COMMUNITY RESEARCH COLLABORATION AWARDS

CALIFORNIA
Breast Cancer
Research Program

Funded by the

CALIFORNIA BREAST CANCER RESEARCH PROGAM

1997–2007

CRC Award Types

The CBCRP offers three funding mechanisms for conducting community based participatory research.

The CRC Pilot award is for a maximum of $150,000* in direct costs for a period of up to 18 months. Indirect costs, over the direct cost limit, are also available. The Pilot award supports the initial phase of the project, including solidifying the working relationship between the community and an experienced scientific researcher, detailing the research plan and methods, and collecting pilot data.

The CRC Full award is for a maximum of $600,000* in direct costs for a period of up to three years. Indirect costs, over the direct cost limit, are also available. The Full award is for projects with a fully developed research plan with supporting preliminary data, carried out by a well integrated team of scientific and community members with a previous work relationship. Typically, the plan supports the completion of the research plan developed and initiated during the Pilot award, although a previous Pilot award is not a requirement for the Full award application.

The CRC Implementation and Dissemination (I & D) Research Award is for a maximum of $150,000 for up to 18 months. Indirect costs, over the direct cost limit, are also available. The I & D award is for CRC funded teams that have completed or are in the final year of a CRC Full Award. The intent of the award is to (1) support the dissemination/implementation of promising interventions (or products) that have been developed and found to be efficacious in a Full CRC Award; and (2) to study effective methods for the broader dissemination, uptake and diffusion of these interventions to inform further community-based dissemination/implementation.

*Prior to July 1, 2004, the award limits for the Pilot and Full CRC awards were $100,000 and $500,000 respectively (direct costs).

For more information about CBCRP's community research collaboration award type, contact:

- Natalie Collins, M.S.W. at 510 987-0646 or natalie.collins@ucop.edu
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- Or 888 313-2277 for either Natalie or Walter

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.

For more information on the entire portfolio, see the CBCRP's website at www.cabreastcancer.org

CRC awards are grouped by the CBCRP's four priority issues:

1. The Community Impact of Breast Cancer: the Social Context
Specific topics include:

> Health Policy

> Health Services

> Sociocultural, Behavioral, and Psychological Issues Relevant to Breast Cancer: The Human Side

> Disparities: Eliminating the Unequal Burden of Breast Cancer

2. Etiology and Prevention: Finding the Underlying Causes
Specific topics include:

> Etiology: The Role of Environment and Lifestyle

> Prevention and Risk Reduction: Ending the Danger of Breast Cancer

3. Biology of the Breast Cell: the Basic Science of the Disease
Specific topics include:

> Biology of the Normal Breast: The Starting Point

> Pathogenesis: Understanding the Disease

4. Detection, Prognosis, and Treatment: Delivering Clinical Solutions
Specific topics include:

> Imaging, Biomarkers, and Molecular Pathology: Improving Detection and Diagnosis

> Innovative Treatment Modalities: Search for a Cure

CRC Grants: Listed by Priority Issue

Contents

Disparities: Eliminating the Unequal Burden of Breast Cancer

Health Policy and Health Services

Sociocultural, Behavioral, and Psychological Issues: The Human Side

Prevention and Risk Reduction: Ending the Danger of Breast Cancer

Innovative Treatment Modalities: Search for a Cure

Breast Health Project for Hmong Women and Men in California

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Funded 1999

Final Abstract, Full Award

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 (45%). 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). Hmong women are among those at highest risk for health problems and underutilization of life-saving screening services due to high rates of low education, poverty, language isolation, and cultural barriers. Life is Precious (LIP) was a three year community collaborative outreach project developed in response to this disparity. LIP's goal was to increase mammography screening rates among women in the Hmong community, primarily in the Southern California area. In a collaborative effort with the UCLA School of Public Health and CSU Fullerton, three community-based organizations were involved in the implementation of this breast health education project: Families in Good Health (FiGH) in Long Beach [comparison community], Stone Soup (SS) in Fresno, and the Union of Pan Asian Communities (UPAC) in San Diego.

LIP was the first intervention project initiated by the Hmong community, which focused specifically on Hmong women and breast health education. It was uniquely designed to educate both Hmong women and men about breast cancer by developing culturally specific education materials to teach them how to increase the chances of early detection and treatment through mammography screening, clinical breast examinations (CBE), and breast self examinations (BSE), as well as to build community capacity to provide the services needed for optimal cancer treatment should that be necessary.

Two innovative strategies were used in this 3-year project to reduce inequities in breast cancer outcomes and disseminate needed information to the community. The first involved the enlisted support of Hmong men in the community in an effort to capitalize on the cultural strengths of social support, family integrity, and decision making styles to promote breast screening practices among women. The second was the analysis of successful strategies utilized by other programs in hard-to-reach ethnic minority populations and cross-cultural theoretical constructs in order to identify those culturally specific elements of an educational program that require tailoring for cultural congruence to more cost effective health promotion programs in the future. These outreach strategies also used participatory action processes.

At the start of this project, no published studies existed on breast cancer early detection practices among the Hmong community or any studies on any ethnic group that utilized the strategy of enlisting men or male leaders of sociocentric or familial cultural groups to promote the use of breast screening services. Data from our CBCRP funded pilot study in 1997 which assessed breast cancer knowledge, attitudes, and behaviors among Hmong women and men, indicated that although Hmong women have among the lowest screening rates of any ethnic population in the US, they expressed a desire for more information, a desire to have the men included in education, and a willingness to go for screenings.

The LIP project was conducted in three communities consisting of two intervention communities (SS and UPAC) and one comparison community (FiGH). During the first year, a cohort baseline survey was conducted to determine current community practices in breast screening behavior, breast self-examination (BSE), clinical breast examination (BSE) and mammography in all three communities. A total of 552 women were interviewed: the two intervention communities: of 301 women from SS and 151 women from UPAC; and 100 women from FiGH, the comparison community. Various educational materials were also developed that included: a breast health curriculum, a bi-lingual flipchart (Hmong and English), bilingual brochure (Hmong and English), in language video (Hmong with English subtitles), and a key chain made of beads to represent the various sizes of lumps that can be detected by the different forms of screening.

In year two, Intervention Workshops were conducted in the two intervention communities. Each community targeted 150 women and 150 men to do a 3-4 hour education session, which involved pre- and post-tests. Evaluation forms (focus groups, one-on-one interviews, and participant evaluations) were completed for every 50 people reached in the workshops in order to measure the appeal, applicability, and effectiveness of the intervention.

In the third year, a follow-up survey was conducted to measure the changes in breast cancer screening, knowledge, and attitudes at baseline. The same 552 women targeted at baseline were contacted in the follow-up survey. An attrition rate was calculated at 20% for a total of 434 women who completed the follow-up survey. Our final sample consisted of 243 from SS, 111 from UPAC, and 80 from FiGH, which was about the predicted overall 20% attrition. The reasons for the 20% loss to follow-up were attributed to deaths and participants moving to different geographic locations. We also conducted a process and impact evaluation, and implemented the intervention in the comparison community. Although the comparison community was not required by the proposal to conduct the educational workshops all team members felt it was only ethical to provide the information and materials to all the Hmong Communities who participated in this project.

The model used in this project identified universal elements of an effective breast health screening program and critical, culture specific points within the program that were tailored for this hard to reach population. Implicit and explicit similarities and differences of future programs might be more accurately crafted to be culturally congruent and increase the use of early detection and screening for Hmong women and other rarely reached populations to increase the magnitude of success.

An article on this work appeared in the *Journal of Health Education* in the Spring 2001 issue (vol. 16, No. 1)

Samoans and Breast Cancer: Evaluating a Theory-based Program

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

Funded 1998

Final Report, Full Award

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.

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.

Disparities: Eliminating the Unequal Burden of Breast Cancer

Increasing Breast Health Access for Women with Disabilities

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Ann Cupolo Freeman, Alta Bates Medical Center
Carol D’Onofrio, Dr.P.H., University of California, Berkeley

Funded 1998

Final Report, Full Award

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 5 key research questions: (1) What is the prevalence of barriers to breast screening among women with physical disabilities? (2) Are these barriers, and 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 upˇ-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 (1) analysis and reporting of the NHIS data, (2) analysis and reporting of the local survey, (3) the final draft of the BHAWD manual, and (4) 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.

Breast Cancer Prevention and Control Among Deaf Women

Barbara Berman, Ph.D., University of California, Los Angeles
Heidi Kleiger, Greater Los Angeles Council on Deafness, Inc.

Funded 2001

Final Report, Pilot Award

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 unique population. Building on a seven-year research partnership between the Greater Los Angeles Council on Deafness, Inc. (GLAD) and the Division of Cancer Prevention and Control Research, UCLA School of Public Health and Jonsson Comprehensive Cancer Center (UCLA) this CBCRP CRC Pilot project is aimed at developing effective breast health-related programming for this underserved and understudied population, and to disseminate what we learn throughout the Deaf Community. To achieve this end we are conducting first-ever in-depth exploratory research to obtain the information we need to craft such a program.

We used the signed languages of the Deaf to interview 69 deaf women 40+ years of age to learn about their knowledge, perception and practices relevant to breast cancer/breast health; the factors that affect these perceptions and behaviors; and their views and preferences with respect to breast health programming (Aim 1). Seven of these women are breast cancer survivors so that we can also learn about the experiences deaf/hh women have when it comes to detection, treatment, and survivorship (Aim 2). Subjects were recruited through GLAD, including women deafened late and early in life, and those who have been deaf life-long. We are paying special attention to issues of privacy and cultural sensitivity in the Community in all aspect of the research; the procedures we are using allow us to overcome formidable barriers to research and data collection among the Deaf. All interviews have been completed, videotaped and transcribed. Data analysis is in progress.

Once all data have been analyzed we will invite 6-8 of the women we interviewed to help us draft plans for a program we will test as part of a CRC Full research award. 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 interpret our results, and plan our next steps. Meeting all CBCRP requirements for an effective Community-Research Collaboration is allowing us to move towards 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 significant research questions, promises great potential benefit for the Deaf Community, and makes a valuable contribution to the battle against breast cancer, a battle that we will win only when we reach all women, state and nationwide.

(Note: A continuation of this project was funded as a full award in 2006.)

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

Funded 2001

Final Report, Pilot Award

The principal goal of the CRC pilot study was to design and pilot test intervention materials to enhance the knowledge, attitudes and behavior surrounding participation in breast cancer chemoprevention trials among African American physicians and African American women from the community. Project activities targeted two specific groups: health care providers who are members of the Association of Black Women Physicians (ABWP) and community women who are served by the ABWP “Second Sundays” breast health education program. During the course of the study we completed all of our proposed aims.

To better understand provider knowledge and beliefs about chemoprevention trials and develop education materials for providers, we conducted key informant interviews, focus groups and completed a survey by mail with members of the ABWP. From this work, we have identified common barriers to physician recommendation of clinical trials including: risk of investigational therapeutic agent, the difficulty in scheduling time to discuss prevention with patients, lack of familiarity with research trials that are available, lack of time to discuss research trials with patients, lack of knowledge of eligibility, patient distrust of doctors and medical research, and the failure of other trials to disseminate results back to the community.

From the community viewpoint, issues raised included the need for more information about medical trials, need for African American investigators to be involved in the trials, fear of medication and side effects, distrust of research (including the Tuskegee trials) and time constraints.

The results of these activities were used to develop and deliver an educational Continuing Medical Education program to ABWP providers in April 2002. We helped the ABWP develop an educational presentation on breast cancer chemoprevention that ABWP providers delivered to African American women in the community through their “Second Sundays” program. Over 150 women in the community were reached through this pilot program.

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

Funded 2002

Final Report, Pilot Award

African Americans, while diagnosed less frequently with breast cancer than whites, continue to have a greater proportion of women with late stage disease and greater mortality from breast cancer. Regular mammography and prompt follow-up offer the best opportunity for breast cancer early detection, yet, while the Cancer Detection Programs: Every Woman Counts (CDP: EWC) provides free access to breast cancer screening for low-income, uninsured and underinsured women in California, African American women are not utilizing the program at the same rate as women of other racial/ethnic groups. This qualitative Community Research Collaboration pilot study investigated possible reasons why African American women may not take advantage of CDP: EWC screening and diagnostic services.

We conducted telephone interviews with staff at 56 CDP: EWC service delivery sites in the San Francisco Bay and Los Angeles areas to determine the organizational/system-level characteristics that may be associated with a higher utilization of positive breast health and breast cancer behaviors (e.g., initial screening, repeat screening, prompt follow-up and diagnostic services) by African American women. We also conducted face-to-face interviews with 26 African American women who obtained screening or screening and follow-up services at CDP: EWC clinics or who called the program's 800 telephone number seeking a referral for services but who did not obtain the services.

The patient interviews explored- from the African American woman's perspective-secondary access factors such as doctor-patient communication and perceptions of being treated with respect and cultural sensitivity, which have been shown to be associated with the use of breast cancer screening. We found three important secondary access factors in the provider interviews: lack of outreach to women who do not use health services; inability to systematically track women in need of repeat screening and diagnostic services; and logistical hassles, such as waiting time in the clinic for a screening appointment and needing to visit multiple clinics ("too many hoops"). Patient interviews confirmed many of the findings from the provider interviews. In addition, while in general women reported receiving culturally sensitive care, they interpreted the negative aspects of care that they experienced-such as long waiting times in the clinic, receipt of a painful mammogram, not being given any explanation, and not being listened to-as a lack of respect. Historically for African Americans these factors convey racism.

We developed a number of hypotheses based on our findings that can be tested in future studies. Based on the study findings to date we conclude that: (1) more outreach activities are needed, especially to women who do not use health care services; (2) low-income uninsured and underinsured African American women are extremely diverse in terms of educational, employment, cultural and religious background. Therefore different types of outreach interventions are needed to reach these women and meet their needs; (3) a navigator program to provide education and advocacy skills for women who call the 800 number could be helpful in reducing the number of women who fail to obtain screening after inquiring about available services; (4) women interpreted the negative aspects of care that they experienced-such as long waiting times in the clinic, receipt of a painful mammogram, unsatisfactory explanations about procedures, and not being listened to as a lack of respect, which historically for African Americans conveys racism; (5) training providers and clinic staff-specifically in showing respect (e.g., tone of voice, choice of words), appropriate listening skills and body language-may help staff interact in a more culturally sensitive way with African American women; and (6) the physical environment of the clinic is important to women. Crowded waiting rooms and lack of signs letting women know where to go are perceived as barriers to screening. A clean facility with culturally relevant pictures on the walls and instructional materials are perceived as facilitators.

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

Funded 2003

Final Report, Pilot Award

The specific aims of this project were to develop and pilot test the Total Arm Care Intervention (TACI) - a psycho-educational intervention to reduce risk for lymphedema among women undergoing treatment for breast cancer.

Qualitative data regarding need for the intervention were collected from 3 focus groups (N=28). Eight of the participants were African American, 9 were Caucasian, 6 were Latina, and 5 were Asian. Two focus groups were conducted in English (1 at WCRC, 1 at Highland Hospital). One focus group was conducted in Spanish (at WCRC). Themes from the English speaking focus groups included: (1) women wished that they had been told about lymphedema prior to their surgery, (2) they were most often told by a nurse or cancer patient navigator, rather than by their physician, (3) breast cancer support groups help with dealing with lymphedema, (4) women were motivated to do whatever stretching exercises they were given, (5) stretching exercises were generally drawn in stick figures on paper and Xeroxed, (6) stretching exercises (finger walking, arm lifts, broomstick) help with pain, (7) infections in the lymphedema affected arm can be very bad—even life threatening. Additional themes from the Spanish speaking group included: (1) providers do not take requests to avoid puncturing the affected arm seriously (one women reported that her physician attempted to give her chemotherapy through her lymphedema affected arm), (2) lymphedema related information is only offered in English, (3) stretching exercises are difficult to do when you are tired from work, (4) it is difficult to do stretching exercises from examples on paper.

For the intervention stage of our project the intervention manual and pre and post measures were developed. Five women were recruited surveyed and measured. All women were recruited from posted notices at health care settings. Participants included 3 Asian women (ages 55, 47, 44), 1 Caucasian woman age 51, and 1 Latina, age 27. Three participants had not been informed about lymphedema prior to their interview, two had been informed. Those who had been informed were told by Cancer Navigators.

Data collected suggests a need to offer information regarding prevention and management of lymphedema early in breast cancer treatment. Such information may assist to prevent and reduce arm symptoms as well as educate patients to seek prompt medical attention when symptoms appear.

Completion of project recruitment was delayed due to unexpected institutional barriers and expiration of allotted grant award time.

Reducing Disparities Among Korean Women

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Annette Maxwell, Dr.P.H., University of California, Los Angeles

Funded 2003

Final Report, Pilot Award

The study was conducted jointly by the Korean Health, Education, Information and Research Center (KHEIR) and the UCLA Division of Cancer Prevention and Control Research. The goal of the study was to develop and pilot test an intervention to increase the low mammography rescreening rate among low-income Korean American (KA) women served by KHEIR.

We developed a print information in Korean language based on in-depth interviews with KA women and focus groups with KA women and KHEIR staff and pilot tested it in 2 clinics, KHEIR and Koryo Health Foundation.

The process of developing the print intervention together with KA women worked well. Women provided valuable suggestions and feed back. Mailing of the print intervention was very feasible for the two participating clinics, since it could easily be inserted in the existing routine mailing and did not require extra staff time. Both clinics will continue to include the brochure into their reminder mailings. The effect that was achieved with the print intervention was small: clinic records show only a 6 percentage point increase at Koryo Health Foundation (from 32% to 38%) and no change at KHEIR (25%, probably due to the temporary loss of service at KHEIR just prior to the intervention period). This suggests that although a print intervention such as ours may encourage some women to obtain repeat screening, more intensive efforts are needed. Additional efforts such as phone calls could be focused on those women who did not respond to the print intervention. Such an approach has been used successfully in prior studies.

Our findings also demonstrate the importance of validating self reported screening. At Koryo Health Foundation, self reported screening rates were 13 percentage points higher than clinic records (51% versus 38%). Reasons for this discrepancy could be social desirability bias, face-saving bias, or a telescoping effect, which is the tendency of subjects to report a more recent date than the actual date of screening. We have no explanation for the 12 percentage point discrepancy at KHEIR in the other direction (13% self report versus 25% clinic records). We have learned from this study that it is wise to pilot test an intervention in more than one clinic because unforeseen events can impact even a short pilot study such as this.

The project brought together a multi-ethnic and multi-disciplinary team from the community and academia and provided an important training opportunity for a KA junior investigator. Overall, the experience of working together in this study was positive and both partners are interested in joining forces again in a future study.

Partnership to Reduce Health Disparities in Spanish Speakers

Molly Bergstrom, Women's Cancer Resource Center
Rena J. Pasick, Dr.P.H., University of California, San Francisco, Comprehensive Cancer Center

Funded 2005

Final Report, Pilot Award

Many community agencies utilize lay health worker models to conduct outreach and provide services to Latina women. However, these models vary significantly, and there is little research that identifies common challenges and synthesizes their solutions. The primary aim of our pilot study was to conduct an 18-month project based in Alameda County to prepare for a 3-year evaluation trial.

The specific aims were to: (1) identify the variable components of LHW models in theory, and in practice locally; (2) from the perspective of all relevant stakeholders, assess the strengths and limitations of each component specific to breast cancer education, screening, abnormal follow-up, and cancer patient support among Spanish-speaking women, and (3) create a research plan to test and compare for effectiveness and cost-effectiveness alternative LHW components. Secondary aims were: (a) To build the research and organizational capacity of the ACLCC; (b) To inform the development of a model for Comprehensive Cancer Center-community based organizations partnerships; (c) To explore another common interest, the cultivation of advocacy among Latina breast cancer survivors.

We used qualitative methods to achieve our primary aims, including 6 key informant interviews with directors of agencies that have lay health worker programs and 2 focus groups with lay health worker managers, and 3 lay health workers. To achieve our secondary aims, UCSF researchers trained ACLCC members in qualitative research methods including conducting interviews and focus groups, and coding and analyzing qualitative data. The ACLCC and UCSF-CCC jointly created the guides for each interview and focus group, jointly conducted the interviews and focus groups and collaborated on the analysis of the data.

We found that promotora programs operate on multiple levels: (1) to empower promotoras as individuals and community members; (2) to increase awareness of specific health issues and access to health through informal social networks and formal planned events, and (3) to foster social change through these activities. Because neither of the two primary Latino clinics in Alameda County had a promotora program addressing breast cancer during our research, we were unable to fully address Aim 2; however, we overcame this barrier by developing a Full CBCRP proposal which would involve the development, implementation, and evaluation of breast cancer promotora programs at each of the two primary clinics in Alameda serving Latinos.

In addition to submission of a full proposal, other major accomplishments include the identification of variable components of LHW programs, successful collaboration of UCSF & ACLCC, enhanced research capacity of ACLCC, presentation of findings at a community forum, and development of a manuscript outline for publication in a public health journal. Based on these successes, we now plan (as discussed in our full proposal) to develop two breast cancer education and outreach programs in order, for the first time, to develop a prospective understanding of how and why program objectives are accomplished.

The overall goal will be to develop theory that predicts and explains effectiveness of promotora breast cancer outreach and education programs by elucidating the processes involved in all phases of development and implementation of two programs, and the influence of these processes on impacts and outcomes.

Addressing Cultural and Tribal Issues in Breast Cancer

Linda Navarro, Turtle Health Foundation
Marlene von Friederichs-Fitzwater, Ph.D., University of California, Davis

Funded 2006

Initial Abstract, Pilot Award

Breast cancer is the second leading cause of cancer death among American Indian women. Deaths from breast cancer could be reduced by more than 30% in American Indian women if current recommendations for screening were followed. American Indian women have the poorest cancer screening rates of any ethnic group, and those with breast cancer have had the lowest 5-year survival rate when compared to other ethnic groups. Research has found that health beliefs were positively associated with breast cancer screening in multivariate analyses. Previous studies have identified the individual and community influences of Native identify on women's health and their health care decisions. While some efforts have been made to produce materials that are culturally sensitive, they have been text, non-interactive video or computer-based and have not taken an integrative or holistic approach. Building on this theme of "connecting to nativeness," the UC Davis Cancer Center and the Turtle Health Foundation, Inc., an American Indian nonprofit headquartered in Sacramento, CA, are partnering to undertake this pilot study to determine the usefulness of a culturally-sensitive, interactive, multimedia DVD, that can be used with standard DVD players and TV monitors, to increase awareness and knowledge of breast health and breast cancer risk reduction among American Indian women. We are integrating the principles of indigenous healing (nutrition, exercise/movement, spirituality, etc.) with Western medicine in the development and evaluation of a unique educational/information intervention on breast health and breast cancer risk reduction in a program we've entitled the "Mother's Wisdom Breast Health Program." A preliminary study by the Co-PIs (with a small grant from the Susan G. Komen Foundation), resulted in the development and testing of a prototype of the DVD program with 50 American Indian women in the Sacramento area. We will use the information from the preliminary study to make any necessary revisions and then fully develop the content areas and script and tape video presentations for testing with 100 American Indian women in California in this pilot study.

Our hypothesis is that American Indian women will be receptive to an educational intervention that is culturally sensitive, interactive and visual, thus, such an intervention will increase their awareness of the importance of breast health and breast cancer risk reduction. Future studies will examine whether such interventions actually change screening behaviors of American Indian women. Specifically, the research questions we are seeking to answer with this proposed project are:

1. What specific strategies and methods work in integrating traditional health and disease beliefs and values with Western medicine in an educational intervention to increase awareness of breast health and breast cancer risk reduction among American Indian women?
2. Will one educational intervention model of breast health and breast cancer risk reduction work across several American Indian tribes in California?
3. Is a DVD format a viable delivery channel for breast health and breast cancer risk reduction information for American Indian women?

American Indian women will be invited to screenings where they will watch the DVD on a TV monitor and also have an opportunity to test it on laptop computers. They will complete an evaluation of the program and results will compiled, analyzed and shared through journals, professional meetings, tribal health meetings and the media. The results will also provide the data for further research to determine if increasing awareness and knowledge of breast health and breast cancer risk reduction results in lifestyle changes and screening behaviors.

So little is known about risk reduction strategies to prevent the incidence of cancer and mortality throughout Indian Country, making this pilot study timely with high translational potential if successful.

Community involvement: An American Indian Advisory Council of 10 women from six tribes will be expanded to represent more tribes in California and the program will be tested and evaluated through American Indian health organizations and tribal health clinics.

Southeast Asian Breast Health Navigation

Mary Anne Foo, M.P.H., Orange County Asian & Pacific Islander Health Alliance
Marjorie Kagawa-Singer, Ph.D., M.N., R.N., University of California, Los Angeles

Funded 2006

Initial Abstract, Pilot Award

Southeast Asian (Cambodian, Laotian, Thai, and Vietnamese) women have the lowest rates of breast cancer screening among Asian and Pacific Islander women. Many Southeast Asian (SEA) women encounter enormous barriers to breast cancer screening and treatment services due to limited English proficiency; lack of transportation; living in impoverished conditions; working long hours and not being able to take time off from work for health care appointments; and lack of information and resources for their communities. While some studies exist showing lower screening rates among SEAs, there are very few studies and programs focused upon the Cambodian, Laotian, Thai, and Vietnamese communities in relation to cancer prevention and treatment. In recent years, there has been an increasing emphasis on the importance of employing community health outreach workers and navigators to reach those who have traditionally been labeled as “hard-to-reach.” However, while some studies have defined, described, and evaluated health navigator programs using a hospital and clinic-based model, relatively few studies have examined health navigator programs in community-based settings. And no studies to date have looked at patient navigation in Southeast Asian communities. Therefore, we are proposing a study to document what patient navigators do and describe how they perform their work to help women in the SEA communities to access breast health services.

By identifying and understanding the essential elements involved in a community-based patient navigation program, we will then develop a formal curriculum that can be used to train patient navigators helping women with breast health services in other underserved communities.

We seek to answer the following three research questions: (1) what are the important factors at the individual, interpersonal, and larger community levels that need to be addressed in an effective breast health navigation program? (2) how do navigators culturally tailor their strategies to help Southeast Asian women obtain necessary services from initial breast cancer screening exams through diagnostic, treatment and rehabilitation services? (3) what specific training components are necessary in a navigation program curriculum to successfully increase access to and utilization of quality breast health services for SEA women?

The project focuses on two main ideas: (1) that there are certain activities that can be done through patient navigation (interpretation, transportation, case management, social and family support, education, improved relations and communications with their provider, resource development, etc.) that help support a low income, limited English speaking Southeast Asian woman to be able to access breast health services; and (2) that this information can be used to develop a training curriculum for patient navigators helping women with breast health services in other underserved communities.

We will interview 24 medical care providers and 14 community health navigators and will train bilingual/bicultural facilitators to conduct focus groups with 120 women to understand their experiences and perceptions of the elements needed in a patient navigation model to help support women gaining access to breast health prevention, diagnostic, treatment, and rehabilitation services. Findings from our study will also help us to develop a formal patient navigation curriculum that can be tested for its impact on increasing breast health among low income SEA women.

No published studies have looked at patient navigation in SEA communities, so our project will be the first of its kind to look at patient navigation for breast health services in these communities. The project is also unique in that we will be studying navigation processes and experiences not just from the navigator point of view, but from the multiple perspectives of the patient, medical provider, and navigator in order to identify the essential elements and describe the processes, skills, and strategies needed for a successful patient navigation training curriculum and program.

SEA community members are involved in every aspect of the program, including acting as co-investigators and advisory committee members. Community members, leaders, and health workers as well as breast cancer survivors and advocates helped to initiate and conceptualize our research study. They will also help guide the development of focus group and interview questions, review of translations, and will help us to interpret and disseminate our study findings. Our interviewers come from the SEA community and are all bilingual and bicultural and have more than 20-30 years of experience working in their communities. In addition, community members will help us to develop easy-to-understand reports summarizing the study findings and will organize bilingual community forums to publicize and disseminate the study results.

The Breast Cancer Experience of Slavic Women

Roman Romaso, Slavic Assistance Center
Deborah Paterniti, Ph.D., University of California, Davis

Funded 2006

Progress Report Year 1, Pilot Award

Breast cancer ranks high among potential health problems of Russian immigrants. Even women with high levels of education and general knowledge about breast cancer risks were shown to neglect most breast preventive practices, including regular breast self-exams, yearly clinical breast exams, and mammograms. Particularly low awareness and poor preventive practices have been found among older (more than 60 years of age) and the less integrated immigrants. Women immigrants face multiple social and cultural processes that can adversely impact their breast health, and better understanding of and interventions aimed at Slavic immigrant women in the United States is necessary.

Our research is focused on answering the following question: How do first and second generation Slavic immigrant women come to understand breast health and care? Our greatest barriers to date have been to gain Institutional Review Board (IRB) approval for recruitment to and conduct of focus groups with Slavic women. IRB concerns have included translation of materials (flyers, interview schedule and recruitment script) by an impartial party (not affiliated with the research project) and development of a plan for recruitment that did not include obtaining health-related information. We overcame the IRB concerns by paying to have all materials translated into Russian by UC Davis Translation Services and by detailing the recruitment script, ensuring that it did not include the collection of any health-related information prior to obtaining potential human subjects' consent to participation in the focus group interview.

We have formed a strong collaborative partnership with the Slavic Community Center of Sacramento that has enabled us to design an in-depth focus group interview guide and to recruit 24 women from the Sacramento area to participate in the first of six focus group discussions on breast health and care. Oversight has been provided through meetings with Community Advisory Board of members from the Slavic Assistance Center, whose members have knowledge and training and/or direct experience in Slavic women's health-related issues. The Advisory Board is scheduled to meet subsequent to the conduct of four focus groups to assist with the interpretation of responses and the preliminary development of a community-based educational program by and for Slavic women.

Our project is designed to develop a program for Slavic women who might serve as community-based health educators. The program will develop tools and materials to train Slavic women to assist women in their community in developing a better understanding of breast health, access to breast cancer prevention and screening as well as recognizing avenues for seeking care for breast cancer.

Increasing Mammography among Latinas with Disabilities

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Steve Kaye, Ph.D., University of California, San Francisco

Funded 2006

Progress Report Year 1, Pilot Award

Both women with disabilities and Latinas are less likely to obtain mammograms than their non-minority counterparts. This project aims to develop and evaluate the effectiveness of an intervention to increase mammography rates among a population of Latinas with disabilities, through a combination of health education and improved physical and programmatic accessibility of healthcare facilities. To meet these objectives, initial efforts focused on establishing and enhancing community partnerships, including the formation of an Advisory Committee. Primary partnerships are in place with a chain of nonprofit community health centers, local Medi-Cal managed care agency, local chapter of the American Cancer Society, Area Agency on Aging, In-Home Supportive Services, a community organizing group that promotes literacy and involvement in the community, the health department and an independent living center in Hayward, CA.

The first aim of the project is to to use peer education to teach Latinas with disabilities about the importance and availability of mammography, along with training in healthcare self-advocacy. Currently, we are awaiting a second round of human subjects approval. The intervention will begin in June 2007. Data collection instruments, including pre- and post-interevention surveys, subject recruitment flyer, recruitment and follow-up scripts have been created. Each form was developed in English and translated into Spanish. Bilingual and bicultural members of the Advisory Committee have reviewed the Spanish versions for word choice and cultural appropriateness. Additionally, the initial intervention curriculum has been developed, tentatively including an innovative method (Breast Cancer Bingo) developed by a new partner organization (Latinas Contra Cancer).

The second aim is the assessment of local mammography facilities for overall and mammography-specific accessibility, and to work in partnership with providers to improve accessibility, and reassess to measure changes. We formed partnerships with healthcare organizations, including the health department, to begin assessment of accessibility of local healthcare facilities, beginning with those offering mammograms. The third aim is to educate local healthcare providers, community leaders, and community members about barriers to obtaining needed breast cancer screenings and on successful strategies to overcome such barriers. This portion of the project will take place in Year 2 of the project.

Mammography Screening for Latinas with Diabetes

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Steve Roussos, Ph.D., M.P.H., San Diego State University Research Foundation

Funded 2006

Symposium Abstract, Pilot Award

Latinas experience health disparities in both breast cancer and diabetes. Latinas have a lower survival rate than non-Latina white women, due predominantly to later diagnosis. Latino mortality rates of Type 2 diabetes are 1.5 times higher than non-Latino groups. Breast cancer and diabetes are linked in two ways that may be used to reduce disparities for both illnesses for Latinas. First, obesity/overweight and inactivity – both preventable – are leading risk factors for both breast cancer and diabetes for Latinas. Second, women with diabetes are less likely to receive age-appropriate mammography despite more health visits (where the complexity of caring for chronic illness is predicted to interfere with mammography).

This Collaborative Pilot Award project will advance an existing community health center and researcher partnership to improve cultural and linguistically appropriate services (CLAS) in the Central Valley, home to one of the highest concentrations of Latinos in the USA. The Pilot Award project will develop and test an intervention that adds breast cancer prevention to an evidence-based, culturally-tailored Diabetes Program serving Latinas in order to improve mammography.

The Specific Aims of this Pilot Award are:

1. Develop an intervention that incorporates breast cancer prevention into an evidence-based diabetes program in a manner that is consistent with the program's cultural tailoring to Latinos.
2. Assess differential change in mammography compliance for Latinas age 40 and over in the diabetes program alone with those participating in the diabetes + mammography program.
3. Identify and prepare the programmatic/intervention components, research components, and infrastructure of the community-research partnership necessary to apply and successfully implement a Full Award.

A Collaborative Team will consist of members from GVHC, CBEACH, and the Community Advisory Group (CAG) representing community members with a stake in breast cancer, diabetes, and health disparities. The Team will modify the diabetes registry to track and prompt for age-appropriate mammography, modify monthly mailers so that culturally tailored education and reminders include breast cancer prevention (while avoiding stigma and fear related to mammography), and train the diabetes program team to comply and support mammography screening guidelines. Once developed, the intervention will be tested by comparing changes in age-appropriate mammography among participants in the diabetes program versus the diabetes-mammography program. Diabetes program participation rates and self-management variables (e.g., HbA1C levels) will be tracked to assess influences related to the intervention. The Pilot project will provide information on intervention appropriateness and feasibility, ideal recruitment and retention strategies, estimated effect size, and protocols that would support planning and implementation of a Full Award to assess the efficacy of the intervention.

Screening and cancer disparities for Latinas are correlated with cultural and linguistic factors. Given that over 25% of Latinas have diabetes, adaptation of diabetes care to take advantage of more frequent visits and opportunities to strengthen patient-provider relationship may allow for a quick and non-threatening way to improve mammography for Latinas.

Fresno Breast Cancer Navigator Pilot Program

Mary Wallace, San Joaquin Valley Health Consortium
John Capitman, Ph.D., California State University, Fresno Foundation

Funded 2006

Progress Report Year 1, Pilot Award

Over the past four decades, the proportion of women who participate in mammography screening has increased, but women of color continue to have more advanced stages of breast cancer at diagnosis. Although screening is still important, it is not sufficient to close the racial gap in breast cancer deaths partly because disparities are influenced by differences in completing several steps involved in breast cancer care from abnormal screening through complete diagnosis, treatment and after care. Although use of a breast cancer navigator offers a practical solution, the optimal design of this approach is not known. The purpose of the study is to: (1) assess the need for a Breast Cancer Navigator intervention model to address racial/ethnic and insurance related disparities in breast cancer care at a Fresno safety net hospital; (2) Design and pilot test a Breast Cancer Navigator service responsive to the health system and community context; (3) Evaluate the feasibility and acceptability of the evidence-based navigation service using a formative evaluation approach; and (4) Build a collaboration network to support a full demonstration of the breast cancer navigation service.

We are currently in the program development phase of the project. We have made great progress towards achieving phase-one objectives. We had a successful project launch meeting to introduce the project to community partners. During this meeting, we conducted assessment/consultation with community members who are patient peers (i.e., survivors), CBOs and clinical/research team to identify factors responsible for service gaps. This group provided invaluable feedback regarding the need for the project, desirable characteristics of the navigator and stated a willingness to be a resource for the project. We held several research partner meetings to reach consensus on procedures/methods for phase-one, including IRB procedures for all protocols, chart audit and protocols for the retrospective study and instruments for qualitative interviews. We have developed process monitoring protocol and research instruments as well as translated questionnaires and related tools (e.g. patient brochures, recruitment fliers) into Spanish and Hmong and received IRB approval from all institutions involved. We have recruited navigators and completed phase-one training requirements for them.

We had an almost 6-month delay in getting the IRB approval through four institutions. We learned a lot about the process, especially the level of effort required to culturally adapt the instruments and materials to the target population. Finding a Hmong translator who could both speak and read the language proved to be a big challenge. Most could speak but could not write or read the language. Similarly, finding navigators who were both bilingual/bicultural and trained to take on the retrospective chart review component of the job was challenging. As this collaborative effort involves partners from different disciplines, we have learned to overcome these differences by focusing on what is best for moving the project forward.

The major accomplishment for phase one is that we have built a successful coalition to do the project. We have also completed the development of materials and instruments that will be used in both phases of the project and we have received institutional Human Subject Protection approval from the four institutions involved in this project.

We will continue with phase one activity. The next steps are to conduct the qualitative interviews and the retrospective chart review.

Factors Influencing Breast Cancer Screening Among Older Thai Women

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Mary Jo Clark, Ph.D., R.N., University of San Diego

Funded 2006

Symposium Abstract, Pilot Award

Asian women have lower rates of breast cancer but higher mortality rates than other racial/ethnic groups due to late diagnosis. Little information has been obtained regarding breast cancer screening in subsets of Asian women such as Thai immigrant women.

The aims of the study are: (1) to identify factors that influence mammography screening among Thai immigrant women in Southern California; and (2) to determine the extent to which these factors are present in the population and their importance in screening decisions.

Focus groups were conducted with Thai immigrant women in Los Angeles and San Diego counties to identify factors that influence participation in mammography screening. Focus group findings were then used to construct a telephone survey questionnaire to determine the extent to which identified factors were present in the Thai population.

Members of the Thai community helped to identify factors influencing mammography use by Thai women. They also validated the researchers' interpretation of the focus group findings and used those findings to construct a telephone survey questionnaire to examine the extent of identified factors in the population. The women also served as a source of contacts for obtaining telephone survey interview participants. Findings of both portions of the study will be used by community members to design subsequent interventions to promote mammography screening in this ethnic population.

Factors in each of six dimensions of health were found to influence mammography screening in this cultural population. For example, age (a biophysical factor) was found to influence women's beliefs about their chances of developing breast cancer. Similarly, cultural beliefs in karma and family and work responsibilities, both sociocultural factors, limited participation in screening activities. Physical environmental factors (e.g., distance to screening services, inconvenient location), sociocultural factors (e.g., family or work responsibilities), behavioral factors (e.g., using breast self as a substitute for screening) and health system factors (e.g., lack of insurance) also influenced screening behavior.

Knowledge of the extent of the identified factors in the Thai population will help us design programs to improve mammography screening and early diagnosis of breast cancer screening in this population and subsequently to reduce breast cancer mortality rates.

Breast Cancer Prevention and Control among Deaf Women

Heidi Kleiger, Greater Los Angeles Council on Deafness, Inc.
Barbara Berman, Ph.D., University of California, Los Angeles

Funded 2006

Initial Abstract, Full Award

The Deaf and Hard-of-Hearing (Deaf/HH) are a unique minority community. Cut off from the hearing world by culture and language, the Deaf/HH are often poor, have limited education, and, on average, adults read at a 5th grade level. Often the Deaf/HH have poor communication with doctors, less health knowledge, poorer health practices, and are fearful due to incomplete and incorrect health information. Services, including breast cancer programs and messages that make a great difference in the lives of hearing women, are not accessible to this population. There are virtually no tailored breast health and breast cancer programs for Deaf/HH women, in part due to lack of the kind of research that has been critical in developing effective programs for hearing women. Deaf-friendly breast health programs, based on research conducted by and with this underserved community, are badly needed.

We seek to develop, evaluate, and distribute a tailored breast health educational program for Deaf/HH women. In our study, women who have had a screening mammogram in the prior 12 months will be classified as “adherent to ACS guidelines.” We will test the following primary hypothesis: change in the proportion of adherent women between baseline and follow-up will be greater among women in the intervention (who receive our program) than the control group. As secondary questions we will look at the program’s impact on breast cancer knowledge, communication with physicians, clinical breast examination, and exercise.

We have three major aims to accomplish this goal, and we have taken critical steps towards achieving them.

(Aim 1) Produce a comprehensive, multi-media tailored breast cancer program for deaf/hh women. We obtained UCLA OPHS (IRB) Administrative Approval and are finalizing program content through an intensive iterative process involving our research team, expert consultants and community Advisory Committee members. We hired a Field Coordinator, a member of the deaf/hh community, a uniquely qualified videographer who has initiated the process of DVD development and filming, and a graphic artist who is participating in DVD and written material development.

(Aim 2) Evaluate the effect of the program on: breast cancer screening behavior, knowledge and awareness of breast health and breast cancer, and on lifestyle behaviors and physician communication relating to breast health through an RCT that includes 180 deaf/hh women 40+ years old with high school or less education from diverse race/ethnic groups. We revised our protocol to include “usual care” breast health information in the control group, and increased the number of subjects (to 200) in the RCT. We included 40 women (including 20 breast cancer survivors) in a companion demonstration project funded by the Susan G. Komen Breast Cancer Foundation.

(Aim 3) Dissemination of study findings: These will primarily occur beginning in year 02. Excellent progress is now being made in achieving all study aims and goals. We are meeting all challenges in this work through close, constant collaboration among members of the academic-community research team, community members, and our participating consultants.

Disparities: Eliminating the Unequal Burden of Breast Cancer

Breast Health Behaviors of Immigrant Afghan Women

Joan Bloom, Ph.D., University of California, Berkeley
Aida Shirazi, Afghan Coalition

Funded 2007

Initial Abstract, Pilot Award

Early detection and treatment of breast cancer can save lives. Despite evidence that early detection leads to decreased breast cancer mortality, it continues to be underused by minority women, especially new immigrants. Research shows that Muslim immigrant women are less likely to use breast care health services and are more likely to die from breast cancer. Due to the on going war crisis in Afghanistan, there has been an increase in the number of immigrants to the United States from this country. It is estimated that there are more than 60,000 Afghans in the United States. The Bay Area is home to the largest Afghan community in the US with an estimate of more than 30,000. Research conducted outside of United States indicates that Afghan immigrant women, diagnosed with breast cancer, are ten years younger compared to western women. In addition, they are usually diagnosed with breast cancer at a more advanced stage. This places Afghan women at very high risk of death from breast cancer. To our knowledge no one yet has studied Afghan immigrant women's understanding of breast health. We plan to examine, the beliefs, knowledge, attitudes, needs and barriers of this underserved population in Northern California about breast health care and early detection.

The question(s) or central hypotheses of the research in non-technical terms:

The central question in this proposal is to understand how Afghan women in Northern California view their breast health. In this pilot study, we hope to:

1. Learn more about what the Afghan community members believe to be their greatest concerns and barriers to receiving breast health care.
2. Learn more about Afghan women's knowledge and attitudes about breast health care and their opinions about their sources of health information.
3. Identify the specific cultural/religious characteristics needed to adapt an existing "successful" community breast health education and promotion program to the needs of the Afghan Women.

The information that we will learn from this study not only has the potential to increase breast health awareness among Afghan women, but may also help increase breast cancer awareness and the likelihood of early detection among other Muslim women in California and the US.

In this qualitative project we will conduct face-to-face-interviews with 50 first generation immigrant Afghan women, 40 years of age and older with limited English proficiency and no personal history of breast cancer who live in Northern California. The participants will be recruited through the Afghan Community. Trained bilingual community members will conduct the interviews in the women's native language (Farsi). Qualitative methods and software will be used to analyze the interviews and develop new knowledge regarding the knowledge, attitudes, and barriers to receiving breast health care.

By conducting in-depth interviews with Afghan women we can learn more about the existing barriers in access and utilization of breast health care services from the women's personal point of view. Not only does this group of women face cultural barriers as other groups do, but also religious barriers (taboos) that may preclude them from learning about their breast health and using existing services. Afghan culture/religious values are utilized in all phases of the research.

The proposed pilot project is a collaboration between the Afghan Coalition located in Southern Alameda County and the School of Public Health at UC Berkeley. We have already established a dynamic and interactive Community Advisory Board. People from the Afghan Coalition and Afghan community will participate in all aspects of the project, both as members of the Advisory Board and as project partners. The Advisory Board meetings have been very successful in the preliminary planning of the research project to develop a partnership where there is equity of control and participation by the community and research partners. Both the community and research team have certain roles in all phases of the project. Community Co-PI and the Scientific Co-PI will work together to direct the project. The members of the Afghan Coalition will continue to participate in all aspects of the design and implementation of the project from the development of the instruments, to the data collection, data analysis and interpretation, and writing of reports and manuscripts. The community will be directly involved in recruiting the study participants, conducting interviews, and transcribing and translating the interviews and providing feedback. The lay community members (grass roots) will have an active role in recruiting community members and will participate during the entire duration of the research to share their insights and experiences with the group.

Increasing Annual Recall in State Early Detection Programs

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Gregory A.Talavera, M.D., M.PH., San Diego State University

Funded 1997

Final Report, Pilot Award

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 rescreened

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.

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

Funded 1998

Final Report, Pilot Award

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

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, he 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.

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

Funded 1999

Final Report, Pilot Award

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.)

Return 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

Funded 2001

Final Report, Full Award

The objective of this study was to describe the factors predicting return to work among a multi-ethnic sample of women at baseline (0-3 months) and at 6 and 12 months after breast cancer surgery. Specific aims include: (1) To determine the percentage of women who return to work during the twelve months after breast cancer surgery and to compare this percentage across ethnic groups, (2) To compare the percentage of women who return to pre-surgery work levels during the twelve months following breast cancer surgery and to determine this percentage across ethnic groups. (3) To describe the predictors for returning to work during the twelve months following breast cancer surgery.

Three hundred and ninety-nine working women were enrolled in this study: 34% Caucasian, 29% African American, 21% Latino, 8% Asian and 3% of other ethnic backgrounds. Ninety-three percent identified as heterosexual, 5% lesbian, and 2% bisexual. The mean age of the sample was 50.6 (21-66), the mean years of education completed was 11.7 (0-20). Sixty-one percent reported a lumpectomy and 39% mastectomy. The mean income before breast cancer surgery was reported to be $1,503 ($0-$3,600), the mean income at baseline (within three months after surgery) was reported to be $1,207 (Range = $0-$3,200).

At the six month follow-up, 116 respondents (29%) were interviewed. Their average number of weeks off from work was 3.87 and their average income at six months after breast cancer surgery was $1,346 (Range = $0-$3,100). Less than a third (29%) had returned to work at six months. Respondents at six months reported significant levels of symptoms. More than half had noticeable swelling (51%) or pain (51%). Fatigue was commonly reported, with 16% indicating extreme levels of fatigue.

The most recent follow-up was at twelve months. Early analysis indicates only a slight increase in return to work after one year (33%). Symptoms common at 6 months persisted at the one year mark. Swelling was reported by 42% and pain by 45% of respondents. Extreme fatigue was just as prevalent at 12 months (18%). At twelve months 22% reported a relationship change and 34% told us their housing situation had changed. We anticipate that by September of 2006, we will be able to determine the quality of these changes. The mean number of weeks off from work at twelve months was 8.19. The mean income at twelve months after surgery was $1,375 (Range = $0-$3,100), still below pre-surgical levels. The data strongly suggests that ability to earn an income suffers significantly among low-income breast cancer survivors, and women may never return to their pre-surgery levels. Workplace and disability policy changes to accommodate these losses may significantly improve quality of life for this group.

Decision Support in Rural Underserved North Coast Counties

Sara O'Donnell, Mendocino Cancer Resource Center
Julie Ohnemus, M.D., Humboldt Community Breast Health Project
Jeff Belkora, Ph.D., University of California, San Francisco

Funded 2004

Final Report, Pilot Award

This project grew out of the relationship between leaders of two North Coast cancer resource centers (Humboldt Community Breast Health Project and Cancer Resource Centers of Mendocino County) and an academic researcher at the University of California, San Francisco (UCSF). The community resource centers had been implementing, on a small scale, elements of UCSF decision support services including Consultation Planning (CP), a type of visit preparation intervention for patients to use in creating a list of questions for their doctors. The small-scale, exploratory implementations of CP by North Coast resource centers appeared to show great promise for rural, underserved patients.

Resource center leaders identified the expansion of CP as a key opportunity and challenge. They wanted to extend the reach of CP into the farthest corners of the county and support the most underserved residents, including Frontier, Latina and Native American breast cancer patients. To this end, in 2003, our project team applied for and was granted a Pilot Award from the California Breast Cancer Research Program to study Decision Support in Rural Underserved North Coast Counties.

We had three specific aims. 1. Needs Assessment/ Requirements Development: Review records; conduct interviews with Native American and Latino community representatives; document the requirements for culturally competent CP; and revise the CP intervention accordingly. 2. Acceptability: Interview and survey Native Americans and Latinas who have dealt with breast cancer issues in the past to determine the acceptability of revised CP. 3. Viability of tele-CP: Review records and interview and survey recent recipients of CPs conducted by telephone to determine whether this was a viable mode of delivery for resource center clients.

We reviewed records for 121 resource center clients, and interviewed and surveyed 15 cultural advisors (9 Native American and 6 Latino/a), 22 breast cancer survivors (including 6 Native Americans and 6 Latinas), and 7 resource center staff. We met a total of 48 times to conduct 15 Requirements interviews, 12 Acceptability interviews, 17 tele-CP interviews, and 4 focus groups with cultural advisors and other stakeholders. In addition, we held 33 internal meetings directly related to this pilot study.

Our record reviews showed that both in-person and tele-CP were associated with high satisfaction (8.67/10, n=67) and decision self-efficacy (39.94/44, n=54) levels among rural, White clients of the resource centers, including breast cancer patients, but that the resource center client base did not include representative proportions of Native American and Latina breast cancer patients. As a result, the resource center sites took steps to strengthen and formalize their relationships with those communities, including the establishment of referral agreements and medical translator training. During the study, we employed these referral agreements and cross-cultural relationships in recruiting and interviewing 15 cultural advisors and 12 Latina and Native American breast cancer survivors, along with 10 past recipients of tele-CP. These key informants unanimously endorsed the concept of visit preparation, and unanimously endorsed our approach (Consultation Planning, average acceptability score = 3.4/4, average satisfaction = 9.4/10), while adding suggestions for improvement. We documented the suggestions for improvement in a CP requirements document.

After reviewing these requirements, the resource center leaders and academic partners specified revisions to the resource center physical infrastructure, processes, techniques, and tools in order to meet the needs stated above. For example, the Cancer Resource Centers of Mendocino County organized a training workshop to certify 25 medical interpreters, and now contracts with Nuestra Casa (a local Latino community agency) to have all CP documents translated. Regarding outreach, the Humboldt Community Breast Health Project continued to recruit members to its Hispanic Outreach Team, and to build its relationship with the Potawot Health Village. Other changes were made to the CP training manual and reference guides (checklists and procedures). For example, during the intake process for Consultation Planning, we specified that CP providers should ask patients if any family members should be specifically included or excluded from the CP process, as a way of surfacing and honoring how patients wished to negotiate the involvement of their family members. New infrastructure specifications include private offices with closed doors for staff or volunteers conducting CP or tele-CP, and a sign indicating that a CP session is in progress. For tele-CP, one process change in response to requests is that whenever possible, CP providers will send to the client a picture of the resource center and its staff and volunteers (with the CP provider circled on the photo) along with other advance materials such as the CP prompt sheet.

We have now been funded to compare, in a Full Award, the impact of CP and tele-CP on cost and quality of life outcomes for rural, underserved breast cancer patients in Mendocino County. If this study shows that tele-CP is more cost-effective than in-person CP, we hope to expand our use of tele-CP in Mendocino, and provide technical assistance to other resource centers or agencies wishing to implement this service in their communities.

If proven cost-effective, our community-driven enhancements to Consultation Planning could help us expand our program delivery from 86 clients in 2003 to the several hundred patients making breast cancer diagnosis, treatment, and follow-up decisions each year in Mendocino County. Our changes to Consultation Planning will ensure that the intervention is better adapted to the needs of Native American and Latina breast cancer patients. Thanks to telephone delivery, Consultation Planning could also be delivered to other rural areas in California, which consists of 11 percent of the population spread over 75 percent of the land mass in California. Finally, Consultation Planning could assist in addressing the 20,000+ annual breast cancer diagnoses in California, whether rural or urban.

Peer Mentoring Program to Promote Breast Cancer Clinical Research

Michelle Rakoff, Breast Friends
Annette Maxwell, Ph.D., University of California, Los Angeles, Division of Cancer Prevention and Control Research
John Link, M.D., Long Beach Memorial Medical Center

Funded 2004

Initial Abstract, Pilot Award

Clinical trials are a mechanism for testing new cancer therapies and at the same time, providing opportunities for patients with cancer to obtain state-of-the-art treatment. However, only a small fraction of newly diagnosed breast cancer patients enroll in a clinical trial. Patient barriers to enrollment include confusion about study procedures, misconceptions regarding the trials, and misunderstandings of research versus standard medical care. A Clinical Research Mentoring (CRM) program that is developed with significant input from breast cancer survivors can assist newly diagnosed breast cancer patients in deciding whether or not to join a treatment trial and will lead to increased recruitment to breast cancer clinical trials.

First we will interview breast cancer survivors to explore why some decide to join a clinical trial and why others decline. We will also discuss with several groups of breast cancer survivors what might have helped them to make their decision. Based on what we have learned, we will then design a training program and a multi-disciplinary team will train 10 breast cancer survivors as CRMs. We will match newly diagnosed breast cancer patients with CRMs and assess how many will join a clinical trial, and how the CRM program influences knowledge and attitudes of these patients.

This study is innovative because the concept of utilizing peer educators who have successfully been used to change various health behaviors is applied to a new area: Participation in breast cancer clinical trials. In addition, our research collaboration is innovative, with a clinical partner, a community partner and a partner with expertise in research methodology. Finally, we see our study as a step toward creating a new culture in the breast cancer treatment environment, where patients become partners with doctors to move forward breast cancer research.

(Note: This study ended prematurely due to clinical trial closing.)

Consultation Support for Diverse, Rural Breast Patients

Joy Hardin, Ed.D., Humboldt Community Breast Health Project
Jeffrey K Belkora, Ph.D., University of California, San Francisco, Center of Excellence for Breast Cancer Care
Sara O'Donnell, Mendocino Cancer Resource Center

Funded 2005

Progress Report Year 1, Pilot Award

Breast patients are increasingly advised to "take a tape recorder" and "bring a friend along to take notes for you" when meeting with a physician. This common-sense advice has even been evaluated in urban teaching hospitals and cancer centers, and has proven effective in increasing patient satisfaction and knowledge. However, no one has evaluated and implemented these or other consultation support interventions in rural areas with diverse populations. The goal of the present follow-on pilot study is to conduct a formative evaluation of interventions aimed at supporting diverse rural patients and breast cancer specialists during decision-making consultations.

At the end of the first year of our project, we have concluded various project setup tasks, solicited more community input, revised our protocol in response to this community input, and are beginning to document stakeholder needs for consultation support. The most significant change in our protocol was an amendment of our research question, which had previously been stated as "How can we help breast cancer patients absorb, understand, and act upon information presented in a decision-making consultation?" Further community input led us to expand the question to be more open to whatever forms of consultation support that were deemed necessary or valuable by patients, physicians, or community health agency staff. Along with other less significant changes, we submitted a revised protocol to the UCSF Institutional Review Board. Our research question now reads, "How can we help breast cancer patients and their specialists get the most out of major medical appointments leading to treatment decisions?" We have updated our interview guides to reflect this aim, and we are now interviewing 12 doctors, 8 community health agency staff, and 12 breast cancer survivors to determine critical success factors and barrier promoting or inhibiting productive patient-physician consultations. We began these requirements and specifications interviews in April 2006, and as of May 31st have conducted 6 interviews out of a projected 32. Building on the work of our first CBCRP funded pilot study (2004), we are including Native American and Latina breast cancer survivors as well as doctors and agencies who serve the Native American and Latino communities.

We are on target to conclude this formative research within a second project year. We expect that this work will lead to new supportive services, perhaps implemented by our resource centers, which will address significant patient and physician needs. Future work will go beyond formative research to evaluate the impact of these new interventions.

South Asian Women with Breast Cancer: What are Their Needs?

Roshan Bastani, Ph.D., University of California, Los Angeles, Division of Cancer Prevention and Control Research
Beth Glenn, Ph.D., University of California, Los Angeles, Division of Cancer Prevention and Control Research
Zul Surani, B.S., SAATH: South Asian Cancer Foundation

Funded 2005

Progress Report, Year 2, Pilot Award

Breast cancer is a growing problem among South Asian women in the United States. While increasing numbers of South Asian women are diagnosed with breast cancer every year; few published studies have examined the unique needs of this population.

Currently, we are conducting semi-structured qualitative interviews to capture information about the needs and experiences of these women. Our initial task was to identify and train women from the community serve as interviewers. We have recruited and trained 8 interviewers from the community. Topics of trainings included human subjects' issues, techniques for conducting open-ended interviews, review of the data collection instrument and interview guide, and some background regarding cancer. Interviewers speak English and a variety of South Asian languages including Hindi, Bengali, Urdu, and Sinhalese among others. Saath, the community partner in this study, has also been successful in identifying study participants. Thirty-five eligible participants have been identified from the community and interviews have been completed and transcribed for 14 of these women. The other identified women will be interviewed within the next several months and we will identify and complete interviews with five additional women for a final sample size of 40.

We are in the process of identifying the 10 individuals who will complete key informant interviews. Key informants will include physicians and other health care providers, leaders of faith-based organizations, and leaders of community-based organizations that serve the South Asian community. Identifying and recruiting women to complete study interviews has been the primary challenge faced by this study. A number of strategies have been employed including advertisements in ethnic print media and conducting outreach at cultural events, health fairs, and religious settings. Study staff have found that many survivors are interested in contributing to research by participating in the study but are hesitant due to the ongoing stigma of breast cancer in the community.

Some major accomplishments of this project include: (1) training and retention of bilingual interviewers; (2) identifying participants in the study through community outreach (3) making contacts and networks with community members and stakeholders; (4) coordination between UCLA and Saath project staff; and (5) building trust with South Asian breast cancer survivors and key community figures. In the next seven months, we plan to complete interviews with identified women, identify and complete interviews with 5 additional women, complete interviews with 10 key informants, conduct data analyses, and outline the essential components of an intervention tailored to the needs of South Asian women.

Telephone-based Decision Support for Rural Patients

Sara O’Donnell, Mendocino Cancer Resource Center, Inc.
Jeff Belkora, Ph.D., University of California, San Francisco

Funded 2006

Progress Report Year 1, Full Award

Breast cancer patients are often advised to write down a list of questions before talking to their surgeons or oncologists about treatment decisions. However, without support, newly diagnosed patients may be too overwhelmed to make a list of their questions. Over the last 30 years, studies have shown that patients benefit from having a researcher or nurse prompt them for questions before an upcoming appointment. In some of these studies, the researcher or nurse then wrote down the patient questions so that the doctor could be sure to address them. The studies have not been translated into practice. Today, few facilities are providing this support, known as visit preparation, perhaps because of the cost or organizational challenges. Our team, a partnership between a rural community resource center and a university research group, has implemented a form of visit preparation known as Consultation Planning (CP).

We have made CP work in our communities by training resource center staff to deliver the service in face-to-face interviews with patients. We now wish to expand CP for delivery to more diverse patients, including Native American, Latina and Frontier (extremely rural) residents. We also would like to deliver it by telephone (tele-CP), since this might be less costly and more convenient for all parties. We have collected initial data suggesting that CP is appropriate for diverse patients (including Native Americans and Latinas), and may still be effective when delivered by telephone.

We are thus proposing a bigger, more detailed study to evaluate the effectiveness of delivering CP by telephone versus in person, and explore the costs to the patient and resource center.

We ask whether tele-CP is as effective as in-person CP in improving a patient’s confidence in her ability to participate in decision-making with her doctor. We question whether tele-CP saves the patient and resource center time or money compared to in-person CP. We will also track other outcomes such as quality of life and follow-through with appointments and treatments.

We will invite all 90 Mendocino patients diagnosed every year with new or locally recurrent breast cancer to join our study. We need 144 over a three-year period in order to make our study scientifically valid. Patients that agree to join our study will be assigned (through a process similar to a coin flip) to tele-CP or in-person CP. A resource center staff member will use the assigned method to help the patients prepare a list of questions for their surgeon or oncologist. Before and after the CP session and their doctor’s appointment, patients will fill out short surveys describing their confidence, anxiety, confusion, quality of life, and costs to them of doing the CP session (e.g. travel time). From these surveys, as well as other records, we will determine whether tele-CP was as good as in-person CP, and whether it was more convenient or less costly.

The proposed study is unique in a number of ways. It is the first study of whether non-researchers (resource center staff) can perform visit preparation in a way that improves patient participation, decision making, quality of life, and other outcomes. It is the first study of whether visit preparation can be delivered by telephone. And it is the first study of visit preparation among underserved, rural, diverse patients including Latinas and Native Americans.

Our resource center is in its 10th year of service to the residents of Mendocino County. It is supported entirely by grants and donations, and served 546 new clients in 2005, of whom 65 were breast cancer patients. As a result of our Pilot Study, we are formalizing referral agreements with other community health agencies (including Nuestra Casa and Consolidated Tribal Health), all six primary care clinics in the County, both medical oncologists, and the only general surgeon who specializes exclusively in breast cancer. Representatives from these partners, along with patient representatives, make up our project’s 27-member community advisory board. Our advisors have guided the design of this study based on our pilot study featuring 37 interviews and 121 survey responses. We also convened a community feedback session in January 2006 attended by 14 providers, 11 agency representatives, 10 breast cancer survivors, 6 community health leaders, and 2 pilot study subjects. Thanks to this community input, we took pains to formulate a study in which every participant will get a supportive intervention. We have also budgeted for the resources necessary to invite all eligible Mendocino residents to participate in our study, including all Native American, Latina, and Frontier (extremely rural) breast cancer patients.

Science Literacy & Breast Cancer Clinical Trials Education

Natasha Riley, M.A., Vista Community Clinic
Georgia Sadler, Ph.D., M.B.A., University of California, San Diego

Funded 2007

Initial Abstract, Pilot Award

Many factors contribute to the unequal burden of breast cancer among diverse communities. Clinical trials or "research studies," offer promising solutions to medical advances. Low participation rates in clinical trials, especially among minorities, are a barrier to the advancement and generalizability of medical knowledge and health impact on survivorship among these populations.

Low participation by minorities is a problem because: (1) it limits researchers' ability to apply findings to diverse populations; (2) it often means that minorities will be given medical care based on research studies that involved mostly white middle class communities; and (3) it means that the cutting edge medical care options usually associated with clinical research will not be available to minorities. All of these factors contribute to the unequal burden of breast cancer among minorities. One reason why minorities do not participate in clinical trials is lack of information about the role of clinical trials and the importance of participants of diverse characteristics. This pilot study addresses that problem by providing an educational program to increase awareness of, and knowledge about, clinical trials information.

Research questions will not be directly tested in the pilot study. The pilot study will develop the tools needed to test the educational program to be developed. The larger study will test whether participants who receive the educational program (the experimental group) show: 1) increased scientific knowledge about clinical trials and 2) a positive shift in attitudes and behaviors toward clinical trials after participating in the study. This pilot study will also test whether increased knowledge and a positive shift in attitudes and behavior are related. The results in the experimental group will be compared with a group given different information (the control group). The larger study will also test whether the group given the educational program will demonstrate a greater rate of participation in a simple breast cancer-related research study than the control group. Finally, the study will test whether the test group demonstrates greater willingness to become a "Clinical Trials Ambassador" (one who learns about future clinical trials and helps the research team to recruit other participants). Standard questionnaires will be used to help measure change between the two groups of participants.

This project will focus on creating a single program, called the Scientific Literacy and Breast Cancer Clinical Trials Education Program. This program will be pilot tested with a group of African American and Hispanic American women. The program will use a "sisterhood" theme that will draw all women together against the common enemy of breast cancer. Building on program work already done by the National Cancer Institute, a single education program will be created in English and Spanish. This project will also test group surveys in English and Spanish to assure that they are reliable when used with Hispanic American women. These surveys have already been shown to work well with African American women. After proving the surveys' reliability, a trial run will be performed with the educational program and surveys with a small group of women. If this plan works, a larger study will be done to determine the effectiveness of the educational program.

This pilot study will educate women about breast cancer clinical trials and the importance of participation. While it will use many elements of the NCI's cancer education program, its use of a "sisterhood" theme as its foundation is innovative and is anticipated to appeal to women of all ethnic groups. The program will be tested in English and Spanish with Hispanic and African American women.

This project will also evaluate the usefulness of a number of paper and pencil surveys when used with Hispanic Americans. These surveys are commonly used in breast cancer and other research studies, but have not yet proven effective with Hispanic Americans. If this pilot project works, a larger study will follow. If the program is effective it will be made available to other breast cancer researchers and health educators. Community involvement: Focus groups have already contributed direction on the topic and design selected for this study. Community input will continue throughout the project. Staff from the five VCC clinics that serve low income, minority women will advise the research partner. VCC will benefit by gaining research skills and experience in creating partnerships. UCSD will benefit from this partnership by gaining additional experience working with disadvantaged women and enhancing its community connections. The partnership will help both groups better serve the community.

Sociocultural, Behavioral, and Psychological Issues: The Human Side

A Community-based Workbook for Helping Rural Cancer Patients

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

Funded 1997

Final Report, Pilot Award

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 Loba, 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 31)

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

Funded 1997

Final Report, Pilot Award

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.

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)

Funded 1998

Final Report, Full Award

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 reduces the human and economic cost of breast cancer in California by validating community groups usually offered free to women with breast cancer.

A Support Group Alternative for Rural and Isolated Women

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

Funded 1998

Final Report, Full Award

This study was initiated by women survivors of breast cancer living in a rural community in California who formed a partnership with academic researchers to develop and evaluate the effects of *One in Eight,* a community-based workbook-journal for geographically and economically isolated women diagnosed with primary breast cancer. After a pilot study demonstrated that this psychoeducational invention was effective in reducing traumatic distress and improving coping among subgroups of rural women living with breast cancer, this larger study was implemented. Our partnership was joined by Dr. Bodai, head of the Kaiser Foundation Research Institute.

This current study was conducted to evaluate the short-term and longer-term effectiveness of *One in Eight* in helping women who are newly diagnosed with breast cancer to psychologically adjust to their diagnosis, cope with their cancer diagnosis and its treatment, and feel emotionally supported. We also wanted to examine the psychological needs of this HMO population of women newly diagnosed with primary breast cancer. The recruitment sites included three Kaiser facilities in the greater Sacramento area. The sample included 151 participants who were enrolled into the study, assessed at baseline, randomized to intervention condition (workbook-journal plus educational materials/ educational materials alone) provided with the intervention, and then reassessed at 3-and 6-month follow-ups. The sample was predominantly comprised of women from groups that tend to be socially isolated and underserved, including age 65 or older (32%), living over 20 miles from their health care facility (35%), disabled with a hearing loss (17%) or other physical impairment (18%), having a high school education or less (17%), and being unemployed (40%). Participants also included 13% of ethnic minority background (3% Native American, 3% Asian American, 1% African American, and 3% Latina/Chicana) and 2% lesbian. Follow-up rates for the 3-month and 6-month assessments, respectively, were 89% and 85%. At baseline 64% of the women met screening criteria for clinical depression on the Center for Epidemiologic Studies–Depression scale. Furthermore, 15% of the women at baseline met screening criteria on the Posttraumatic Stress Disorder Checklist–Specific scale for posttraumatic stress disorder in reaction to their diagnosis and treatment for breast cancer. Both depressive symptoms and traumatic stress symptoms are found to be far higher in this population than in previous studies of women diagnosed with breast cancer. This underscores the importance of evaluating interventions such as *One in Eight* to reduce these depressive and traumatic stress symptoms.

Women who received the workbook-journal, compared to those receiving usual care, reported significantly greater reductions in depression at the 6-month follow-up ($p < .05$). Among women who met criteria for depression at baseline, those who received *One in Eight* were significantly less depressed at the 3- and 6-month assessments ($p = .01$). Similarly, among women who reported greater PTSD symptoms at baseline, those who received the workbook-journal had greater decreases in PTSD symptoms at the 3-month follow-up ($p = .001$). Furthermore, women who received the workbook-journal reported greater improvements at 3 and 6 months in knowledge of how to cope emotionally with breast cancer ($p < .05$). These results suggest that a low-technology, community-based intervention such as the workbook-journal can significantly reduce depression and PTSD symptoms and enable better emotional coping with breast cancer.

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

Funded 2001

Final Report, Full Award

We found in a previous pilot study funded by the CBCRP that newly diagnosed women with breast cancer (sojourners) who were matched with a peer navigator improved significantly over the course of one year on their trauma symptoms, emotional well-being, cancer self-efficacy, and desire for information on breast cancer resources. Navigators (trained peer counselors with whom sojourners were matched) maintained baseline levels of these measures, but increased in dissatisfaction with their interactions with their medical team and increased emotional suppression. WomenCARE in Santa Cruz, and Stanford collaboratively conducted this initial study providing the background for their continued collaboration on the current clinical trial.

In the current clinical trial of this peer navigator intervention, it was necessary to repeat the methodology of the previous study with the addition of randomizing the newly diagnosed women to either be matched with a navigator or to be in a control group. It was necessary to conduct this further study because the control group allows us to see whether the changes we saw in our first study would have happened whether or not these women received a navigator.

In the current study, all newly diagnosed women (104 women) were recruited within 2 months of diagnosis. They all received a one-time nurse visit giving them information on local breast cancer resources, then half were randomized, through a process similar to a coin toss, to receive a navigator and half received no further intervention but filled out questionnaires over time at baseline, 3, 6, and 12 months. The women who received a navigator could have this intervention for up to 6 months. Sojourners (newly diagnosed and matched women) were matched with navigators on a list of preferences that they rank ordered. Peer navigators (36 peer counselors) had received a breast cancer diagnosis at least one year earlier. We trained them in listening skills and knowledge of local resources and supervised them once per month. Navigators also completed questionnaires at baseline 3, 6, and 12 months.

We found that sojourners were significantly higher than controls on marital satisfaction by the end of the study, and decreased more on anxiety and distress if they were initially high on these measures. They also improved their ability to regulate their emotions by decreasing suppression if initially high, and increasing restraint of hostility if initially low. Navigators were able to provide this intervention with little change in their levels of psychosocial functioning, with the exception of a significant increase in distress. These results are preliminary and await the completion of the final follow-ups. At the end of the trial we will investigate further the meaning of these results by further analysis and by conducting focus groups with sojourners, controls, and navigators. A peer navigation intervention may decrease the human and economic cost of breast cancer.

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.

Funded 2001

Final Report, Full Award

This three-year, community-based study applies social network theory to test the effectiveness of a culturally tailored, Chamorro lay health advocate intervention to increase breast cancer screening rates among Chamorro women age 50 years and older in the counties of Los Angeles and Orange. The study employs a quasi-experimental (intervention and control group), prospective cohort, pretest/posttest 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 the network of Chamorro women in the intervention vs. control communities.

During the third year of the study, we accomplished all of the proposed major activities: (1) recruited and surveyed a total of 422 women in Northern and Southern California about their breast cancer knowledge, attitudes, and behaviors as well as their social networks; (2) developed a training curriculum for lay health advocates in Southern California; (3) recruited and trained 11 Chamorro women (5 in Southern California, and 6 in Northern California) in basic breast cancer knowledge as well as educational skills; (4) developed incentive and educational tools, including a “bingo” card game to educate women in small social settings; (5) developed a draft follow-up survey to assess changes in women’s knowledge, attitudes and behaviors; (6) administered the follow-up survey with a total of 324 women (for a total response rate of 76.8%); and (7) disseminated all of the data and training/education materials to the comparison site (Northern California). While this study will provide vital information on breast health promotion for Chamorro women, the results will help inform the development of successful network-based strategies for the promotion and evaluation of breast cancer screening among ethnic minority women from similarly small, tight-knit populations across California.

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)

Funded 2001

Final Report, Full Award

The overall aims of this randomized study were to:
(1) Evaluate efficacy of face-to-face (F2F) and Online Internet support groups (OSG). We hypothesize that participation in both TWC's F2F and OSG support will improve attitudes and beliefs about their illness, and quality of life, decrease marital strain and levels of depression. (2) To test mediators of group support in both the FTF and OSG.

We were not able to recruit a sufficient number of women to accomplish both of these aims. Details of our recruit efforts and statistics on the sample we studied are provided in the scientific report. An analysis of the OSG vs. F2F groups using the FACTB scale to measure quality of life, the CESD scale to measure depression, PTGI scale to measure emotional growth, and MINIMAC to meassure coping and pain. No significant differences were found in changes over time for both groups or the groups (F2F vs. OSG) on the FACTB, CESD AND MINIMAC measures. The sample size did not permit an analysis for Aim 2. During the course of our work, we soon realized that recruitment was a serious problem and made a number of changes in how we recruited. We also set out, using some of the resources of the BCRP grant (not the field staff) to embark on a series of studies that would broadly expand our knowledge about OSG, particularly peer-facilitated BC groups. These studies are summarized below.

First in importance was the finding that peer facilitated large internet groups for women with breast cancer result in substantial positive improvement in quality of life and lowered depression. Our analysis of peer led cancer OSG suggested that one possible mechanism for this success is the ability of women to search among such groupsfor one that they believe matches their needs through the mechanism of "lurking" before posting a message. Much of our effort during the BCRP grant has been directed towards isolating characteristics of the participants and the group conditions or processes that lead to positive outcomes of the group members. We found that the expression of specific negative emotions in the group is associated with positive change and that professionally facilitated OSGs are more likely to enhance the frequency of such expressions. We found that certain therapeutic factors (helpful group experiences) are linked to positive change. We also found that the norms of the groups (the regulatory group culture) enhanced these HGEs. Leader behavior made a difference and certain types of behavior are more successful in creating a group where participants make positive change. This leader behavior works by enhancing the group's cohesiveness. When we compared F2F and OSG we found that by and large they are more similar than different in both processes and content of discussion. In a study of those who drop out of OSG, we found that they experience at the outset of the group more fear and anxiety about the group. Finally, in looking at various non-gender related cancers, we found that men rarely gave expression to the critical negative emotion compared to women with the same cancers.

These studies have provided invaluable information on how OSG can be improved to maximize their effectiveness.

Sociocultural, Behavioral, and Psychological Issues: The Human Side

Expanding Rural Access: Distance Delivery of Support Groups

Cheryl Koopman, Ph.D., Stanford University School of Medicine
Mary Anne Kreshka, Sierra College
Susan Ferrier, R.N., Northern Sierra Rural Health Network

Funded 2004

Progress Report Year 1, Pilot Award

Northern Sierra Rural Health Network (NSRHN) and Stanford University School of Medicine are collaborating to determine whether the video-conferencing technology resources already in place can be used to expand access to support services for women living with breast cancer. The study has three primary aims: Aim 1: Determine the feasibility and acceptability of using an existing videoconferencing network to reduce rural/urban inequities in access to psychosocial support for women with breast cancer residing in rural northeastern California. Aim 2: To evaluate whether the psychosocial support needs of women with breast cancer living in rural northeastern California, as they are understood by the women themselves, can be met through the use of videoconferencing. Aim 3: Support the capacity of the communities in the target region to use videoconferencing to improve access to psychosocial support for women with breast cancer.

We are recruiting 40 rural women living with breast cancer from Plumas, Modoc, and Siskiyou Counties for the research. Each participant provides informed consent, completes baseline assessments on validated quality of life measures, participates in 8 weekly support groups conducted by video conferencing, receives the workbook-journal One In Eight, and completes a follow-up assessment. A brief interview is included in the follow-up assessment to elicit feedback about the intervention and the mode of delivery.

Thus far, two groups have been completed that used videoconferencing to provide facilitated group support to 14 women with breast cancer. Follow-up assessments are being conducted for these 14 women. Attendance in the first two groups has been excellent. Participants, including the older women, have adapted quickly to the technology, readily turning to the content of discussion. Participants are excited about pioneering the use of videoconferencing to provide social support for women with breast cancer. These women have expressed appreciation at being able to learn from women in other geographic areas about how breast cancer is treated in other communities. The group facilitator has found it more difficult to use visual cues to augment auditory ones in a group using the video-conferencing modality. Also, she finds it more challenging to encourage interaction because of the time lag in the sound of speech.

This project is continuing its outreach activities, with Mary Anne Kreshka, Susan Ferrier, and Rebecca Parsons are traveling to strengthen and expand community relations for the purposes of recruiting more women into this study. This research has the potential to inform the design and implementation of technology-based intervention that would be readily accessible to rural women with breast cancer. Our future plans are to disseminate the findings and train health care providers with the hope of establishing one or more types of psychosocial support delivered via videoconferencing as part of routine care for rural women with breast cancer on a continuous basis.

(Note: A continuation of this project was funded as a full project in 2007. See page 51)

Underserved Women with Breast Cancer at the End of Life

Beverly Burns, M.S., B.A., L.Ac., Charlotte Maxwell Complementary Clinic
Shelley Adler, Ph.D., University of California, San Francisco

Funded 2005

Final Report, Pilot Award

End-of-life care, in general, is extremely inadequate in the U.S. For low income, underserved women, this problem is more acute since the risk of death is higher and their needs are less likely to be met.

The research questions were: 1. what are the beliefs, values, concerns, expectations, and goals about end of life from the viewpoints of underserved women with breast cancer, their physicians, CAM practitioners, and informal caregivers? 2. What communication about end-of-life issues takes place among underserved women with breast cancer, their physicians, CAM practitioners, and informal caregivers?

In order to answer our research questions, we recruited and interviewed 10 underserved women with metastatic breast cancer from among the clients at the community-based Charlotte Maxwell Complementary Clinic, as well as the physician (oncologist), CAM provider, and informal caregiver that the client selected as being most integral to her care. We developed and piloted semi-structured interview guides for patients (4 sessions), informal care givers (2 sessions), and CAM practitioners and physicians (1 session each). We focused on the women's values, needs, expectations, and concerns at end of life, as well as the communication that occurs between them and their healthcare providers. Next, we made digital audio recordings of these interviews and had them transcribed. Finally, our research team studied the contents of these interview transcripts in order to develop an understanding of the needs of underserved women with metastatic breast cancer at end of life and how best to meet these needs.

We have conducted a study that conforms to the requirements of a true community-based participatory research project: community members were involved in all phases of the research process, including identifying the issues of concern; developing assessment tools; collecting, analyzing, and interpreting data; determining how data could be used to inform actions to improve community health; designing, implementing, and evaluating interventions; and disseminating findings.

Analysis of the data is still ongoing, but a number of major and recurring themes in patients' experiences at the end of life are:

- The enormous impact of financial crises resulting from a cancer diagnosis
- Patients, particularly mothers, are uncomfortable in the “sick role”
- Patients had major concerns about inadequate preparation for death
- Patients did not hesitate to talk about dying.

Most CMCC clients have not made decisions or have not clarified their choices related care during end of life or their wishes for what should be done after they die.

Patients also were interested in working through the Five Wishes planning tool that is provided to all CMCC clients, although our experience is that only about 5% of CMCC clients actually fill out the form and use it. (Five Wishes is a document that provides a legally binding plan for the way an individual wishes to be cared for during serious illness.)

Our pilot CRC study established the strength and mutual benefit of our community-research collaboration and pointed to two areas of community interest regarding future work. We will (a) design a narrative method, an "ethical will" intended to improve the quality of CMCC clients' end of life by reducing suffering through enhancing meaning and (b) develop a community peer-based system to support women through the process of completing the Five Wishes booklet (a document that provides a legally binding plan for the way an individual wishes to be cared for during serious illness).

(Note: A continuation of this project was funded as a full project in 2007. See page 52)

Psychosocial Support Services for Latinas with Breast Cancer

Anna Nápoles-Springer, Ph.D., University of California, San Francisco
Carmen Ortiz, Ph.D., Circulo de Vida

Funded 2005

Final Report, Pilot Award

Latina breast cancer patients infrequently use cancer support services, even though they may be at higher risk of psychosocial morbidity than White women. This under use has not been well-studied In this collaborative study by the Academic Partner (AP), UCSF, and the Community Partner (CP), Círculo de Vida (CDV), we obtained data on: (1) facilitators and barriers to use of support services among Spanish-speaking Latinos with cancer; (2) the psychosocial needs of this population; and (3) suggestions for a peer support counselor (PSC) program for Spanish-speaking Latinas with breast cancer. We conducted a telephone survey of 89 Spanish-speaking Latino cancer patients referred to CDV (including people who did and did not accept services); about 70% were Latinas with breast cancer with less than a high school education. We completed semi-structured interviews with 29 Latina breast cancer survivors who had and had not used support services (most were diagnosed within two years of the interview), and 17 interviews with community advocates working with Latinas with breast cancer (patient navigators, cancer support and education specialists, oncology social workers).

We found that the greatest barriers to use of support services in this population were: lack of transportation, lack of familiarity with the nature of support services, and being unaware that services were available in their local area. For women who had used support services, the most frequently mentioned benefits were, in order of importance: (1) the ability to discuss cancer related issues with a fellow cancer survivor; (2) support and compassion received; and (3) information on cancer and its treatment. The two dominant psychosocial needs in the period following diagnosis were help in addressing an intense fear that they were dying and information to address their sense of powerlessness largely due to the lack of cancer and treatment information in Spanish and the physicians' time constraints. Community advocates identified four key areas that are critical for addressing the psychosocial needs of this population: (1) the provision of simple information in Spanish on breast cancer, treatments, treatment side effects, and management of side effects; (2) knowledge of community resources; (3) cultural sensitivity; and (4) patient empowerment.

With systematic input from community members, survivors, and professionals, we wrote a resource manual for community organizations on developing a PSC program, and pilot-tested a training program with seven new PSCs. Working with a large group of community organizations, community advocates, and Spanish-speaking Latina breast cancer survivors, we submitted an application for a full CBCRP CRC award to continue our work in this area. Using a randomized, controlled trial design, the proposed study will test a social-cognitive theory-based, peer-delivered intervention that has been adapted for use with Spanish-speaking Latinas with breast cancer. This program could serve as a model to meet the psychosocial needs of other vulnerable women diagnosed with breast cancer.

Sociocultural, Behavioral, and Psychological Issues: The Human Side

Informal and Formal Support and Needs among Samoan Survivors

Sala Mataalii, Samoan National Nurses Association
Sora Park Tanjasiri, Dr.P.H., M.P.H, California State University, Fullerton

Funded 2006

Initial Abstract, Pilot Award

While considerable literature exists supporting the need for formal social support programs for breast cancer survivors, only a few studies have looked at the roles that informal supporters (i.e., family and friends) play in survivor quality of life and survival. The latter, however, is of considerable relevance for ethnic/racial women from culturally collective communities, such as Samoans and other Pacific Islanders (PIs). Breast cancer is the leading cancer for Samoan women, yet there exists no studies on the relative importance of informal and formal support for their long term survival and quality of life. This study proposes to explore informal and formal support in a very ethnically close community of Samoans in Southern California.

This exploratory pilot study addresses two key questions of central importance to Samoan breast cancer survivors: (1) What are the formal and informal social support needs of Samoan women diagnosed with breast cancer? (2) To what degree do informal and formal social support mechanisms fulfill these needs for current Samoan survivors? By answering these questions, we hope to not only increase the knowledge base regarding social support among survivors, but also contribute to the refinement and testing of an existing community-based social support model to measure the specific impacts on changes in quality of life among Samoan survivors.

This pilot study uses qualitative, exploratory approaches to explore the social support needs and experiences of Samoan breast cancer survivors and their informal supporters. Based upon grounded theory, we will recruit and interview approximately 20 Samoan survivors, along with approximately 40 of their informal supports (approximately 2 per survivor). Using techniques such as theoretical sampling and constant comparisons, we hope to identify and understand the range of social support experiences among Samoan survivors.

We believe this is the first study of its kind to explore the differing needs for, and roles of, formal and informal social support among breast cancer survivors. Furthermore, the exploration of such issues in the ethnic community of Samoans provides us an excellent opportunity to understand how such cultural values such as family connectedness and holism impact survivors use of differing social support mechanisms.

The genesis for this study arose from questions posed by the community-based partner, the Samoan National Nurses Association, regarding the impacts of their existing social support program on survivors and their families. After attending the June 2005 CBCRP workshop, SNNA's Executive Director (Marion Hannemann) met with CSUF's Dr. Tanjasiri to discuss the idea of proposing a study that explores the social support needs of Samoan survivors. Throughout the entire proposal development phases (from concept paper, to bidder's training, to now), three SNNA staff (Ms. Hannemann, Mataalii, and Tupua) have actively participated as a leading partner. To ensure that this pilot effort continues to meaningfully involve members of the general Samoan community, we have also developed a Community Advisory Board with membership reflecting the diversity of viewpoints and experiences of community leaders and cancer survivors, all of whom are Samoan and are actively involved in promoting the well being of the Samoan community.

There are over 50,000 Samoans in California. While Samaoan and other Pacific Islander women have high rates of breast cancer incidence and mortality, there are few studies of their survivorship and social support needs after diagnosis. This 18-month pilot CRC study is a collaboration between two groups: the Samoan National Nurses Association (Sala Mataalii, Co-PI) and California State University, Fullerton (Sora Tanjasiri, Co-PI). The aim of the study is to explore the social support needs of Samoan breast cancer survivors from two groups: one who have participated in SNNA's support group program, and who have not participatedin the program. In addition, two of each survivors family members or friends (i.e., supporters) will also be invited to participate in order to understand their roles in providing social support to the survivor. Over the past year, the collaborative has undertaken the acivities: (1) convened the members of our Community Advisory Council to guide development of our methods and interview guides, (2) conducted two focus groups with community leaders to identify the social support issues to be explored with survivors, (3) finalized indepth interview guides for survivors and their supporters; (4) identified and trained three nurses from SNNA in recruitment and consent processes, qualitative interviewing skills, and conducting the qualitative interviews; (5) transcribed and translated interviews; (6) conducted data analyses using Atlas.ti software; and (7) presented preliminary results to research staff and Community Advisory Council members for feedback and discussion. Long term goals include the sharing of all data analyses with study participants and the larger community, and preparing a larger, three-year study to evaluate the effects of SNNA's support groups on the lives of Samoan survivors.

Sociocultural, Behavioral, and Psychological Issues: The Human Side

Sister Survivor: African American Breast Cancer Coalition

Kimlin Ashing-Giwa, Ph.D., Beckman Research Institute of the City of Hope
Gloria Harmon, Women of Essence

Funded 2007

Initial Abstract, Pilot Award

Although African Americans bear some of the heaviest burden among all medically underserved breast cancer survivors, few investigations and interventions have focused on addressing the needs of African American breast cancer survivors (AABCS). AABCS are diagnosed with more advanced cancer, experience lower survival and greater morbidity and mortality (ACS, 2006) as well as lower physical and functional well-being (Ashing-Giwa et. al., 2006 in press). These negative outcomes indicate that the support needs of AABCS are extensive (Ashing-Giwa, 1997). However, few to no services exist for AABCS in the Inland Empire, particularly Riverside and San Bernardino Counties, and the Antelope Valley. The long-term goal of this study is to document, characterize, and evaluate support group services for AABCS to underserved areas of the Inland Empire. The immediate goal of this proposed pilot study is to understand and document "what works" among established AA support groups and assess the unmet needs of African American survivors within support groups as well as survivors who live in the underserved areas of the Inland Empire.

The Study Research Questions:

1. What are the benefits and unmet needs of participants from five established peer-led African American support groups?
2. What is the most culturally-appropriate paradigm or best model for developing a breast cancer support group for African American survivors (based on what has worked in the past for the established support groups)?
3. What are the unmet needs of African American survivors in the Inland Empire region and how might a support group meet these needs?

This study will involve two phases. Phase I of the study will attempt to answer the first two research questions through interviews with support group leaders, as well as focus group discussions with breast cancer survivors of five established African American cancer support groups in Los Angeles. The product of phase I will be the development of culturally-responsive "Guide" on how to set up and run a breast cancer support group for African American survivors. Phase II involves conducting three needs assessment focus groups with African American breast cancer survivors and five key informant interviews with leaders in the Inland Empire to assess the needs and resources for starting a support group in that region.

This study is innovative because it has never been done before. The findings will have the potential to benefit the broader community through: (1) an increased understanding about the role and benefits for peer-led support groups in underserved survivors that directly benefit members, (2) the utility of the guide to inform the development of support groups for African American and other underserved survivors, and (3) the coalition building between the African American breast cancer survivors (AABCS) and support groups in LA, and the further expansion of this coalition and network to AABCS in the Inland Empire. Moreover, through our expanded networks from diverse community based organizations and other ethnically diverse breast cancer support groups, we can build multiethnic coalitions. We can partner with other organizations to expand research and support services to other underserved BCS including Latina, Asian and immigrant breast cancer survivors.

In preparing this application, Dr. Ashing-Giwa and the coalition have met several times to discuss and plan for the study. These community leaders are crucial partners in developing culturally appropriate study procedures, recruiting participants, and serving as overall program champions. In fact, the initial program idea belongs to Gloria Harmon, director of Women of Essence (WOE), and the goals and purpose of the proposal have been shared and discussed during numerous meetings between Dr. Ashing-Giwa and the support group leadership over the past 5 years. Additionally, each of the five partner organizations in this project has its own community advisory committee. We will actively involve these community advisory committee members as well as community members from the Wellness Community, American Cancer Society (ACS), Michelle's Place, and the Community Health Councils, Inc. (CHC) in our research study by meeting with them on a bi-monthly basis (every two months) throughout the study. We will hold strategic planning meetings so that committee members can help guide the direction of the study as well as give us valuable input regarding the appropriateness and salience of study methods, instruments and activities. We will hold meetings both in the Inland Empire and in the LA area to accommodate the different regions and foster coalition building.

Expanding Rural Access: Distance Delivery of Support Groups

Mary Anne Kreshka, M.A. and Jim Perkins, Dr.P.H., Northern Sierra Rural Health Network
Cheryl Koopman, Ph.D., Stanford University

Funded 2007

Initial Abstract, Full Award

Strong research evidence demonstrates that professionally led support groups can significantly improve quality of life for women with breast cancer. However, women with breast cancer who live in rural areas have little or no access to professionally led support groups. Northern Sierra Rural Health Network (NSRHN) serves a nine-county region of NE California covering 33,000 square miles with an average of fourteen residents per square mile (compared to two hundred thirty-two for the state as a whole). The primary sources of medical care are community health centers and small rural hospitals. Residents have to travel great distances over two-lane roads to access specialty care.

In our CBCRP-CRC pilot study conducted collaboratively by NSRHN and Stanford University in 2003-05, we tested the feasibility of offering professionally led support groups to women with breast cancer using the workbook journal “One in Eight” by videoconferencing. A small group of women can be together in one location that is familiar to them (their local clinic), while they participate interactively with a facilitator and other women at other sites by video. Using a split-screen, the women in each site see the women in all the other sites and the facilitator. Based on the success of that project, we are proposing a controlled study to assess the general acceptability and therapeutic value of this support group format on a larger sample of women.

The study will answer two questions about women with breast cancer in rural communities: 1) Will they find this support group format utilizing videoconferencing acceptable and rewarding?; and 2) Will they report a greater sense of emotional and informational support, and less depression and traumatic stress, than the control groups of women who wait to participate until after the first groups have ended?

A total of 100 women with breast cancer in the north state will participate in the study. They will be randomly assigned either to an immediate eight-week support group using videoconferencing and the workbook journal, or an eight-week group that will begin after the first group ends (“wait-listed”). The women who are wait-listed will serve as the control for the women receiving the support group. The women in both groups will complete questionnaires before and after the first group. Results of the women who participated in the group will be compared with those who did not. Thirty of the women in the groups will also be interviewed afterwards to get their direct feedback on the support groups. The wait-listed women will receive the support group after their data have been collected.

Videoconferencing technology allows multiple sites to connect into real-time interactive meetings. Thus, women isolated by distance, weather and cost can experience the benefits of interpersonal support without leaving their home communities. NSRHN is the largest rural telemedicine network in California, with equipment in 31 rural/frontier healthcare facilities. It has been used primarily for specialty medical consults (over 5,000 since 2000). This technology is increasingly available in rural communities throughout the state and the nation. We are proposing an innovative use of this already existing network to fill a need for professionally led support groups for women with breast cancer. Over 2.5 million women live in rural California statewide, over 33 million in rural areas across the United States. These figures suggest that over 312,000 women in California, and over 4 million women nationwide, could potentially benefit from support groups by videoconferencing. This project will also suggest the effectiveness of videoconferencing support groups for other conditions (e.g., rural residents with HIV/AIDS; family caregivers of individuals with dementia).

Underserved Women with Breast Cancer at the End of Life

Beverly Burns, M.S., B.A., L.Ac., Charlotte Maxwell Complementary Clinic
Shelley Adler, Ph.D., University of California, San Francisco

Funded 2007

Initial Abstract, Full Award

In the U.S., women with low incomes who are also ethnic minorities are diagnosed with breast cancer at relatively later stages and have lower rates of survival, but most end-of-life research has focused on white European American, middle class patients in hospitals or extended care facilities. What little is known about the end-of-life experience does not necessarily apply to underserved women dying from breast cancer. Based on our pilot CRC study of women with metastatic breast cancer, we developed a narrative intervention—the construction of an ethical will—to decrease suffering and distress among underserved women at the end of life.

This three-year qualitative and quantitative study will evaluate a narrative intervention—the construction of an ethical will. The goal of our intervention is to reinforce dying women's sense of the meaning of their lives and ease concerns regarding death. An ethical will is an enduring document that expresses an individual's values, beliefs, life lessons, hopes, love, and forgiveness in the form of a written legacy for loved ones.

We will enroll 120 women, ages 18 and over, who are currently receiving services from CMCC and who have metastatic breast cancer and a prognosis of less than one year to live. Participants will meet four times with a trained interviewer—each audio-recorded session will last approximately 45 minutes. Before the ethical will construction intervention, the interviewer will ask open-ended questions about the participant's current quality of life and will also administer a series of quality-of-life measures. The four semi-structured interview guides emphasize the broad content areas from which we will, in partnership with each client, build an ethical will. The fourth interview is devoted to a review of the legacy document we will have prepared from transcripts of the three previous interviews—the interviewer will read the text and then work with the participant to edit it to reflect her wishes. After the intervention, the quantitative measures will be re-administered and the interviewer will ask a series of questions about the participant's current quality of life, as well as the experience of constructing an ethical will and participating in the study. All methods have been pilot tested during our pilot CRC study.

Through qualitative content analysis of the interview data and interviewer field notes, we will develop "legacy documents" as well as a conceptual model of the experience and needs of end of life among underserved women with breast cancer.

Ethical wills are typically constructed by middle- and upper-class (and usually white European American) people to create a permanent legacy of their experiences and wishes. We believe that the experiences, life lessons, and hopes of multiethnic, underserved women with breast cancer are equally of value—and that the process of finding meaning by creating a permanent legacy has the potential to decrease suffering at the end of life. Symptoms relating to psychological distress and existential concerns may even be more prevalent than pain and other physical symptoms among women with metastatic breast cancer. Our pilot CRC participants agreed that issues such as meaning and purpose need to be acknowledged within the realm of quality end-of-life care, but we found few specific methods of addressing existential suffering at the end of life that had been developed and tested—noticeably absent are interventions that are appropriate for underserved women with breast cancer.

We challenge practices that separate the researcher from the "researched" and we promote the forging of a partnership between researchers and the community of interest. We have contributed equally to the creation and design of the proposed project in terms of the concept paper, this CRC proposal, and our long-term goals involving dissemination and implementation. Research team members from CMCC and UCSF will continue to share equally in the decision making process at our weekly team meetings and we will continue to work closely with the Community Advisory Board that we formed during the pilot CRC. As was the case with our pilot CRC, data will be owned jointly by CMCC and UCSF and all decisions regarding availability of data for analysis and dissemination of results through presentations and publications will be made by the full research team. Dr. Adler will continue to train all team members in the research methods used--CMCC research team members thus learn qualitative and mixed-method research techniques that will allow them to identify and investigate future questions of interest to the community.

Breast Cancer Risk Factors: Lesbian and Heterosexual Women

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Stephanie Roberts, M.D., University of California, San Francisco

Funded 1998

Final Report, Full Award

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%) that 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.

Marin County Breast Cancer Study of Adolescent Risk Factors

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

Funded 1998 & 1999

Final Report, Pilot Award and Full Award

Marin Breast Cancer Watch (MBCW—as of 2006 called Zero Breast Cancer) 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 actors 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 nondifferential) 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.

Breast Cancer Risk Profile of Vietnamese Nail Salon Workers

Kim-Dung Nguyen, Asian Health Services
Peggy Reynolds, Ph.D., California Department of Health Services, Environmental Health Investigations Branch

Funded 2005

Progress Report Year 1, Pilot Award

This project is designed to systematically collect preliminary data that will characterize the Vietnamese women currently employed in nail salons in Alameda County, in order to help inform future targeted interventions for addressing barriers to health care access and utilization, and for reducing occupational exposures in this immigrant worker population. The overall goal is to gain a better understanding of the breast cancer risk profile of Vietnamese nail salon workers in order to plan for future research and interventions. The two primary aims of the pilot project are to: 1) build a collaborative relationship between the community and the research partners that will lay the groundwork for future research and intervention efforts; and 2) collect baseline information that will inform future intervention and epidemiologic research, among Vietnamese female nail salon workers.

Our first year has focused on building a collaborative relationship between the two new partners, Asian Health Services (AHS) and the Northern California Cancer Center (NCCC). In order to clarify expectations for each partner, a staff survey has been designed and completed by all participating staff to assess perceived level of control and participation by AHS and NCCC in different areas of the project, including budget, data ownership and workload. The survey will be administered again at the end of the project to evaluate changes in perception resulting form the collaboration.

The two partners have prioritized community participation to build upon the collaborative nature of the project. First, they have convened an Advisory Committee, composed of members of the Vietnamese community to provide guidance on the project direction as well as the design of the focus groups and survey instrument. Second, to ensure a broad perspective, the project staff have also sought input from key stakeholders such breast cancer advocacy organizations and research scientists by participating in the California Healthy Nail Salon Collaborative, a multi-organizational collaborative that seeks to proactively address the environmental health issues facing the nail salon community. With these activities, the two partners have begun to establish a solid working relationship that emphasizes community participation.

Our second aim is to collect baseline information on the Vietnamese nail salon workers. We have conducted two focus groups with nail salon workers to gather information on health concerns, work environment, background and attitudes towards the industry. The two groups were stratified by length of U.S. residence (i.e.= or > 5 years). We found a striking difference between the two groups in their attitudes towards this profession. Currently, we are in our final stages of survey development and expect to begin conducting the survey in the next month.

(Note: A continuation of this project was funded as a full project in 2007. See page 56)

Breast Cancer Risk Profile of Vietnamese Nail Salon Workers

Linda Okahara, Asian Health Services
Peggy Reynolds, Ph.D., Northern California Cancer Center

Funded 2007

Initial Abstract, Full Award

Concerns about the chemical composition of cosmetics have recently garnered considerable attention. Nail salon workers, in particular, have been the focus of health concerns because they routinely handle nail care products containing organic solvents, some of which can cause cancer or affect a woman's endocrine system. The nail salon industry is one of the country's fastest growing professions; California has over 300,000 nail salon workers. Additionally, over 80% of California's nail salon workforce is comprised of Vietnamese immigrant women. Surprisingly, despite the size of the workforce, the chronic exposure to cancer-related chemicals and the high proportion of underserved immigrant workers, no human health studies have been conducted to date for this workforce. Understanding breast cancer risks in this worker population will allow us to explore the potential risk relationship between cosmetic compounds and breast cancer.

Asian Health Services (AHS), a community health center serving the Asian indigent population, and the Northern California Cancer Center (NCCC), a non-profit organization dedicated to cancer research, partnered in a CBCRP-funded pilot study of Vietnamese nail salon workers. Findings from our focus groups and surveys of over 200 nail salon workers suggest that many workers are concerned about the chemicals they work with and are experiencing health problems commonly associated with high levels of exposure to solvents (e.g. headaches, rashes and respiratory problems), underscoring the need for a more in-depth investigation of breast cancer risk in this workforce.

To begin to elucidate the relationship between cosmetic compounds and breast cancer, we will address two questions:

1. Do nail salon workers have higher breast cancer rates than the general population, or the Vietnamese population, in California? Higher rates among workers would indicate a potential link between breast cancer risk and their work-related exposures.
2. Do Vietnamese nail salon workers have workplace exposures to organic solvents that exceed health-based standards? Measured levels of exposures that are higher than the recommended levels by regulatory agencies would inform future health interventions, health policy and future research focusing on this workforce.

To address the first question, we will link the California cosmetology licensee file to the California Cancer Registry file to estimate breast cancer rates in this workforce compared to the general population. Since all nail salon workers are required to be licensed by the state, we will be able to examine the breast cancer experience for the entire California workforce. Similarly, we will compare rates between Vietnamese nail salon workers and the California Vietnamese population; this restricted analysis will allow us take into account other factors (e.g., homeland exposures) that may influence breast cancer risk in this subpopulation.

To address the second question, we will recruit 80 Vietnamese nail salon workers in the greater San Francisco Bay Area to wear a small personal air-monitoring device on their shirt collars during their work shifts, in order to will measure levels of benzene and toluene, two solvents associated with cancer, in addition to total hydrocarbons, which reflect a mix of solvents. Each worker will contribute 2–3 measurements, which will also allow us to examine variability in exposures to individual workers as well as differences in exposure levels between salons and workers.

Our project has three innovative elements: First, we will use complex record-linkage strategies to link between the licensee file and the cancer registry to estimate breast cancer rates. Second, since no race/ethnicity information is collected on the licensee file, we will develop and test a new list-assisted surname and first name methodology to identify workers of Vietnamese descent for restricted Vietnamese analyses. Third, we will use a non-invasive and cost-effective method to measure individual exposure to solvents for a sample of workers. Together these strategies will bring us closer to an assessment of occupational risks for this workforce.

Chemotherapy Induced Ovarian Damage: Prevention and Impact

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Lynn Westphal, M.D., Stanford University
Lucy Berlin, M.S.,Young Moms with Breast Cancer

Funded 2002

Final Report, Pilot Award

Early menopause is also associated with rapid bone loss (median loss 7.8% by 1 year), increased risk of cardiovascular disease, low libido and vaginal atrophy. Preventing early ovarian failure is important to young women with breast cancer, including women who have completed childbearing.

The purpose of this study was to evaluate whether premature menopause can be avoided by administration of the GnRHa (G) triptorelin, during adjuvant chemotherapy (aCTx) for breast cancer. aCTx results in reduced ovarian reserve, with symptoms including infertility and premature menopause. It appears that younger women experience more severe quality of life disruption and clinical distress from breast cancer diagnosis and treatment and unwanted infertility is severely distressing, especially when it is a result of cancer treatment. Its potential is sufficiently distressing that some women may consider forgoing or abbreviating life-saving chemotherapy.

First, we designed a phase II clinical trial targeting women aged 35-44 (at higher risk for aCTx induced menopause due to age) scheduled for aCTX for early stage breast cancer to see if concurrent use of ovarian suppression would preserve ovarian function in this group at high risk for ovarian failure. Consenting patients received G to temporarily suppress ovarian function. Hormone levels (estradiol and FSH) were measured during and after aCTX; quality of life (QOL) and recovery of menses were tracked. Second, we wanted to gain a detailed understanding of how chemotherapy-induced ovarian toxicity influences treatment decisions and post-treatment life of young women with breast cancer, and, how the path to these outcomes is influenced by information and choices given after diagnosis. Specifically we wanted to learn (a) how serious is the impact of ovarian toxicity on young women? (b) what information do they need after diagnosis about ovarian-related issues and options? (c) given a clinical trial of CT+G, what would affect young women's interest in participating? We designed ethnographic interview questions that covered these issues, and iteratively developed a retrospective survey, with decision-making vignettes to probe attitudes and information needs.

Phase II clinical trial. We enrolled 12 patients in the clinical trial. Three patients were not evaluable for recovery of menses due to disease progression or oophorectomy. All 9 patients recovered menses within 15 months following aCTx. Treatment was generally well tolerated; the major side effects were menopausal. One patient carried a pregnancy to term.

Qualitative study. We recruited 41 participants with a broad sampling. 24 women participated in audiotaped interviews, and 31 completed the surveys. Most women experienced at least temporary CRA. Women in their 30s had more severe menopausal symptoms, and felt unprepared for the QOL impact of chemotherapy related amenorrhea (CRA). MDs rarely mentioned the symptoms women found most distressing: low libido, vaginal dryness, disturbed sleep, and mood swings. 25% had tried to preserve fertility. 45% of women diagnosed under age 40 assumed that a pregnancy would be risky; most of those did not tell MDs their fertility goals. 40% of women diagnosed in their 30s had unwanted CRA within 2 years. Despite more uncertainty in survival benefit, an ovary-sparing regimen was the 1st choice for 67% of women with hormone receptor positive disease, and 83% of women with receptor negative tumors. 54% chose ovary-sparing regimens for their top 3 choices. Women were highly interested in a trial of G+CTX: Overall 23/37 expressed interest in participating if their doctor approved. If CT+G were known to be safe, this proportion rose to 33/37. 50% would have chosen 2-4% lower absolute recurrence-free survival odds in order to get a regimen with low odds of infertility/menopause.

Treatment with the GnRH agonist triptorelin in order to preserve ovarian function during aCTx in premenopausal women appears safe and well tolerated. The feasibility of this trial was limited by concerns regarding primary treatment of breast cancer, and the age restrictions within the trial. The study raised awareness of fertility and menopause concerns within the patient and oncology community, established relationships between breast oncology and the fertility specialists at UCSF and Stanford, and began to explore one option that might improve that chance of preserving ovarian function. Womens' preference for ovary-sparing regimens and for G+CTX suggests that young women facing treatment decisions need information on CRA and pregnancy safety, and would welcome even preliminary data on the survival benefits and menopause/infertility risks of chemotherapy regimens with less toxicity to ovarian function such as doxorubicin followed by a taxane, or G plus chemotherapy, as studied in this trial. An ongoing national trial is investigating G in women with receptor negative disease.

Index

By Author

Index

By Title

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