data sources, enabling a more comprehensive analysis of both patient and community characteristics influencing BCSAD. Ultimately, state and local policymakers and health services leaders should have the data to:

1. Develop a better understanding of the community risk factors and resources unique to their geographic area
2. Become more aware of effective community level interventions leading to better cancer prevention and control
3. Have a data driven rationale for allocating resources to improve policies, programs, and health services

**Initial
Abstract,
RFA (2001)**

The Impact of Structure on Quality of Breast Cancer Care

Katherine Kahn, Ph.D., University of California, Los Angeles

Quality of health care is usually conceptualized in terms of the structure of care (e.g., setting, financial, and organizational arrangements), process of care (e.g., education, diagnosis, and treatment), and outcomes of care (e.g., survival, recurrence, and quality of life). Understanding how structure impacts processes and outcomes is vital to quality improvement efforts, yet little is known about the structure of care for patients with breast cancer. The study of structure is necessary to understand how well the health care system is meeting the needs of breast cancer patients, to distinguish the types of medical organizations that deliver adequate and optimal care from those that do not, and to distinguish groups of patients who systematically do and do not receive adequate and optimal support from their health care organizations.

The goal of this study is to understand how the different structural aspects of care impact the quality of care for breast cancer patients. The findings of this work will help policymakers, healthcare organizations, providers, and patients understand ways in which structure of care influences processes and outcomes and identify barriers to optimal care delivery, and will result in recommendations about how to eliminate those barriers and most effectively target quality improvement interventions.

With input from patients and providers in the community, we will develop a valid survey to collect data about the structure of care for breast cancer from individuals at three levels of the healthcare system responsible for providing care: the medical office, the medical group, and the health insurance plan. Topics will include financial incentives and organizational policies that support patients, providers, and coordination of care. Data about the structure of care will be merged with patient data about baseline characteristics, treatments, and outcomes 14 months after diagnosis for a cohort of newly diagnosed breast cancer patients (enrolled in an ongoing study of breast cancer care), will be analyzed to learn what aspects of structure enhance or diminish the quality of care that patients receive.

Although the medical marketplace has begun to recognize that consumers demand quality, many healthcare organizations remain focused on strategies to contain costs. Previous studies examining structure and the quality of care have tended to measure structure very broadly (e.g., comparing fee for service to managed care). Few have addressed the effects of the many new, complex arrangements on quality, particularly in the context of care for breast cancer. Without more precise and detailed information, the ability of policymakers and organizations to design and implement effective quality improvement interventions is severely compromised. The strengths of our study design include:

1. Development of a survey based on previous research and the input of community, patient, and physician advisors to address specific details of structure for breast cancer care
2. Measurement of structural characteristics at not just one, but three important organizational levels of healthcare delivery: the actual provider's office, the medical group, and the health plan
3. Data collection from multiple physician specialties essential to high quality breast cancer care (oncologists, radiation therapists, surgeons, primary care)

These findings will provide a comprehensive view of the quality of care for women with breast cancer and inform policymakers about opportunities for interventions to improve the quality of care and outcomes for breast cancer patients.

Race/Ethnicity, Socioeconomic Status, and Breast Cancer

William Wright, Ph.D., Public Health Institute

Women from different race/ethnic groups or socioeconomic levels in California are not equally affected by breast cancer. The California Cancer Registry (CCR) has collected statewide breast cancer data since 1988, and it is a valuable resource for research on cancer incidence and mortality. The California Women's Health Survey (CWHS) is an annual telephone survey that collects health practices data on random samples of California women. Our research project utilized CCR data and CWHS data to investigate the relationship between race/ethnicity, socioeconomic status, and the stage of breast cancer at diagnosis. There were three specific aims addressed.

Aim 1. *Determine whether the relationship between socioeconomic status (SES) and stage at diagnosis for breast cancer in California varies for different race/ethnic groups.* We employed an innovative statistical method, log-multinomial regression, which to our knowledge has not been previously used to analyze stage at diagnosis for breast cancer or any other cancer. Log-multinomial modeling allowed us to simultaneously evaluate the relationship between SES and in situ, or early stage disease. The relationship between SES and the probability of in situ disease was strongest for Asian/other women, and for early stage disease the relationship was strongest for Hispanic women. Controlling for SES did not eliminate race/ethnic differences in stage at diagnosis. We also found that the relationship between SES and stage at diagnosis for different race/ethnic groups depended on how stage was categorized.

