

SPANISH SPEAKING
WOMEN'S CANCER INITIATIVE



Program Evaluation
September 2004

Evaluation Conducted By

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SSWCI Collaborative Partners

American Cancer Society, California Division, Inc.
Anna's Program and Hospice and Palliative Care of Contra Costa, Inc.
Contra Costa Health Services Department Patient Navigator Program
La Clínica de La Raza - Fruitvale Health Project, Inc.
The Wellness Community of San Francisco East Bay
Women's Cancer Resource Center

Acknowledgements

The participating organizations of the Spanish-Speaking Women's Cancer Initiative (SSWCI) wish to gratefully acknowledge the tremendous leadership and support of the John Muir/Mt. Diablo Community Health Fund in developing and sustaining the work of our collaborative. The commitment of Grace Caliendo, CEO and the Health Fund Board of Directors to improving the health of underserved populations has been the foundation for our success. Through their convening, the Initiative came to life and through their on-going support Latino women have a greater likelihood for early diagnosis of cancer and survival from the disease.

Funding for the Spanish-Speaking Women's Cancer Initiative and this evaluation study was provided by grants from the John Muir/Mt. Diablo Community Health Fund and The California Endowment.

From 2001 through 2004 the Community Health Fund provided \$1 million to support planning, implementation and evaluation of the Spanish Speaking Women's Cancer Initiative. The Fund is the only grantmaking entity within Contra Costa County focused exclusively on health issues. Its mission is to improve the health and well-being of residents living within central and east Contra Costa County communities, with an emphasis on uninsured, underserved and overlooked populations. Its grantmaking goal is to achieve fundamental improvements in the health status of families, children and youth, seniors and other vulnerable adults by expanding access to affordable, quality health care and to promote health education and wellness.



THE CALIFORNIA ENDOWMENT

The California Endowment is a private, statewide health foundation created in 1996. The Endowment's mission is to expand access to affordable, quality health care for underserved individuals and communities, and to promote fundamental improvements in the health status of all Californians. The California Endowment provided \$610,000 to support the work of the Spanish Speaking Women's Cancer Initiative.

Introduction

Under contract with the Spanish Speaking Women's Cancer Initiative (SSWCI), The Center for Applied Local Research (C.A.L. Research) conducted an independent evaluation study of the Spanish Speaking Women's Cancer Initiative. C.A.L. Research is a non-profit consulting group dedicated to applying social sciences and related skills to help improve human services at the local level. The purpose of this report is to describe the findings of the evaluation study.

Summary of Evaluation Findings

The Spanish-Speaking Women's Cancer Initiative addresses the critical and specific needs of underserved, uninsured Spanish-speaking women for cancer-related services. The evaluation demonstrates that the Initiative has:

- Developed a successful culturally relevant model that promotes early detection of cancer among Latinas.
- Increased the availability of culturally relevant cancer-related services for Latinas with little or no English-language skills living in east and central Contra Costa County
- Improved the responsiveness of the health care system and each organization to the needs of Latinas for early detection of cancer and cancer treatment services.
- Enhanced the quality of life and perceived potential for recovery of Latinas diagnosed with cancer who participate in the services of SSWCI.
- Developed a strong public/private partnership that integrates services and maximizes use of resources to provide a continuum of cancer-related care and services.

Evaluation Methodology

The purpose of the SSWCI study was to:

- a. Evaluate the effectiveness of the overall WCI model and strategies in improving access to cancer information and detection, treatment and related support services for monolingual Spanish-speaking women in selected geographic regions of Contra Costa.
- b. Assess whether programs, activities, and services are achieving their desired outcomes.

- c. Determine where improvements could be made.
- d. Document the initiative/collaborative history, processes and lessons learned, particularly "best practices" that are transferable to other programs serving disadvantaged populations.
- e. Document individual organizational and broader systems changes.

C.A.L. Research employed the following strategies to assess the effectiveness of SSWCI in meeting its goals and objectives. Our culturally and linguistically competent researchers collected and analyzed:

1. Quantitative and qualitative data to test overall collaborative and program level effectiveness against impact and performance level indicators by conducting the following:
 - Surveys of community providers, SSWCI clients and SSWCI partners
 - Review of relevant community-level data
 - Review of performance measures over the life of the initiative



2. Anecdotal information from partner agencies, community organizations and SSWCI clients through surveys, case studies and interviews of clients, partner agencies and funders.

The evaluation report is divided into two main sections, 1) the Initiative background and 2) the Evaluation Results. The Background section provides a review of pertinent literature and data, a history of the Initiative and a description of the overall program approach. The Evaluation Results section provides a summary of results from the evaluation strategies, including, client survey and focus group results, provider survey results, and collaborative and organizational interviews.

Background

Rationale and Need for the Spanish-Speaking Women's Cancer Initiative

Elena *In 1997, Elena was diagnosed with cervical cancer at the hospital where she had just given birth to a son. Elena already had several small children to care for at home. A young immigrant from Guatemala, with only a second grade education, she spoke no English and had little experience with health care here or in her county of origin. With no way to communicate her fears to her English-speaking doctors, it was six years before she returned for cancer treatment once she was discharged from the hospital. In 2003, Elena was diagnosed with Stage 3 cervical cancer. This time, however, the hospital was able to refer her to the Spanish-Speaking Women's Cancer Initiative for support. The Initiative was able to provide her with a bicultural, bilingual advocate to guide her through cancer treatment and link her to emergency funding, transportation, food and in-home support services. With the support of the SSWCI programs, she has maintained her treatment protocols, learned about the disease and how to take care of herself, gained support from other women under-going treatment, and has a brighter picture in terms of recovery.*

Nationally, Hispanics have the highest incidence rates of invasive cervical cancer of any group, and twice the incidence rates of non-Hispanic White women.⁽¹⁾ Cervical cancer mortality is also markedly higher among Latinas. Latina women in Contra Costa County (the geographic area targeted in this effort) have the highest rates of cervical cancer in the state.⁽²⁾ Of women over age 25, 7% reported never having a pap test, another 6% had

According to the Contra Costa Health Department, breast cancer is the most common cancer among women in California. In Contra Costa County, breast cancer rates (151.2 per 100,000) are higher than the rate for all of California (127.4 per 100,000). While Hispanic women have lower rates of breast cancer compared to non-Hispanic White women, it is the leading cause of cancer death among Hispanic women.⁽⁴⁾ The American Cancer Society and the California Department of Health Services recommend that women 40 years and older be regularly screened for breast cancer by having a clinical breast exam and a mammogram once a year. In a recent survey, the most common reason given by Latina women in Contra Costa for not having had a mammogram was the "doctor did not tell me that it was needed" (approximately 50%) followed by cost/lack of health insurance (22%).

Low rates of screening participation increase the likelihood that Hispanic women will be diagnosed at a more advanced stage of the disease resulting in poorer outcomes and higher mortality.⁽⁵⁾ Early detection and access to treatment is critical to saving lives. Efforts in Contra Costa over the past several years have improved the potential for early detection among minority groups. In 1992 in Contra Costa, African American and Latina women were the least likely to have their breast cancer diagnosed at an early state. By 1997, African American, Latina and white women had the same likelihood of having their breast cancer diagnosed at an early state.



not had one in three years.⁽³⁾ Of 22,000 Hispanic women in Contra Costa over 40 years of age surveyed by the California Health Information Survey, only 74% had a mammogram in the past 2 years, another 20% had never had a mammogram. The percentage (66.6%) of those receiving a mammogram in the past two years is significantly lower among Mexican Americans, the largest Hispanic group in Contra Costa.

However, in 2000 these rates began again to diverge along with the significant increase in the Latino population in the county. Despite improvements, approximately 30% of breast cancer among Contra Costa women of all races continues to be diagnosed at a late stage.



While underutilization of screening procedures is a significant problem, access to treatment, compliance with a treatment regimen, and quality of care following positive screening tests may be even more important. There is compelling evidence that race and ethnicity, gender, income and disabilities correlate with persistent, and often in-

creasing, health disparities among U.S. populations. Health disparity can be the outcome of differences in rates of access, utilization, and application of health care services. The Institute of Medicine (IOM) Report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, identified significant variation in the rates of medical procedures by race, even when insurance status, income, age, and severity of conditions are comparable. Their research confirmed that minorities are less likely to receive even routine medical procedures and experience a lower quality of health services. Research indicates that persons from ethnic/racial minority groups, including Hispanics/Latinos, are "less likely to receive appropriate staging procedures, procedures to monitor for cancer recurrence, and appropriate radiation and chemotherapy." They are also less likely "to receive aggressive therapy in cases where this therapy is considered appropriate."⁽⁶⁾

An uninsured, underinsured woman with breast cancer in California may have to access up to three separate programs to obtain screening and treatment services, and in some cases, the services may not be available at all. It is all too easy for low income or immigrant women, facing a serious disease on top of the daily stresses of their lives, to get lost in the shuffle, significantly delaying diagnosis and treatment.⁽⁷⁾

Poverty impacts screening rates. Nationally, according to the American Cancer Society, of low income Hispanic women, 86% reported having a mammogram at some point in their lives, compared to 92% of higher income Hispanic women. A greater disparity exists between low and higher income women in reported regular mammography. Of higher income women, 64% reported having their last mammogram within the past year, while 53% of low income women reported having a mammogram within the past year.⁽⁸⁾ (Low income is defined as having a household income equal to or less than 200% of the Federal Poverty Level - FPL - and higher income is defined as having a household income greater than 200% of the FPL.)



Cultural factors also influence cancer behaviors. *Redes en Accion Latino Cancer Report*, states that among Latinos "false perceptions of cancer risk and causality as well as negative attitudes about proven preventive strategies ("it wouldn't matter anyway") heighten the need for research on risk communication in the Hispanic/Latino population." Luquis and Cruz who researched the knowledge, behaviors and concerns about breast cancer among a group of Hispanic women in Pennsylvania found that participants had a minimal knowledge of breast cancer, perceived a diagnosis of cancer as fatal, and had a high anxiety level about cancer. Most women reported that their physicians had encouraged them to practice preventive behaviors, however, a significant number reported that they had not followed those recommendations.⁽⁹⁾

In 1999, the IOM convened representatives of several community-based cancer prevention and health promotion organizations to provide data on areas for NIH research on cancer treatment and prevention programs for minority and medically underserved communities. The community representatives highlighted several recommendations for further review, including:

- Greater sensitivity to culturally appropriate outreach efforts
- Follow-up services available for individuals after cancer screening
- Strategic plans to address the survivorship needs of ethnic minorities
- Environmental risk factors to be prominent in research studies
- Support of existing community-based efforts to address environmental issues
- Studies of paraprofessional community health workers who may be especially effective in addressing the

needs of cancer survivors in minority and medically underserved communities.⁽¹⁰⁾

According to the CDC Office of Minority Health, the demographic changes over the next decade will amplify the importance of addressing disparities in health status. California and Contra Costa County are at the leading edge of this change. Groups currently experiencing poorer health status are expected to grow as a proportion of the total U.S. population. The CDC states, “the future health of America as a whole will be influenced substantially by our success in improving the health of these groups.”⁽¹¹⁾

The SSWCI exemplifies a collaborative partnership that provides culturally relevant cancer detection, emotional and practical patient support and case management for highly vulnerable populations where a multitude of risk factors including low education levels, poverty, language and cultural barriers contribute to poor health outcomes.

History of SSWCI

In 2000, the Spanish Speaking Women’s Cancer Initiative was developed in response to problems Latinas living in Central and near East Contra Costa County experienced in learning about and accessing cancer-related health care services. Latinos are the fastest growing population in the county, but many “fall through the cracks” of the health care system due to barriers including language and communication problems, fear and mistrust, lack of access to or knowledge of affordable health

insurance, and cultural beliefs and stigmas related to cancer. In early 2000, health care providers at Contra Costa Health Services Department and Mt. Diablo Hospital recognized that many Spanish-speaking women were being diagnosed in the late stages of cancer and having difficulty negotiating the health care system in order to be diagnosed and treated, reducing their chances of survival. Following the loss of one such patient who had been “lost in the system”, staff of the Contra Costa County Patient Navigator Program felt a call to action.

The John Muir/Mt. Diablo Community Health Fund played an instrumental role in bringing together potential partners to clearly identify the problem and develop a solution. A year long process of action planning began by convening a group of community organizations with a background in cancer support services and health care provision to underserved populations. These included the County Health Services and La Clínica de La Raza - Fruitvale Health Project, Inc., a federally qualified community health organization with a long history of providing culturally competent primary health services to the underserved, particularly Latinos. The Community Health Fund provided funding and participated in the





process that resulted in an action plan to build a partnership of organizations to reduce the incidence of late diagnosis of cancer among Latinas residing in east and central Contra Costa County. The resulting plan promoted the vision of an affordable, culturally and linguistically competent continuum of care that linked County Health Services cancer screening, diagnostic and treatment services with community-based health care, screening outreach to Latinas, health education, and supportive services for women diagnosed with cancer.

Once the Initiative plan was developed, the Community Health Fund sought the financial support of The California Endowment for the Initiative. With funding of \$1.6 million over 4 years that began in January 2000 and ended in December 2004, the Spanish-speaking Women's Cancer Initiative started in earnest in 2001. The strategies of the Initiative include: (1) culturally and linguistically competent outreach and preventive health education in the Latino community to improve screening rates and early diagnosis, (2) interagency client-centered case management of and advocacy for women through the diagnostic and treatment process, (3) culturally and linguistically competent continuum of support services for women with cancer and their families, and, (4) health care system change to remove barriers to care for underserved Latinas.

The partner organizations in the Spanish-Speaking Women's Cancer Initiative are:

La Clínica de La Raza - Fruitvale Health Project, Inc. (La Clínica) is a federally qualified health care organization with community-based health clinics in the East San Francisco Bay Area of Northern California. The mission

of La Clínica is to improve the quality of life of the diverse communities we serve by providing culturally appropriate, high quality and accessible health care for all.

American Cancer Society, California Division, Inc. (ACS) is a community-based voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives, and diminishing suffering from cancer, through research, education, advocacy, and service.

Contra Costa County Health Services Department (HSD) is a comprehensive county health system that meets the needs of county residents in a variety of ways including operating a county hospital in Martinez and several community clinics throughout the county. The **Patient Navigator Program** is part of the women's health division of HSD. The Navigators provide medical interpretation, referrals, health insurance information and related services.

Hospice & Palliative Care of Contra Costa, Inc. is an independent, not-for-profit, community-based health care provider in operation since 1977. **Anna's Program**, a program of Hospice, provides emotional, practical, and spiritual support to women with advanced breast cancer.

The Wellness Community of San Francisco East Bay (TWC) is the Bay Area affiliate of a national non-profit organization with 21 sites dedicated to providing free emotional support and education for people with cancer and their loved ones.

The Women's Cancer Resource Center's (WCRC) mission is to empower women with cancer to be active and informed consumers and survivors. Located in Oakland, California, WCRC provides cancer support services at the Contra Costa Regional Medical Center.



Overview of the SSWCI

SSWCI is organized around a set of goals and strategies to address the cancer-related needs of a specific population.

Goals and Objectives of the SSWCI

Chart 1: Goals and Objectives		
Goal I. To reduce risk of late diagnosis of cancer among uninsured, underserved Spanish-speaking women in Contra Costa County through increased awareness, accessible screening and education	Goal II. Improve access to culturally and linguistically appropriate medical care and coordinated services that support quality of life for Spanish-speaking women diagnosed with cancer	Goal III. Strengthen and institutionalize inter-agency collaboration to sustain continuum of care and influence broader systems of care for Spanish-speaking women and their families
Objective 1: Increase awareness of women's cancers, dispel myths and improve screening rates for Spanish-speaking women in central and eastern Contra Costa County utilizing community education, outreach, and media Objective 2: Provide access to cancer screening for uninsured Spanish-speaking women Objective 3: Provide navigation, advocacy and interpretation and screening for Spanish-speaking women receiving services through the County Health System	Objective 1: Connect uninsured and underserved Spanish-speaking women to diagnostic services Objective 2: Provide coordinated care management to Spanish-speaking women diagnosed with cancer Objective 3: Provide emotional and practical support to Spanish-speaking women undergoing cancer treatment, and their families, including end of life support Objective 4: Provide cancer education to Spanish-speaking women diagnosed with cancer to improve their knowledge of cancer treatment, self care and decision-making	Objective 1: Improve case management, coordination of care and seamless services for women diagnosed with cancer Objective 2: Reduce barriers to cancer screening and treatment services for underserved Spanish-speaking women, including financial, language and transportation Objective 3: Increase awareness of and referral to SSWCI services by local health care providers and community organizations Objective 4: Assist 2-4 regional communities or organizations in replicating the core strategies of the SSWCI Objective 5: Improve public awareness and promote policies and systems change that reduce health disparities and increase access to health care

Initiative Target Population

The Spanish-Speaking Women's Cancer Initiative (SSWCI) focuses on underserved, uninsured women and their families identified as Latino or Hispanic living in central and eastern Contra Costa County in Northern California. Contra Costa is one of the rapidly growing counties of the nine making up the Greater San Francisco Bay Area. Twenty percent of Contra Costa's population of 948,000 is Hispanic or Latino, the fastest growing segment of the population of the County.⁽¹²⁾ In some cities of eastern and central Contra Costa County 25%-49% of the population is Hispanic or Latino.⁽¹³⁾ The communities served through the initiative range from neighborhoods in the more densely populated areas of the county to rural communities with a combined total estimated population

of more than 100,000 Latinos. Many Latinos in these communities live below the federal poverty level, have no health insurance or primary care provider, and speak Spanish as their primary language ⁽¹⁴⁾. In one targeted neighborhood of 25,000, 49% of the population is Latino (mostly Mexican and Central American), 61% qualify as low income, 50% of adults are without health insurance and many are undocumented immigrants. In the more eastern rural areas of the county, lack of access to services and limited availability of health care is common. As in many areas in California, cost of housing as a percent of income and lack of adequate public transportation contribute to poorer health outcomes for those living in poverty.

Of a random sampling of 34 women being served at the time of the evaluation by SSWCI partner organizations, more than 70% were between 41 and 70 years of age. Ten percent were younger than 41 and 7% percent older than 70. Fifty-nine percent were born in Mexico, 15% in Peru and 6% in Guatemala. Seventeen percent completed no more than 5th grade; another 13% only completed through 8th grade, 33% stopped after graduating from high school; and 10% had earned a college degree. The significant majority of the clients (88%) spoke mostly Spanish and almost the same percentage (85%) read mostly in Spanish. Some were not literate in English or Spanish. More than half were married, while 20% were separated or divorced. Only 10% were single and the same percentage was widowed. A high number of participants had children (82%), of whom 64% had between one and four children. They had a variety of cancer diagnoses, including breast, bone, cervical, colo-rectal, and lung cancer. The most common diagnosis among this group of women was breast cancer (47%). After they were diagnosed with cancer, many of the clients reported significant financial and emotional changes in their lives. As an example, some found their financial situation had deteriorated to the point where they had to move in with relatives. Some women had been abandoned by their husbands or partners. Most clients had to stop working or lost their jobs. Many reported that lack of insurance, beliefs about cancer, and overwhelming difficulties accessing the health system created significant delays in receiving cancer treatment.



Lack of access to information and quality health care, as well as cultural, economic, and linguistic barriers puts this population at greater risk for negative outcomes from disease. The programs and services of the Spanish-Speaking Women's Cancer Initiative are addressing the key barriers to early detection and treatment of cancer with culturally and linguistically competent programs and staff that:

- