



CALIFORNIA
**Breast
Cancer
Research**
PROGRAM

**COMMUNITY RESEARCH
COLLABORATION (CRC) AWARDS**

FUNDED by the
**CALIFORNIA BREAST
CANCER RESEARCH
PROGRAM**

1997–2003

For more information about CBCRP's
community research collaboration award type,
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Community Research Collaboration (CRC)

The **California Breast Cancer Research Program** (CBCRP) is eager to increase awareness of its activities among community groups interested in breast cancer.

The CBCRP believes that innovative and creative research is best achieved by bringing together people with different perspectives to share their knowledge, skills, and experience. Furthermore, the CBCRP believes that breast cancer survivors, advocates, activists, and concerned community members must be included in these partnerships because they bring their own unique, valuable perspective to the process.

In 1997, the CBCRP created Community Research Collaboration awards (CRCs) to bring community members and experienced researchers together to study breast-cancer related issues that are of interest to both groups.

This booklet contains abstracts of all CRC projects funded to date. Some of these projects are complete, others are in progress, and others are just underway.

CRC Awards are grouped by the CBCRP's nine Priority Issues:

- Health Policy and Health Services: Serving Women's Needs
- Sociocultural, Behavioral, and Psychological Issues Relevant to Breast Cancer: The Human Side
- Etiology: Finding the Causes
- Earlier Detection: Improving Chances for a Cure
- Innovative Treatments: Search for a Cure
- Racial/Ethnic Differences in Breast Cancer: Eliminating Disparity
- Biology of the Normal Breast: The Starting Point (no CRCs to date)
- Prevention: Ending the Danger of Breast Cancer (no CRCs to date)
- Pathogenesis: Understanding the Disease (no CRCs to date)

For more information on the entire portfolio, see the CBCRP's web site at www.cbcpr.org

CRC FUNDED GRANTS: Listed by Priority Issue

EARLIER DETECTION: Improving Chances for a Cure

- Breast Screening Program in the Hmong American Community (1997 Pilot Award; 1999 Full Award) page 7
- Increasing Annual Recall in State Early Detection Programs (1997 Pilot Award) page 8
- Increasing Breast Health Access for Women with Disabilities (1998 Full Award) page 9

ETIOLOGY: Finding the Causes

- Breast Cancer Risk Factors: Lesbian and Heterosexual Women (1997 Pilot Award; 1998 Full Award) page 10
- Marin County Breast Cancer Study of Adolescent Risk Factors (1998 Pilot Award; 1999 Full Award) page 11

HEALTH POLICY and HEALTH SERVICES: Serving Women's Needs

- Study of Inadequate Follow-Up of Mammographic Abnormalities (1998 Pilot Award) page 12
- Samoans and Breast Cancer: Evaluating a Theory-Based Program (1998 Full Award) page 13
- African American Women and Breast Cancer: What Works? (2002 Pilot Award) page 14

INNOVATIVE TREATMENTS: Search for a Cure

- A Community-Based Workbook for Helping Rural Cancer Patients (1997 Pilot Award; 1999 Full Award) page 15
- The Efficacy of a Retreat for Low-Income Women with Breast Cancer (1997 Pilot Award) page 16
- Do Community Cancer Support Groups Reduce Physiological Stress? (1998 Full Award) page 17
- Chemotherapy-Induced Ovarian Damage: Prevention and Impact (2002 Pilot Award) page 18

RACIAL/ETHNIC DIFFERENCES: Eliminating Disparity

- Correlates of Lymphedema Severity and Access to Intervention (2003 Pilot Award) page 19
- Reducing Disparities Among Korean Women (2003 Pilot Award) page 20

SOCIOCULTURAL, BEHAVIORAL, and PSYCHOLOGICAL ISSUES: The Human Side

- Returning to Work and Quality of Life after Breast Cancer Surgery (2001 Full Award) page 21
- Returning to Work and Quality of Life after Breast Cancer Surgery (1999 Pilot Award) page 22
- Alternative Support for Rural and Isolated Women in an HMO (1999 Full Award - based on 1997 Pilot, see page 15) page 23
- Does a Peer Navigator Improve Quality of Life at Diagnosis? (2000 Pilot Award; 2001 Full Award) page 24
- Breast Cancer Prevention and Control Among Deaf Women (2001 Pilot Award) page 25
- Efficacy of a Community Program in Increasing Access to STAR (2001 Pilot Award) page 26
- A Network-Based Intervention for Chamorros in Southern California (2001 Full Award) page 27
- Effectiveness of Internet vs. Face-to-Face Support Groups (2001 Full Award) page 28

INDEX

page 29

COMMUNITY RESEARCH COLLABORATION

Breast Screening Program in the Hmong American Community

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Mary Anne Foo, M.P.H., and Sora Park Tanjasiri, Dr.PH, 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 our Web site at www.cbcrp.org/research/.

**Initial
Abstract,
Full Award
(1999)**

COMMUNITY RESEARCH COLLABORATION

Increasing Annual Recall in State Early Detection Programs

Nicole A. Howard, CHG Foundation

Gregory A. Talavera, M.D., M.P.H., San Diego State University

Final Report, Pilot Award (1997)

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.

COMMUNITY RESEARCH COLLABORATION

Increasing Breast Health Access for Women with Disabilities

Mary E. Smith, M.S., C.R.C., Disabled Community Health Clinic, Alta Bates Medical Center
Ann Cupolo Freeman, Alta Bates Medical Center
Carol D'Onofrio, Dr:PH, Northern California Cancer Center

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
Year 3,
Full Award
(1998)**

COMMUNITY RESEARCH COLLABORATION

Breast Cancer Risk Factors: Lesbian and Heterosexual Women

Suzanne L. Dibble, D.N.Sc., Lyon-Martin Women's Health Services
Stephanie Roberts, M.D., University of California, San Francisco

Final
Report,
Full
Award
(1998)

Scientists have explored the risk factors for the development of breast cancer with the small amount of information that is "known" about lesbians, and have proposed that the risk of developing breast cancer may be two to three times higher for lesbians than for heterosexual women. The purpose of this project was to determine whether lesbians have a higher risk profile for the development of breast cancer compared to heterosexual women. We distributed surveys to lesbians age 40 and older throughout the state of California. Additionally, we asked each lesbian participant to have a heterosexual female friend who lives in California and a sister (if they have one) closest in age to fill out an identical survey.