Aim 2. *Investigate whether the relationship between SES and reproductive risk factors for breast cancer differ by race/ethnicity.* SES itself is not a risk factor for breast cancer stage at diagnosis; rather, it is a surrogate for factors such as access to medical care and utilization of breast cancer screening procedures. We evaluated CWHS data to determine whether the relationships between SES and factors related to breast cancer stage at diagnosis could help explain the relationships between SES and stage at diagnosis observed in Aim 1. Women with high SES were more likely to have had a mammogram or a clinical breast exam. This relationship was strongest for Asian/others, and may explain the strong relationship between SES and the probability of in situ disease among Asian/other women. SES was inversely related

to body mass index (BMI) for all race/ethnic groups; that is, as SES increased BMI decreased. Small, early stage breast tumors are more difficult to detect in women with high BMI (i.e., women who are overweight or obese). This relationship between SES and BMI was greatest for Hispanics, and may explain the strong relationship between SES and the probability of early stage disease observed among Hispanic women in the CCR data.

Aim 3. *Evaluate the importance of considering race/ethnicity when calculating breast cancer incidence rates.* We showed that, due to the way race data were collected on the 2000 US Census, the CCR will be unable to calculate race-specific breast cancer incidence rates for cases diagnosed in 2000 and beyond. That is, now that the census' characterization of race ethnicity in the US population (our denominator in rate calculations) has changed, it is no longer entirely compatible with cancer case counts (our numerator), which is derived from hospital records. Furthermore, for the same reason, the CCR will be unable to monitor race-specific trends in breast cancer incidence rates.

These preliminary results provide insight on the unequal burden of breast cancer in California. These results may be useful for designing more effective interventions that will target certain race/ethnic groups who are at risk of being diagnosed with late stage disease. These results also identify a potential concern regarding monitoring race-specific breast cancer for cases diagnosed after 2000.

**Final Report,
IDEA
(2000)**

Breast Health Project for Hmong Women and Men

Marjorie Kagawa-Singer, Ph.D., M.N., R.N., University of California, Los Angeles

Mary Anne Foo, M.P.H., Orange County Asian and Pacific Islander Community Alliance

Breast cancer is the leading cause of cancer death in Asian American and Pacific Islander (AAPI) women, yet AAPI women have the lowest screening rates, in aggregate, of all ethnic populations (only 45% of AAPI women report ever having a mammogram). Very little information exists on the breast screening and early detection practices of AAPIs. Although over 57 groups comprise the AAPI category, and they constitute 10.7% of the US population, only seven published manuscripts exist on four groups of AAPI women: Chinese, Vietnamese, Native Hawaiian, and Cambodian women. No studies have been published on Hmong breast screening practices, and these women probably have the lowest screening rates of all AAPI women (25.6% ever having had a mammogram).

This is the first intervention project to focus on Hmong women and breast cancer. Our goal is to test a culturally competent and effective breast health program through two research questions:

1. Will a culturally identified mode of health promotion and the enlistment of husbands and male community leaders increase the use of breast screening and early detection practices by Hmong women?
2. What elements of the tailoring process of breast cancer education outreach are required to motivate Hmong women to obtain mammograms compared to other hard to reach populations?

We propose two innovative strategies to reduce inequities in breast cancer outcomes and disseminate needed information to the community:

- To enlist the support of Hmong men in the community to capitalize on the cultural strengths of social support and decision making styles and the community's capacities to ensure their well-being
- To analyze the cross-cultural theoretical constructs and successful strategies of other programs in hard-to-reach ethnic minority populations in order to identify culturally specific educational elements

that require tailoring for cultural congruence to increase effectiveness, and to identify universal strategies that could be implemented without change to develop more cost effective health promotion programs in the future

Our pilot data indicated that Hmong women expressed a desire for more information and to have the men included in education, and a willingness to go for screenings. We know of no published studies of any ethnic group that have used the strategy of enlisting the men or male leaders of sociocentric or familial cultural groups to promote the use of breast screening services for the early detection of breast cancer.

We will implement the study in three communities: two intervention and one comparison community. In year one the team will design a culturally-based intervention for women and men, develop the educational materials based on our previous CBCRP-funded pilot study findings, and conduct baseline assessments of current community practices, screening rates, and breast health resources. In year two we will implement the intervention in two communities. And in year three we will conduct process-and-impact evaluations and implement the intervention in the comparison community.

We hypothesize that there will be significant improvement in mammograms, BSE, and CBE due to our intervention, and that subsequent programs in AAPI populations and other underserved populations could be designed with greater effectiveness and in a more cost effective manner.

For a progress update, please visit **CBCRP's** Web site at www.cbcrp.org/research/.

(Note: This is a continuation of the 1997 CRC Pilot project, "Breast Screening Program in the Hmong American Community.")

Returning to Work and Quality of Life after Breast Cancer Surgery

Diane R. Estrin, Women's Cancer Resource Center

Rani B. Eversley, Ph.D., University of California, San Francisco

This pilot project has three specific aims: (1) to develop measures to assess perceived support in the workplace (employer support, co-worker support) for women who are attempting to return to work following breast cancer surgery; (2) to test measures to assess perceived support in the workplace (employer support, co-worker support) for women who are attempting to return to work following breast cancer surgery; and (3) to examine the relationship between perceived support in the workplace and the length of time to return to work among women following breast cancer surgery.

Twenty-seven women participated in four focus groups to identify sources of support for returning to work after breast cancer surgery. Pilot survey data was collected from 116 women who had undergone breast cancer surgery.

The mean age of the women who participated in the pilot survey was 47(29-68). Thirty percent were Caucasian, 30% African American, 25% Latina, and 15% women of other ethnic backgrounds. Thirty-seven percent of the women surveyed were currently working full time, 32% part-time, 18% unemployed, 11% percent were of unknown work status. Forty percent reported that they changed jobs after undergoing breast cancer surgery, 17% were terminated or laid off after breast cancer surgery, and 29% felt that they were harassed at their jobs after breast cancer surgery. Sixty-nine percent reported a change in their pay after breast cancer surgery. For the majority of women this appears to be a loss in pay; the mean monthly income prior to breast cancer surgery was \$1812, the mean monthly income after undergoing surgery was \$1167. The mean number of weeks off work reported by the study population was 26(0-144). Race/ethnicity was associated with amount of time off from work and with being off from work one year after surgery. Caucasian women reported a mean number off 23(14-33) weeks off from work, African American women reported a mean of 37(24-50) weeks off from work, and Latina women reported a mean of 11(5-18) weeks off from work ($p<0.01$). African

American women (29%) were almost twice as likely to not be working after one year compared to Caucasians (16%) ($p<0.01$). Four percent of Latinas were out of work after one year. In a multivariate (least squares regression) model to examine the independent associates of the amount of time out of work, children living at the home ($p<0.05$), enrollment in public benefits programs ($p<0.01$) and mastectomy ($p<0.01$) were independently predictive of the number of weeks taken off. Ethnicity, stage of disease, and the new support measures were not independently associated with number of weeks off work.

Our data supports the published literature in finding a high prevalence of problems with returning to work. The data also supports the published literature in finding ethnic differences in returning to work. In our data the ethnic associations appear to be modified by the presence of dependent children, surgical procedure, and receiving public disability. The other new findings from this data include the relative short period of return to work among Latinas and the dramatically lower rate of receiving disability among Latinas, despite relatively high levels of disease progression. This finding warrants additional investigation and may be associated with immigration status.

(Note: The continuation of this project was funded as a CRC full award in 2001.)

**Final
Report,
CRC Pilot
Award
(1999)**

Study of Inadequate Follow-Up of Mammographic Abnormalities

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Arthur H. Coleman, M.D., Bay View Hunters Point Health Care Task Force
Marion M. Lee, Ph.D., University of California, San Francisco

The ultimate goal of this research is to decrease breast cancer morbidity and mortality among African American women in San Francisco. We aimed to identify and describe, from the patient's perspective, factors in their personal and social environment, as well as in the health care delivery system that create barriers to timely, adequate follow-up of abnormal mammograms.

Factors in the personal and social environment of women, as well as in the health care delivery system, are associated with inadequate follow-up of mammographic abnormalities.

In pursuing this area of research, we seek to answer a perplexing question and address an area of concern voiced by the African American community; that is, why is the breast cancer mortality rate higher in African American women compared to whites, and what role does inadequate follow-up play in explaining these racial/ethnic disparities?

Qualitative: First, we conducted in-depth interviews with eight breast cancer experts to identify and explore the reasons why women do not receive timely follow-up of abnormal mammography. Second, we conducted four 2-hour focus groups to explore three domains:

- Issues of social support
- Perceptions of disease and of the health care system
- Logistical barriers, including social and economic influences

Quantitative: Key informant and focus group data contributed towards the development of a culturally specific questionnaire pilot-tested among 51 African American women with abnormal mammograms.

Key informants indicated that access to care, previous experience with the health care system, and family factors (e.g., competing priorities and physician communication) were important predictors of timely follow-up. Several themes appeared within the four focus groups: fear, satisfaction or dissatisfaction with the health care system, time, belief in God, the need for information, and the need for social support were the most common. Fear was expressed most often and was linked to the experience of getting a mammogram, both in the expectation of a painful mammographic procedure and the contemplation of the possibility that the results might reveal a malignancy. Fear was also linked to the loss of a breast or breasts. Fear was considered a barrier and a promoter to follow-up of abnormal mammograms and was often considered the cause of denial.

The earlier breast cancer is diagnosed and treated, the greater the likelihood of long-term survival. Untimely follow-up may negate the benefits of early detection through mammography screening, and inadequate follow-up of abnormal mammograms might explain some of the ethnic differences in breast cancer survival. A full-scale study to further elucidate predictors of inadequate follow-up is planned.

Samoans and Breast Cancer: Evaluating a Theory-Based Program

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Despite the high site-specific incidence of breast cancer and low levels of both awareness and utilization of screening and early detection examinations, no educational programs have been tested among Samoan women. We implemented and evaluated an innovative, theory-based, culturally sensitive, and linguistically appropriate breast cancer control educational program (“intervention”) specially developed for Samoan women. Specific aims were, first, to implement and evaluate (using behavior change theory) the intervention’s effectiveness in enhancing knowledge, modifying attitudes, and most importantly, effecting positive behavior change. Our second aim was to identify individual and structural factors that facilitate or impede behavior change. The outcome of primary interest is the receipt of a mammogram.

We prospectively followed eligible Samoan women recruited from study sites (61 Samoan-speaking churches) in Los Angeles and Orange counties, who were then randomly assigned to two study groups (experimental and control). Over a period of eight months, we administered two surveys (pretest and post-test) and the intervention (to experimental group women after the pretest survey). Eligibility criteria for inclusion included Samoan heritage, age 42 years or older, and no mammogram utilization (never or not within the prior two years). The intervention consisted of three components: specially developed English- and Samoan-language educational materials, skills-building exercises, and interactive group discussions. The intervention addressed different aspects of breast cancer (i.e., risk, severity, susceptibility, screening, and early detection exams).

We surveyed 809 eligible women (experimental group = 406, control group = 403) at the pretest and resurveyed 776 women (experimental group = 391, control group = 385) at the post-test. In addition, we conducted the intervention among 389 experimental-group women.

Preliminary analyses at the pretest revealed that 58.7% of women aged 42 years or older had never had a mammogram and 59.7% of women had never had a clinical breast exam (CBE). Bivariate analyses of socio-demographic variables and mammography utilization revealed that women proportionally more likely to have never had a mammogram were those who were: older (aged 65 years or older), less educated (8 years or fewer), uninsured, unemployed (with <\$10,000 yearly family income), and interviewed in Samoan. Furthermore, multivariate analyses revealed that Samoan women were more likely to have ever had a mammogram if they had positive group norms for obtaining a mammogram, health insurance, positive belief in the efficacy of mammography, fewer misconceptions regarding the causes of breast cancer, fewer culture-specific beliefs regarding the causes of breast cancer, and higher self-efficacy. Analyses to assess the efficacy of the intervention are in progress.

This study underscores the disparate under-utilization of breast cancer screening and early detection examinations by Samoan women. This project enhances breast cancer awareness, increases screening and early detection rates, and over time, could potentially lower morbidity and mortality from the disease in this marginalized community.

**Final Report,
CRC Full
Award (1998)**

Does Mobile Mammography Increase Screening in Older Women?

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Despite consensus that older women should receive screening mammography, screening rates remain sub-optimal. Mobile mammography has the potential of increasing mammography rates in older women; however, its effectiveness in this population is essentially untested.

We conducted a randomized clinical trial to determine the additional benefit of offering on-site screening mammography beyond a health education intervention for low-income, ethnically diverse, urban dwelling older women.

Screening for the study was conducted at 60 community sites where older persons gather. A total of 684 women aged 60–84 years met the eligibility criteria for the study and 73% (n=501) of these participated in the study. Of these, 254 were randomly assigned to the combined health education and mobile mammography group and 247 were assigned to the health education only group. Three months following the intervention, we determined whether a mammogram had been performed since study enrollment on 93% (n=467) of participants.

Our results indicate that the availability of the on-site mammography resulted in higher rates of mammography among these older women (54% versus 39%, p=.0146) compared to those who

received only health education. Of particular interest, on-site mammography availability appeared to be especially effective compared to education only in non-Caucasian women, including African American (64% versus 50%, p=.291), Hispanic (53% versus 29%, p=.016+) and Asian and Pacific Islander (67% versus 38%, p=.024), with the latter two achieving statistical significance. Of the 129 mammograms reported by women who had access to on-site mammography, 120 (93%) were administered on site.

Further analyses will focus on predictors of mammography use among women in both arms of the trial and cost effectiveness of mobile mammography in this population (e.g., the number that would need to be screened at each site to make it cost effective).

These findings will provide further support for mobile mammography as a means of increasing adherence with this important preventive service and may be a particularly effective strategy for populations who have historically low screening rates.

Increasing Breast Health Access for Women with Disabilities

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Ann Cupolo Freeman, Alta Bates Medical Center
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Women with disabilities have been neglected in breast cancer statistics; national, state, and local screening initiatives; screening services; and education. To address these gaps, this project is studying five key research questions:

1. What is the prevalence of barriers to breast screening among women with physical disabilities?
2. Are these barriers, the differences in types and severity of functional limitation, and age and ethnicity associated with differences in screening utilization?
3. To what extent do the outreach, education, and service delivery strategies employed to date by the Breast Health Access for Women with Disabilities (BHAWD) coalition reduce barriers to screening?
4. What changes are needed in BHAWD strategies and in health policy to increase access to breast screening for women with disabilities?
5. What are the prospects for disseminating the BHAWD program to other California communities?

Objectives 1–2 are being studied through secondary analysis of the 1994 National Health Interview Survey (NHIS), its Health Promotion and Medical Access supplements, and its Disability Followback. Results show that regardless of how disability is defined (Activities of Daily Living, Instrumental Activities of Daily Living, Functional Limitations, or having a mobility problem), the odds of being up-to-date with mammograms decrease with the number of physical limitations ($p < .0001$). In all models, the Odds Ratio is better for African Americans than for whites and for women ages 50–64 than 40–49. Being age 75 or older (compared to ages 40–49) decreased the OR. Variables on barriers to screening constructed from the NHIS data are currently being refined after which final models will be run.

Because analysis of the NHIS data set is subject to several constraints, a survey of 320 local women with disabilities was conducted to address objectives 1–3. Analysis of these data is in progress. To address objective 4, the BHAWD Coalition is collaboratively developing a manual that critically reviews BHAWD's experience in increasing breast health access and makes related program and policy recommendations. This manual is in advanced draft form, and when completed will be used in a statewide survey of agencies to address objective 5.

Next steps are to complete the following:

1. Analyze and report the NHIS data
2. Analyze and report the local survey
3. Complete the final draft of the BHAWD manual
4. Complete the dissemination study

Project findings will reduce the human and economic impact of breast cancer for women with disabilities by filling an information void and by informing further research, policy initiatives, and the development of breast screening and education programs.

**Progress
Report,
CRC Full
Award
(1998)**

The Breast Care Center: Innovative Care for the Underserved

Jay Kenneth Harness, M.D., Northern California Cancer Center

Final Report, ITaMoCA Award (1997)

This project has been a controlled evaluation of the effectiveness that Breast Care Centers (BCC) based in county medical centers have in bridging the gap between professionally trained providers and indigent patients with breast cancer. The goal is to foster the provision of care at the highest professional level for indigent women with breast cancer, which facilitates patient adherence to the appropriate clinical recommendations.

The experience of women with breast cancer treated at the Highland Campus of the Alameda County Medical Center (HGH), a county medical center that is working to develop a BCC, has been compared with the experience at the Contra Costa Regional Medical Center (CCRMC), another Bay Area county medical center hospital that does not have an established Breast Care Center. This evaluation was based on the results of interview surveys completed by the patients, medical record data documenting clinical characteristics of the disease, clinical recommendations, and patient adherence to those recommendations. Data collection has been completed at both HGH and the CCRMC. Initial interviews have been conducted with 86 women at HGH and 94 women at CCRMC, and data from those interviews entered into the data-set.

Interim comparative analyses found differences in the respondents' family backgrounds, medical care histories, the short term effects of the care received, the psychosocial effects of being evaluated for clinically suspicious findings and the respondents' satisfaction with different aspects of the care received. Many of the difficulties the respondents reported were linked more to institutional coordination problems than to their indigence or cultural backgrounds. Similar coordination and other inter-provider communication difficulties can be found in the care of more affluent cancer patients.

To address this lack of coordination, the project team has developed and implemented a prospective computerized database at HGH that both generates concise summaries of the current status and clinical recommendations made for the care of all patients reviewed by the HGH Tumor Board, and facilitates tracking the care system's adherence to the Tumor Board's recommendations. Initial steps have been made to extend this approach to the care provided to specific other cancers in other facilities. Imperfections in the coordination of care and the communication among providers adversely affect the cancer care provided in many facilities. The effects of such poor coordination can be particularly severe when patients present with diseases at advanced stages, as is often the case with indigent patients.

This project has fostered the development of database techniques that can be used to improve the coordination of care and communication among providers. This strategy will foster more consistent, timely care, eliminating disorganization and delay. This project has fostered the development of a relatively inexpensive organizational model that can benefit the patient care in different facilities and care-providing organizations that have a variety of social, cultural, and economic backgrounds.

Increasing Annual Recall in State Early Detection Programs

Nicole A. Howard, CHG Foundation

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Research has demonstrated that mortality can be reduced by up to 30% with regular mammography and clinical breast examination (CBE) for women age 50 and older. California's Breast Cancer Early Detection Program (BCEDP) and the Breast and Cervical Cancer Control Program (BCCCP) provide free breast cancer screening to low-income and under- or uninsured women. These programs have been extremely successful in providing initial screening exams; however, evidence suggests that the target population is not adhering to recommended guidelines for annual CBE and mammography every 1–2 years.

The identification of interventions that show potential for increasing compliance for annual re-screening was the primary research question to be answered. In an attempt to learn more about re-screening practices, we carried out the following activities:

1. Reviewed the existing literature to identify interventions that show promise for increasing compliance with annual re-screening
2. Surveyed providers to determine the types of tracking systems that facilities use in order to recall patients for annual screening
3. Reviewed 331 medical records of BCEDP/BCCCP consumers to determine the percentage of clients who were reminded by clinic staff to make an appointment for re-screening
4. Calculated baseline re-screening rates
5. Interviewed consumers to determine factors that influenced their decision whether or not to be re-screened

Among women in our study sample, we calculated a 32% compliance rate with annual re-screening. Of the 106 women who had been seen for a re-screening CBE in 1997, 68.9% received a reminder from the primary care provider. Of the 225 women who had not been seen for a re-screening CBE in

1997, only 38.7% received a reminder. This data suggests that reminders may play an important role in getting women to return for re-screening. However, compliance rates may still remain low with standard anniversary date reminders, since it is likely that many consumers will be lost to follow-up after a period of 12 months. Of consumers initially selected for inclusion in the study, 27.2% could not be contacted (e.g. disconnected telephone, interviewers reached a wrong number, etc.). An additional 25.7% of women could not be reached after repeated calls, suggesting that they too may be difficult to reach with standard re-screening reminders. Women who we were able to be contacted were more than twice as likely to have been compliant with annual CBE re-screening as compared to those who could not be contacted. In order to maximize compliance, we believe that interventions delivered during the 12-month interval between initial and repeat screening may be more effective than standard anniversary date reminders.

Our survey data show that consumers may not be established patients of the BCEDP/BCCCP providers—20.9% of consumers reported a sick visit to the provider during the preceding 12 months and only 7.0% reported visiting the provider for other preventive services. Interventions designed to strengthen the patient-provider relationship may improve compliance with annual re-screening, as it has been well documented that physician referral is a strong predictor of adherence to regular screening.

**Final
Report,
CRC Pilot
Award
(1997)**

Breast Cancer Knowledge/Attitudes: California Pacific Islanders

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California represents a major gateway for Pacific Islanders into the United States. According to the 1990 census, California's populations of Guamanians (25,059) and Tongans (7,919) are the largest outside of these islands. Data from the California Cancer Registry show breast cancer is the most common cancer site for these Pacific Islander American women. This two-year study examined the breast cancer knowledge, attitudes and screening behaviors of two groups of Pacific Islander women—Chamorros (indigenous Guamanians) and Tongans—aged 40 and older in Los Angeles and Orange Counties.

A core philosophy of this study was its partnership with community-based organizations in each of the collaborating communities. Together with the Guam Communications Network, Inc. and the Tongan Community Service Center, this project identified community-relevant and culturally-appropriate strategies for survey design, informant identification, survey administration and analyses.

Between November 1997 and June 1998, 530 women (227 Chamorros and 303 Tongans) completed the surveys. Regarding ever having received a breast cancer screening, among Tongans, 25.7% ever had a clinical breast exam, 25.1% ever had a mammogram, and only 40.4% ever performed a breast self examination. Among Chamorros, 92.8% ever had a clinical breast examination, 76.8% ever had a mammogram, and 37.3% ever performed BSE. According to the American Cancer Society's guidelines for yearly CBE and mammograms, for Tongans only 12.9% had yearly CBEs and 10.2% had yearly mammograms. For Chamorros, while 66.2% had yearly CBEs only 25.3% had yearly mammograms.

Many barriers to screening were identified, including cost, language, and lack of knowledge for both populations.

Harnessing Technology to Improve Mammography Effectiveness

Laura Esserman, M.D., University of California, San Francisco

While mammographic screening is not a cure for cancer, the early detection of breast cancer through screening offers the greatest potential to decrease mortality and thus decrease the human and economic costs of breast cancer. Enormous variation in the interpretation of mammograms and in the recommendations for further evaluation of abnormalities has huge economic and psychological consequences. Others have addressed variation in interpretation of mammograms in the US. We have focused on international interpretation. Cancer to biopsy ratios in Europe and Scandinavia are much higher than those in the US (prior to any biopsy, stereotactic or open). Given this discrepancy, a key question to resolve is whether lower biopsy rates result in lower sensitivity. We investigated whether sensitivity was a function of biopsy rates or of volume and experience.

We have completed a study of mammography interpretation by volume of mammographic cases read in California. We used a standard set of films read by all mammographers in the UK as part of a quality assurance program. In addition to the 60 mammographers in California, mammographers from two high volume mammography programs in Sweden also read the standard film set. Mammographers in the UK, on average, read 1200 cases per month, and are therefore characterized as high volume readers. This allowed the construction and comparison of ROC curves by volume. The analysis of this data effectively demonstrated that there is indeed a correlation between volume of mammograms read and an increase in both sensitivity and specificity. This volume-outcome relationship is at least one factor that promotes efficiency and quality in mammographic services.

Using data from the randomized controlled trials of mammography in Malmo and Stockholm, we are investigating the relationship between experience over time and cancer to biopsy rates (i.e., whether there is a learning curve that has developed as a result of a high-volume, centrally organized screening program). Preliminary data suggests that sensitivity has remained constant over a twenty-year period, cancer to biopsy rates increased, and both interval cancers and false-negative rates have decreased during the same period, demonstrating that increased specificity is learned over time, without impact on sensitivity. Evaluation of the lower cost, more centrally organized approach to screening in both the UK and Sweden suggest that the reorganization of services in California could indeed decrease cost and significantly improve the quality of care. We are currently completing an overview of the Northern California market for mammographic screening. We will construct a market plan that will focus on the different options available to leverage the volume/quality relationship using dedicated, high-volume mammographers. We will present alternative ways of concentrating among high-volume readers who most enjoy this work. In addition, we will explore whether tele mammography can facilitate mammographic services among high-volume readers.

**Final Report,
Research
Project
Award
(1996)**

Promoting Early Detection of Breast Cancer Among Vietnamese

Stephen J. McPhee, M.D., University of California, San Francisco

Final Report, Research Project Award (1995)

The purpose of this project was to increase access to early breast cancer detection services by Vietnamese women. To reduce cultural and economic barriers to breast screening services, we set up a Vietnamese Women's Health Center in a storefront in East Oakland, California. Outreach activities regarding breast screening included

1. Providing counseling, appointment-making assistance, and referrals to free screening services, conducting small group educational sessions, sponsoring health fairs and contests, and distributing culturally appropriate, Vietnamese-language educational materials, including printed brochures, calendars, referrals lists, and a videotape
2. Sponsoring a Vietnamese-language print and electronic media campaign, including publication of a series of newspaper articles and advertisements and broadcasting a series of television and radio interviews and advertisements
3. Involving Vietnamese physicians in in-office distribution of educational materials, an annual health fair, and an annual Continuing Medical Education session

To evaluate the effectiveness of the intervention, we used a pretest/post-test control group design. Alameda County served as the intervention community; Los Angeles and Orange Counties served as the control community. We conducted computer-assisted telephone interviews of separate cross-sectional, random samples of Vietnamese adult women in both communities at pretest in 1995 and at post-test in 1998.

Results showed that between pre- and posttest, women in the intervention community had significant increases in plans to have a clinical breast examination (CBE) but not in recognition, receipt, or currency of CBE. However, rates of CBE recognition, receipt, and plans also increased significantly in the control community. Between pre-

and post-test, women in the intervention community had significant increases in recognition, receipt, plans, and currency of mammography, but rates of mammography recognition, receipt, plans, and currency also increased in the control community. In multiple logistic regression analyses, women in the intervention community at post-test were not more likely to recognize, receive, plan, or be up-to-date for CBE, and were significantly less likely to recognize, receive, and plan mammograms than women in the control community. However, women who reported greater exposure to the various intervention elements were significantly more likely to have heard of, had, and plan a CBE and to have heard of, had, and plan a mammogram than women with lesser exposure.

We conclude that, although the intervention had no beneficial effect among Vietnamese women in the community at large, it had a modest positive impact on those women who reported exposure to the intervention.

Determinants of Breast Conserving Surgery and Survival

Cyllene R. Morris, Ph.D., Public Health Institute

Breast conserving surgery (BCS) is an equally effective alternative to mastectomy for most women with stage I or II breast cancer and is now the recommended alternative for these cases. However, even though BCS utilization has increased in California, 37% of women with small early stage tumors still received a mastectomy in 1996. The physical and psychological impact associated with unnecessary mastectomies represent a human cost that can be minimized by understanding which factors affect the choice of surgical treatment. The purpose of this study was to uncover some of these factors. The specific aims of the project were to:

1. Determine statewide trends of BCS utilization
2. Determine the most significant predictors of choice of surgery for BCS eligible women
3. Compare the five year survival experience of women receiving BCS and BCS eligible women receiving mastectomies

The study was based on early stage breast cancers diagnosed from 1988 through 1996 and reported to the California Cancer Registry (CCR), which is considered to have complete statewide coverage. Our analysis indicates that women of Asian or Hispanic race/ethnicity, 65 years and older, currently married, diagnosed with a centrally located, stage II lobular or comedo carcinoma, residing in less affluent areas, or in a county without a radiation facility were the least likely to receive BCS in California. On the other hand, African American women were more likely to receive BCS than women of any other race/ethnicity. Despite these differences, BCS utilization is increasing steadily in California. The rate of increase in BCS is similar among women of all race/ethnic groups, and is also similar regardless the socioeconomic status in the patient's neighborhood.

The third aim of the project, a comparison of survival for BCS or mastectomy recipients, has been deferred until survival data gathered by the CCR are complete. Understanding patterns of BCS utilization is an important step towards ensuring that California women with breast cancer have an informed choice about their treatment.

**Final
Report,
New
Investigator
Award
(1995)**

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