A total of 765 women (255 per group) contributed data to the triad analysis. There were no significant differences in age, ethnicity, employment status, or insurance status among the three groups. Lesbians had significantly more education than either their friends ($p < .001$) or sisters ($p < .001$). Lesbians were more likely to live in urban areas (50%) than their sisters (31%, $p < .001$). Lesbians had significantly ($p < .02$) less live births, miscarriages, and abortions when compared to their sisters and friends. Lesbians used birth control pills significantly less when compared to their sisters ($p < .001$) and friends ($p < .001$). There were no significant differences in current alcohol use between lesbians when compared to their sisters or friends; however, lesbians reported significantly more problems with alcohol than either their friends ($p < .001$) or sisters

($p = .001$). Lesbians currently smoked significantly less than their sisters ($p = .014$) and had a history of smoking more when compared to their friends ($p = .016$) or their sisters ($p = .023$). Lesbians had a significantly higher BMI (weight to height ratio) than their friends ($p = .009$) or their sisters ($p = .009$). There were no significant differences in weekly exercise, being a vegetarian, or eating a low-fat diet among the groups. There were no significant differences in breast self exam rates or clinical breast examination rates among the groups. Lesbians had statistically significant more breast biopsies than their friends ($p = .006$) and more biopsies ($p = .003$) and mammograms ($p = .005$) than their sisters. There was a trend that the lesbians had more diagnoses of breast cancer (7.8%) than their friends (3.9%, $p < .08$). When the sisters ($n = 324$) were compared using the Gail Risk Model, the lesbians had a significantly higher 5 year (1.2 vs 1.1; $p < .001$) and lifetime risk for developing breast cancer (11.1 vs 10.6; $p = .011$).

In summary, lesbians may have a higher risk profile for developing breast cancer; but it is by no means two or three times higher than for heterosexual women.

COMMUNITY RESEARCH COLLABORATION

Marin County Breast Cancer Study of Adolescent Risk Factors

Margaret Wrensch, Ph.D., University of California, San Francisco

Mary Gould, Marin Breast Cancer Watch

Georgianna Farren, M.D., Marin Breast Cancer Watch

Marin Breast Cancer Watch (MBCW) is a grassroots, nonprofit organization of approximately 350 members, established in 1995 because of community concern about the high incidence of breast cancer in Marin County. MBCW's long range goal is to discover risk factors that may lead to a reduction of breast cancer. With the University of California, San Francisco, we are investigating the question: did adolescent and pre-adolescent experiences differ between women with and without breast cancer in Marin County? Specific factors of interest are: (1) physical development and changes; (2) adolescent stress, family, and social connections; (3) detailed adolescent and contemporary socioeconomic factors; (4) passive and active smoking; (5) alcohol use; (6) residency and migration; and (7) standard breast cancer risk factors.

Few modifiable risk factors for breast cancer have yet been defined, despite studies showing that breast cancer risk is modifiable over a single lifetime. Adolescent factors have been understudied. This study addressed breast cancer etiology (through greater attention to relatively unexplored adolescent and pre-adolescent factors) and prevention (through inclusion of some potentially modifiable behavioral and psychosocial factors).

In the pilot study, we developed the collaboration and pilot data needed to apply for a full proposal to address the question stated above by accomplishing the following:

1. Reviewed comprehensive literature of: (a) the role of pre-adolescent and adolescent factors in breast cancer development, (b) effects of recall (differential and non-differential) on interpretation of results of case control studies, and (c) mechanisms for enhancing recall and minimizing effects of recall bias.
2. Conducted focus groups with random samples of Marin County women with and without breast cancer in order to: (a) review MBCW's overall hypotheses to determine if they adequately represent breast cancer research interests of women

in Marin, (b) develop methods for enhancing recall of pre-adolescent and adolescent experiences and exposures that can be used in population-based research, and (c) evaluate methods for enhancing recall.

3. Developed and evaluated a questionnaire, innovative memory tools, and other interview materials necessary for a full study.

Initial results of the Full Award: Analyses were completed on 285 cases and 286 controls. Statistically significant findings were that cases were more likely than controls to: report being premenopausal; have never used birth control pills; have a lower highest lifetime body mass index; have had 4 or more mammograms in 1990–1994; have begun drinking after age 21; on average, drink 2 or more drinks per day; have the highest quartile of pack years of cigarette smoking; and have been raised in an organized religion.

Cases and controls did not significantly differ with regard to: having a first degree relative with breast cancer; a history of benign breast biopsy; previous radiation treatment; age at menarche, parity, or use of hormone replacement therapy; or age first lived or total years lived in Marin County. Results for several factors differed for women aged under 50 years or 50 years and over.

Our conclusion is that despite similar distributions of several known breast cancer risk factors, case-control differences in alcohol consumption suggest that risk in this high-risk population might be modifiable. Intensive study of this or other areas of similarly high incidence might reveal other important risk factors proximate to diagnosis.

Bringing together community members and scientists in this successful collaboration may encourage other communities to take an active role in cancer research.

Final Report, Pilot Award (1998) and Full Award (1999)

COMMUNITY RESEARCH COLLABORATION

Study of Inadequate Follow-Up of Mammographic Abnormalities

Daramola Cabral Evins, Dr:PH, P.A., San Francisco Dept. of Public Health
Arthur H. Coleman, M.D., Bay View Hunters Point Health Care Task Force
Marion M. Lee, Ph.D., University of California, San Francisco

Final Report, Pilot Award (1998)

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.

COMMUNITY RESEARCH COLLABORATION

Samoans and Breast Cancer: Evaluating a Theory-Based Program

Pat Luce-Aoelua, M.S., National Office of Samoan Affairs

Shiraz Mishra, M.D., Ph.D., University of California, Irvine, Center for Health Policy and Research

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,
Full
Award
(1998)**

COMMUNITY RESEARCH COLLABORATION

African American Women and Breast Cancer: What Works?

Carol Somkin, Ph.D, Kaiser Foundation Research Institute

Priscilla Banks, M.S., African American Advisory Committee on Cancer

Initial Abstract, Pilot Award (2002)

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.

COMMUNITY RESEARCH COLLABORATION

A Community-Based Workbook for Helping Rural Cancer Patients

Mary Anne Kreshka, M.A., Sierra College
Cheryl Koopman, Ph.D., Stanford University

When women are newly diagnosed with breast cancer, they are faced with extremely difficult decisions about their treatment while trying to cope with the fact that they have a life-threatening illness. They deserve all readily available support and information to help them cope with having breast cancer.

To help respond to this need, La Lobe, a grassroots breast cancer support group in Nevada County, teamed up with researchers from the Stanford University School of Medicine to form the Sierra-Stanford Partnership. This partnership's main goal has been to create and evaluate the impact on rural women recently diagnosed with breast cancer of receiving a user-friendly workbook-journal that provides facts, figures, and personal experiences of other women who have been diagnosed with breast cancer. The hope of the Sierra-Stanford Partnership is to help to reduce the human and economic costs of breast cancer by reaching rural women who do not have access to current forms of education or support and help them to make the best possible breast cancer treatment choices.

The Sierra-Stanford Partnership has succeeded in meeting the three aims of our pilot study. First, we recruited and assessed the needs of 100 rural women recently diagnosed with primary breast cancer so that we would become better informed about their needs in order to refine the workbook-journal.

Second, we developed the journal, entitled "One in Eight", which addresses such topics as how to relate to doctors and medical technicians, how to talk to

family and friends, and how to cope with hair loss, energy loss, and other side-effects of chemotherapy. The journal includes poignant stories and provides space for personal reflection, as well as information about local and regional resources to help direct women in their search for education about breast cancer and its treatment.

Third, we evaluated the effects of this workbook-journal on distress and coping among women with breast cancer. We found that women who were randomly selected to receive the journal, compared with women who did not receive it, showed a significantly greater reduction in their traumatic stress symptoms related to having cancer. They also experienced significantly greater increases in fighting spirit toward having breast cancer as well as greater decreases in feeling fatalistic regarding their breast cancer.

We want to refine the workbook-journal to better address the concerns of rural women as well as other potentially socially isolated women living with breast cancer, including those who are physically disabled, of ethnic minority background, of lesbian sexual orientation, and/or who are aged (over 65 years old). We hope to evaluate its impact using a Health Maintenance Organization (HMO) setting for distributing the intervention to these women.

(Note: A continuation of this project, with expanded aims, was funded as a full project in 1999. See page 22.)

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

COMMUNITY RESEARCH COLLABORATION

The Efficacy of a Retreat for Low-Income Women with Breast Cancer

Shoshana Levenberg, B.S.N., Charlotte Maxwell Complimentary Clinic

Ellen Levine, Ph.D., M.P.H., California Pacific Medical Center Research Institute

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

This investigation explored the benefits of a retreat for low-income women with breast cancer. The aims of the project were to identify the needs of low-income women with breast cancer that are not being met by the community at large (e.g., medical care, social support services, transportation, food, child care, etc.), and to determine the acceptability and impact of a retreat designed for low-income women with breast cancer on mood, helplessness/hopelessness, feelings of self-efficacy, and self-determination.

The first phase of the project was to delineate the problems and challenges faced by low-income women with breast cancer. This was accomplished through a working group of low-income women with cancer, who defined the problems that they faced. After these problems were defined, a three-day retreat was designed by this group of women. The second phase of the project included the retreat itself.

Forty-six women participated in the three-day retreat that included workshops and experiences with alternative therapies. At the end of the retreat, women felt that they were more able to cope with problems related to their cancer. The women felt less psychologically distressed (e.g., less anxious, depressed, confused, fatigued, etc.) at the end of the retreat than they had at the beginning of the retreat. These differences were statistically significant. The women were contacted two months after the retreat; they were asked about their ability to cope with the problems defined initially and about their mood state. Two months after the retreat, the women felt that their problems were less severe than before the retreat, and the increased positive mood continued. We hope that this project will be the first in a continuing effort to elucidate the special needs of low-income women with breast cancer and to develop effective interventions with this population.

COMMUNITY RESEARCH COLLABORATION

Do Community Cancer Support Groups Reduce Physiological Stress?

David Spiegel, M.D., Stanford University

Carol Kronenwetter, Ph.D., Cancer Support Services (CSC)

Mitch Golant, Ph.D., The Wellness Community (TWC)

Women with primary breast cancer may benefit from participating in support groups as they cope with treatment and the psychological challenges of survivorship. Studies have documented that these women benefit from support groups run in a university setting; however, no one has documented benefit from community cancer support groups. There are many community cancer support groups that provide service to a large number of women with breast cancer. Therefore it is important to know if these groups are providing comparable service to well-researched support groups. We conducted this study as the first randomized study of community-compared to university-style support groups. Women had a 50/50 chance of being assigned to either a community or a university style support group.

This study evaluated the strengths and weaknesses of two community-based support group interventions for breast cancer patients [The Wellness (TWC) and Cancer Support (CSC) Communities, in the San Francisco area]. We compared them with a type of therapy developed in the university setting (Stanford's Supportive-Expressive group therapy), studied which aspects are most effective, and who benefited the most. We compared these women on several dimensions: change in emotional distress, means of coping with cancer, and social and family support. In addition, change in physiological response to stress was measured using saliva samples.

We were able to achieve recruitment for 6 of 8 groups originally proposed. We randomized 72 women in blocks of 12 taking consecutive women per site until we accrued 12 for each group. Of those, 61 women actually attended groups; of those, 46 women to date completed at least one follow-up and were available for analysis for this report. We screened 108 women, 16 who were screened out on initial phone contact, 20 women began to go through

our baseline interviews and assessments and either decided not to enroll or dropped out before we could compose a group for the second S.F. randomization. Our final two follow-up assessments for our final group in the East Bay are currently (September 2002) being conducted (8 month) and will be conducted in October 2002 (12 month) so they are not available for assay or analysis for this final report.

We examined five outcome variables for this report and found that women participating in the community groups changed at about the same level over the four months of group therapy as the women in the Stanford groups. This was true for depression symptoms, trauma symptoms, social support, self-efficacy, and post-traumatic growth. These analyses are preliminary until we complete our final follow-up assessments.

It is encouraging for the community groups that women benefited at the same rate as they did in the well-researched Stanford groups. Conclusions for this study are somewhat limited because we could not complete the recruitment of our entire sample. However, there is every reason to suppose that community groups are as effective at serving women with primary breast cancer as Stanford's groups, though they are based on very different ideas of therapy. It is important to note that all of these groups were led by therapists, and that we may have found other results if the groups had been led by peers or other types of professionals. This study has the potential to reduce the human and economic cost of breast cancer in California by validating community groups usually offered free to women with breast cancer.

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

COMMUNITY RESEARCH COLLABORATION

Chemotherapy-Induced Ovarian Damage: Prevention and Impact

Hope S. Rugo, M.D., University of California, San Francisco

Lynn Westphal, M.D., Stanford University

Lucy Berlin, M.S., Young Moms with Breast Cancer

Initial Abstract, Pilot Award (2002)

For many young women with breast cancer, the realization that chemotherapy will most likely render them infertile is devastating. Chemotherapy-related menopause in young women produces intensely unpleasant symptoms and results in low libido and rapid bone loss. The ovarian damage increases with age and drug dose, such that 40–70% of 40-year-olds will develop menopause within one year. Data in primates and patients with lymphoma suggest that shutting down the ovaries during chemotherapy with GnRH-analogues (G) reduces ovarian failure, but this has not yet been demonstrated in a breast cancer clinical trial.

The main questions to be addressed in the research are:

1. Are women who receive G during breast cancer chemotherapy more likely to keep their menstrual function, and is the protection of G affected by a woman's age?
2. Are there factors other than age and total dose of cyclophosphamide that affect a woman's odds of developing abnormal or absent menses?
3. What are the experiences, attitudes, and information needs of newly diagnosed young women regarding ovarian damage and post-treatment childbearing?

We will open a phase II clinical trial of the GnRH-

analogue triptorelin before and during breast cancer chemotherapy in 32 women aged 35–44. Because we will include women up to their early 40s, we expect not only to document tolerability and young women's interest, but also to give a preliminary estimate of the effectiveness of the ovarian protection.

Complementary to the clinical trial, we will have 100 young survivors complete a pilot survey about the information they received, the emotional effect of this risk, and their post-chemotherapy menstrual function. We will interview a subset of these women to obtain a deeper understanding of their experiences, attitudes, and needs.

By focusing on women aged 35–44, this will be the first clinical trial of GnRH-analog based ovarian protection in breast cancer patients who have a significant risk of visible ovarian damage after chemotherapy. Unlike other studies, we will focus on quality of life outcomes important to women—the hormonal and menstrual signs of low fertility and peri-menopause, not just immediate menopause. Our survey will add to the scant data on menstrual problems after modern chemotherapy regimens, and the qualitative component will give much needed insights into the attitudes of young women regarding childbearing after breast cancer, their information needs regarding ovarian function and early menopause, and the information and advice they currently receive from their oncologists.

COMMUNITY RESEARCH COLLABORATION

Correlates of Lymphedema Severity and Access to Intervention

Diane R. Estrin, Women's Cancer Resource Center
Rani B Eversley, Ph.D., University of California, San Francisco

Our research team is a collaboration of university and community-based women's health researchers and service providers studying return to work among breast cancer survivors. Our data suggests that ethnic minority women report more arm swelling and pain (presumably lymphedema). We have also learned from our research participants that many were not informed about the possibility of developing lymphedema prior to breast cancer surgery and thus were unable to take any preventive measures. When we investigated the availability of educational materials we discovered that many are inconsistent, non-comprehensive, and often contain components that need to be purchased. The goal of the proposed research project is to develop, test and standardize a low-cost intervention to prevent or reduce the severity of secondary arm lymphedema among breast cancer patients.

We wish to test whether women who participate in our lymphedema education intervention may have decreased or less severe lymphedema symptoms. We will do this as a feasibility trial with the goal of fully testing this intervention in a full-scale trial at a later date.

We propose a descriptive study to develop the components of the Total Arm Care (TAC) Program and a pilot clinical trial to test the TAC Program. For the descriptive study, four focus groups of 8 women each will be convened at the Women's Cancer Resource Center (WCRC). For the pilot clinical trial

women will be recruited and assigned to the TAC or a similar attention comparison group. Women will be measured at baseline prior to surgery, at one month post-surgery, at four months and at eight months. The intervention will be delivered four weeks after their surgery (we need to determine the optimal time using the focus group information). Participants will be recruited from WCRC, the Alameda County Cancer Navigator Program at Alameda County Medical Center (Highland Hospital), and the Charlotte Maxwell Clinic Complementary Clinic (CMCC). Innovative elements of the project in non-technical terms:

If effective, the TAC program will provide a simple, standardized, and culturally sensitive psycho-educational program to assist women with reducing the onset of lymphedema after breast cancer treatment. Resulting education materials will be distributed at no cost through WCRC, CMCC, and the Cancer Navigator as well as other community cancer treatment settings.

**Initial
Abstract,
Pilot
Award
(2003)**

COMMUNITY RESEARCH COLLABORATION

Reducing Disparities Among Korean Women

Soo-Young Chin, Ph.D., Korean Health, Education, Information, and Research Center
Annette Maxwell, Dr.P.H., University of California, Los Angeles

**Initial
Abstract,
Pilot
Award
(2003)**

The focus of this proposal is the low mammography rescreening rate among Korean American (KA) women served by KHEIR through "Cancer Detection Programs: Every Woman Counts" (previously known as Breast Cancer Early Detection Program - BCEDP). This is a concern, given that all the evidence on the effectiveness of mammography in reducing mortality is based on repeat screening at regular intervals. An intervention that is developed for and with significant input from KA women will be culturally sensitive and tailored towards the specific needs of this group, and therefore most likely to be effective in increasing regular screening.

We will explore misconceptions and barriers to regular screening among KA women, factors that may encourage women to get screened on a regular basis and how to best convey this information to KA women. Based on suggestions and feedback from KA women we will then develop one or more interventions and pilot test each intervention with 50 KA women who are due for rescreening. We will compare their rescreening rates with that of women who have not received any intervention (usual care), debrief women to find out if they perceived the intervention as helpful, and estimate how expensive it will be to implement the intervention on an ongoing basis.

This project is innovative in its focus on low-income KA women, who are underserved and underscreened. Other innovative features are our focus on repeat screening, the utilization of an established and very successful outreach program, and the collaboration between a well-established research program at UCLA and KHEIR, the largest KA nonprofit organization in California. Finally, our focus on intervention development is innovative, given that most studies among Asian women are limited to survey research.

COMMUNITY RESEARCH COLLABORATION

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, Department of Social and Behavioral Sciences

The objectives of this study are to:

1. determine the percentage of women who return to work during the 18 months after breast cancer surgery and to compare this percentage across ethnic groups
2. determine the percentage of women who return to pre-surgery work levels during the 18 months following breast cancer surgery and to determine this percentage across ethnic groups
3. describe the predictors for returning to work during the 18 months following breast cancer surgery considering the following variables:
 - race/ethnicity; income; social support for returning to work (using measures developed in the pilot)
 - presence of additional household support; dependent children/elders; enrollment in disability benefits; work flexibility
 - stage of disease; breast cancer treatment; fatigue
4. develop and test the "Women's Work Return Process," a model describing the relationship between the variables that predict women's return to work

We propose a prospective study of women to examine the process of returning to work after breast cancer surgery. This study will be named The Avenues Cohort to describe our collective interest in assisting women to regain employment. The cohort sample will consist of an ethnically stratified sample of 588 Caucasian, African American, and Latina women invited to join the study immediately prior to and in the month following their breast cancer surgery. Women will be assessed at baseline and 6 and 12 months after surgery with an interviewer-administered instrument. Women will be enrolled from the Women's Cancer Resource Center (WCRC) and the Cancer Navigator Program at the Alameda County Medical Center at the Highland Hospital Campus. Data will be entered and analyzed at the research partner's office at UCSF, with consultation from UCSF statistical staff.

Project outcomes will benefit the community by providing direction for services and interventions for women having difficulty with returning to work and will provide essential information for policy makers.

To date (May 2003), data from 248 baseline and 63 follow-up questionnaires has been entered with more collection still ongoing. Latinas report the most rapid return to work and African Americans report the longest intervals off work. Independent correlates of job loss include depressive symptoms and being treated with chemotherapy. Being Latina, having a lower income, and having children living at home were all independently associated with an earlier return to work. Receiving chemotherapy was associated with a lengthier return to work. These data suggest that return to work is associated with economic, family responsibility, treatment, and post-treatment symptom factors.

With respect to racial and ethnic differences in depression, pain, swelling, and fatigue after surgery, an increased number of symptoms were associated with decreased income, receiving chemotherapy, having a mastectomy, and Latina ethnicity. These data suggest an increased rate of post-treatment symptoms experienced by low income and ethnic minority women as well as a need for affordable, culturally appropriate symptom management.

Concerning the use of alternative and complementary therapies (energy medicine, e.g., acupuncture, acupressure, and herbal medicine), nutritional therapies (diets, vitamins, and other dietary supplements) and exercise, our analyses shows that energy medicine and exercise are each independently associated with reporting decreased pain. Also, there were few demographic differences between users and non-users of alternative therapies.

At this stage it is difficult to determine impact, but we are learning that many women receive little preparation for planning income or practical support needs for the time they are unable to work after breast cancer treatment. We are preparing three publications to disseminate our results.

Initial Abstract, Full Award (2001, updated)

COMMUNITY RESEARCH COLLABORATION

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, Department of Social and Behavioral Sciences

Final Report, Pilot Award (1999)

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 due breast cancer. 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 full award in 2001.)

COMMUNITY RESEARCH COLLABORATION

Alternative Support for Rural and Isolated Women in an HMO

Mary Anne Kreshka, M.A., Sierra College
Cheryl Koopman, Ph.D., Stanford University

Women diagnosed with breast cancer require immediate and continuing education and psychosocial support. Support groups, the most common forum for providing these services, are unavailable to women in rural communities and are difficult to access for women in certain isolating circumstances. The Sierra-Stanford Partnership has developed and pilot-tested a Workbook-Journal, an alternative form of education and psychosocial support. This intervention is intended to:

1. Accommodate all women with breast cancer; particularly underserved, isolated, and minority women
2. Be inexpensive for women with limited resources
3. Guide women to breast cancer information and support sources
4. Offer a variety of active coping strategies for women isolated by geography, age, disability, or minority status
5. Communicate emotional support to women newly diagnosed with primary breast cancer

Based on the findings from a CBCRP-funded pilot study, in this three-year study we aim to: (1) Evaluate the short and long-term effectiveness of the Workbook-Journal for improving psychosocial adjustment, increasing active coping, and improving emotional support in women newly diagnosed with primary breast cancer and receiving their treatment in an HMO; (2) Improve breast cancer knowledge in women newly diagnosed with primary breast cancer in an HMO; (3) Explore possible predictors of rural and isolated women who would benefit most from the Workbook-Journal; and (4) Assess the effects of this intervention on the number of medical care phone calls and office visits.

We will recruit 200 women from the Kaiser Breast

Health Center; Sacramento, to participate in a randomized clinical intervention trial. Particular efforts will be made to recruit underserved, isolated, and minority women. Women will be randomly assigned to one of two conditions after a baseline assessment: Education (EDUC) or Workbook-Journal and EDUC (WKBK). Women will receive follow-ups at 3-, 6-, and 12-months. Use of psychosocial services will be tracked and frequency of medical phone calls and medical visits will be determined by chart review.

We hypothesize that women in the WKBK condition will show better psychological adjustment (lower post-traumatic stress disorder symptoms, less depression), more active coping (higher fighting spirit, less fatalism), and higher emotional support than women in the EDUC condition; will have more knowledge about breast cancer and treatment than women in the EDUC condition; and will make fewer phone calls to their oncology providers and have fewer medical office visits than women in the EDUC condition. We also hypothesize that women who have higher levels of post-traumatic stress disorder, depression and life stress and lower levels of social support at baseline, will show more improvement after receiving the Workbook-Journal than women with lower baseline levels of post-traumatic stress disorder, depression and life stress, and higher levels of social support.

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

**Initial
Abstract,
Full
Award
(1999)**

COMMUNITY RESEARCH COLLABORATION

Does a Peer Navigator Improve Quality of Life at Diagnosis?

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

**Initial
Abstract,
Full Award
(2001)**

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.

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

COMMUNITY RESEARCH COLLABORATION

Breast Cancer Prevention and Control Among Deaf Women

Barbara A. Berman, Ph.D., University of California, Los Angeles

Heidi, B. Kleiger, Greater Los Angeles Council on Deafness, Inc. (GLAD)

Programs and messages relating to breast cancer and breast health are often inaccessible and inadequate for women who are deaf or hard of hearing (deaf/hh); there are virtually no programs tailored to the cultural, social, and communication requirements of this population. There has been a lack of the kind of research that has been critical in developing effective interventions for hearing women. We know nothing about the understanding deaf/hh women have of risk factors for breast cancer; their personal breast cancer risk, and screening guidelines; breast health related lifestyle and health practices; and, for breast cancer survivors, awareness of treatment and recovery issues. Nor do we have an understanding of the demographic, psychosocial, environmental, and cultural factors that influence the views or behavior of deaf women with respect to breast health.

Our primary focus is on the CBCRP's breast cancer prevention Priority Area; our research takes an important step towards ensuring that deaf/hh women share in the gains made among hearing women it comes to breast cancer and breast health. By including breast cancer survivors in our study we will also start to examine, for the first time, issues relevant to CBCRP's priority area "socio-cultural behavioral and psychological issues relevant to breast cancer" among Deaf women.

Building on a 5 year research partnership between the Greater Los Angeles Council on Deafness, Inc., (GLAD) and the Division of Cancer Prevention and Control Research, Jonsson Comprehensive Cancer Center at UCLA, our goal is to develop effective breast health related programming for this underserved and understudied population and to disseminate what we learn throughout the Deaf Community. In this pilot study, we propose to conduct the first-ever in-depth exploratory research to obtain the information we need to craft such a program. We will use the signed languages of the Deaf to interview 70 deaf/hh women 40+ years of age to learn about their knowledge, perceptions, and practices relevant to breast cancer and breast health; the factors that affect these perceptions and behaviors; and their views and preferences regarding programming.

Ten of these women will be breast cancer survivors so that we can also learn about the experiences deaf/hh women have when it comes to detection, treatment and survivorship. We will recruit our subjects through GLAD, including women deafened late and early in life, and those who have been deaf life-long. Our experienced, multi-disciplinary, community-research team will draw on what little information is available from past research in the Deaf community, and on established methods, theories, and research among hearing women, as we conduct our study, interpret our results, and plan our next steps. The procedures we will use will allow us to overcome formidable barriers to research and data collection among the Deaf. We will pay special attention to issues of privacy and cultural sensitivity in the Community.

To date (May 2003) we have completed 49 interviews. Once all data have been collected, we will invite 6-8 of the women we interview to help us draft plans for a program we will test as part of a CRC Full Research Award. Meeting all CBCRP requirements for an effective Community Research Collaboration, this study allows us to move toward the goal of excellent, tailored programming for deaf/hh women, a population that has been overlooked in the past. In so doing, our research addresses important research questions, promises great potential benefit for this community, and makes an important contribution to the battle against breast cancer; a battle that can only be won when we reach **all** women, state and nationwide.

**Initial
Abstract,
Pilot Award
(2001,
updated)**

COMMUNITY RESEARCH COLLABORATION

Efficacy of a Community Program in Increasing Access to STAR

Patricia Ganz, M.D., University of California, Los Angeles

Kathleen A. Brown, M.D., Association of Black Women Physicians

**Initial
Abstract,
Pilot
Award
(2001,
updated)**

Breast cancer is the leading type of cancer in African American women. Despite the lower rate of cancer in African American women, the mortality rate is higher than in other ethnic groups. Although the reasons for the differences are not entirely known, contributory factors may include diagnosis at a later stage of disease and a possible difference in the way the tumors behave and respond to therapy. Community outreach efforts to improve survival have focused on improving the early detection of cancer through breast self examination (BSE), clinical breast examination (CBE), and screening mammography.

Although early detection of breast cancer is crucial to improved survival, prevention of cancer through a variety of interventions holds tremendous promise. The enrollment of African American women in chemopreventive clinical trials has been less than optimal, however. Given the potential variability in response to a therapeutic or preventive protocol, greater enrollment of minorities in clinical trials is needed.

The Association of Black Women Physicians (ABWP) and the Division of Cancer Prevention and Control Research at the School of Public Health and Jonsson Comprehensive Cancer Center at UCLA propose to collaborate in the development of an intervention program targeting African American physicians and community women about breast cancer chemoprevention and clinical trials.

The specific aims of this pilot study are to:

1. Develop educational materials for providers through the use of key informant interviews, focus groups, and a survey
2. Conduct focus groups with women from the community
3. Deliver an educational CME presentation
4. Develop a curriculum on breast cancer chemoprevention and clinical trials to be used in the ABWP's Second Sunday program and train volunteers to deliver the program
5. Pilot-test this curriculum

To date (May 2003) we have conducted key informant interviews, focus groups and a mail survey with members of the ABWP in order to better understand provider knowledge and beliefs about chemoprevention trials and develop education materials for providers. From this work we have identified common barriers to recommendation including the difficulty in scheduling time to discuss prevention with patients, lack of familiarity with available research trials, patient distrust of doctors and medical research, and the failure of other trials to disseminate results back to the community. The results of these activities were used to develop and deliver an educational Continuing Medical Education program to ABWP providers in April 2002.

For the community women, we conducted focus groups with African American women from community churches to help understand current attitudes, beliefs and knowledge about breast cancer chemoprevention and research trials in general. We then developed an educational presentation on breast cancer chemoprevention and trained a group of ABWP providers to be health educators in the community. The education module has been presented as part of the ABWP's "Second Sundays" program to two community churches and three more presentations are scheduled for the summer and fall of 2003.

Over the rest of the study period (through December 2003) we will continue this collaborative effort between investigators from the ABWP and the UCLA Division of Cancer Prevention and Control Research to better understand the factors that influence physician recommendation and patient participation in medical research trials and develop strategies that will enhance the participation of African American women in chemoprevention trials for breast cancer.

The long term goal of this CRC pilot study will be to test this approach in a randomized trial to lead to increased participation in chemoprevention clinical trials.

COMMUNITY RESEARCH COLLABORATION

A Network-Based Intervention for Chamorros in Southern California

Sora Park Tanjasiri, Ph.D., University of California, Irvine
Lola Sablan-Santos, Guam Communications Network, Inc.

This three-year, community-based research project applies social network theory to test the effectiveness of a tailored, Chamorro lay health leader intervention to increase breast cancer screening rates among Chamorro women age 50 years and older in Los Angeles and Orange counties. The study employs a quasi-experimental (intervention and control group), prospective cohort, pretest/post-test design, with Chamorro women from Northern California (specifically Alameda, Solano, and Santa Clara Counties) agreeing to serve as the comparison group.

This project hypothesizes that the intervention will significantly increase the rates of appropriate breast cancer screening (baseline and regular breast self-examination, clinical breast examination, and mammography), and that the increased screening rates will be related to increased diffusion of information and skills through naturally-occurring social networks of Chamorro women. During the three-year period, we will undertake the following major activities:

1. Identify Chamorro women 50+ years old who are linked to each other through close social (family and friendship) ties
2. Train 20 Chamorro lay leaders in breast cancer information and screening (modeled after ACS' Special Touch and the Wai'anae Cancer Research Project's lay leader training programs)
3. Implement lay leader-led small-group events to educate women about BSE, CBE, and mammography
4. Link with other projects (OCAPICA's Promoting Access To Health Project) to facilitate screening services for interested women
5. Follow-up with women after 1.5 years of

intervention to measure changes in their behavior and diffusion of those behaviors through social networks

6. Disseminate materials and trainings to Chamorro women in the Bay Area (who served as the "controls") as well as to other Chamorro and Pacific Islander communities (through our network of professional and community contacts)

This study continues a close community-based collaboration established five years ago between Guam Communications Network, Inc., and the University of California, Irvine, and broadens it to include two other Chamorro social groups, the Famalao'an (Chamorro for "the women") and the Bay Area Women's Social Club. While this study will provide vital information on breast health promotion for Chamorro women, we also believe the results will help in the development of the successful strategies for the promotion and evaluation of breast cancer screening to ethnic minority women who are from relatively smaller, tightly-knit communities across California.

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

**Initial
Abstract,
Full
Award
(2001,
updated)**

COMMUNITY RESEARCH COLLABORATION

Effectiveness of the Internet vs. Face-to-Face Support Groups

Morton A. Lieberman, Ph.D., University of California, San Francisco
Mitch Golant, Ph.D., The Wellness Community (TWC)

Initial
Abstract,
Full
Award
(2001)

The use of the Internet for health service delivery has seen explosive growth in the past several years. Current research indicates that 56 million adult Americans go online for help with health problems. Recent surveys indicate that many are from minority communities and the socio-economically deprived, but this growth has not been empirically studied to understand the implications and potential uses of internet use.

The study is a collaborative effort of investigative teams in two universities (UCSF and Stanford) and a community organization (TWC) who have worked successfully together for five years. We propose a randomized study comparing online (ESG) Wellness Community groups and face-to-face (FTF) support groups to a TWC usual-care educational activities group. This will enable us to evaluate the true effects of systematic psychological support delivered in two modalities. Patients will be recruited regardless of their computer skills and after randomization will be offered training and provided E Boxes (Web TV). SeniorNet will provide computer training.

Since TWC is in a position to implement this service quickly and effectively, this study has far-reaching implications. A cost analysis by TWC found that FTF is five times the cost of their ESG groups. TWC has 20 facilities nationwide serving cancer patients. If found effective, online support groups would be made available to many more women than are served currently, particularly in underserved rural populations. As the first random trial of Internet intervention, we believe that the findings may enable increased use of support services for a variety of health problems. The manual for leading online support groups, although based on breast cancer, could be a significant starting point in other health-related Internet support groups.

The CBCRP-funded pilot study found that:

- Women with breast cancer can be

successfully recruited and retained for ESGs

- Two-thirds of the women reside in rural areas or small towns
- Participants showed significant decreases in depression, expressed more zest for life, saw more new possibilities for their future, deepened their spiritual lives, and substantially decreased their negative reactions to their cancer pain
- Critical group processes were isolated that help identify characteristics associated with successful groups

Three broad questions are asked in this research:

1. Do online TWC support groups improve quality of life?
2. What are the psychological characteristics of women who benefit?
3. What are the processes of online groups that facilitate beneficial changes?

To answer these broad questions a series of hypotheses will be tested; primarily that participation in both TWC support settings will improve their attitudes and beliefs about their illness, quality of life, decreased marital strain and levels of depression compared to the usual-care group. We will recruit 240 primary (stages 1–3) breast cancer patients to participate in this randomized trial for 20 weeks.

Measures include:

- **Efficacy:** Depression, Self-Efficacy, Quality of Life, Marital Strain, Personal Growth
- **Mediators:** Personality traits
- **Moderators:** Cancer-Related Coping, Emotional Control, Repression, and Illness Level
- **Process measures:** Leader Behavior, Group Norms, Cohesiveness, Helpful Experiences, Group Content, Analysis of Group Interaction using two computer linguistic dictionaries

index

By Author

Banks, Priscilla, M.S.	page 14
Berlin, Lucy, M.S.	page 18
Berman, Barbara, Ph.D.	page 25
Bliss-Isberg, Caroline, Ph.D.	page 24
Brown, Kathleen, M.D.	page 26
Cabral Evans, Daramola, Dr:PH.	page 12
Chin, Soo-Young, Ph.D.	page 20
Coleman, Arthur, M.D.	page 12
Cupolo Freeman, Ann	page 9
D'Onofrio, Carol, Dr:PH.	page 9
Dibble, Suzanne, D.N.Sc.	page 10
Estrin, Diane R.	page 19, 21, 22
Eversley, Rani, Ph.D.	page 19, 21, 22
Farren, Georgianna, M.D.	page 11
Foo, Mary Ann, M.PH.	page 7
Ganz, Patricia, M.D.	page 25
Golant, Mitch, Ph.D.	page 17, 28
Gould, Mary	page 11
Howard, Nicole A.	page 8
Kagawa-Singer, Marjorie, Ph.D., M.N., R.N.	page 7
Kleiger, Heidi B.	page 24
Koopman, Cheryl, Ph.D.	page 15, 23
Kreshka, Mary Anne, M.A.	page 15, 23
Kronenwetter, Carol, Ph.D.	page 17
Lee, Marion, Ph.D.	page 12
Levenberg, Shoshana, B.S.N.	page 16
Levine, Ellen, Ph.D., M.D.	page 16
Lieberman, Morton, Ph.D.	page 28
Luce-Aoelua, Pat, M.S.	page 13
Maxwell, Annette, Dr:PH.	page 20
Mishra, Shiraz, M.D., Ph.D.	page 13
Roberts, Stephanie, M.D.	page 10
Rugo, Hope, M.D.	page 18
Sablan-Santos, Lola	page 27
Somkin, Carol, Ph.D.	page 14
Smith, Mary, C.R.C.	page 9
Spiegel, David, M.D.	page 17, 24
Talavera, Gregory, M.D., M.PH.	page 8
Tanjasiri, Sora Park, Dr:PH.	page 7, 27
Westphal, Lynn, M.D.	page 18
Wrench, Margaret, Ph.D.	page 11

By Title

A Community-Based Workbook for Helping Rural Cancer Patients	page 15
A Network-Based Intervention for Chamorros in Southern California	page 27
African American Women and Breast Cancer: What Works?	page 14
Alternative Support for Rural and Isolated Women in an HMO	page 23
Breast Cancer Prevention and Control Among Deaf Women	page 25
Breast Cancer Risk Factors: Lesbian and Heterosexual Women	page 10
Breast Screening Program in the Hmong American Community	page 7
Chemotherapy-Induced Ovarian Damage: Prevention and Impact	page 18
Correlates of Lymphedema Severity and Access to Intervention	page 19
Do Community Cancer Support Groups Reduce Physiologic Stress?	page 17
Does a Peer Navigator Improve Quality of Life at Diagnosis?	page 24
Effectiveness of Internet vs. Face-to-Face Support Groups	page 28
Efficacy of a Community Program in Increasing Access to STAR	page 26
Increasing Annual Recall in State Early Detection Programs	page 8
Increasing Breast Health Access for Women with Disabilities	page 9
Marin County Breast Cancer Study of Adolescent Risk Factors	page 11
Reducing Disparities Among Korean American Women	page 20
Returning to Work and Quality of Life after Breast Cancer Surgery	page 21
Returning to Work and Quality of Life after Breast Cancer Surgery	page 22
Study of Inadequate Follow-Up of Mammography Abnormalities	page 12
Samoans and Breast Cancer: Evaluating a Theory-Based Program	page 13
The Efficacy of a Retreat for Low-Income Women with Breast Cancer	page 16



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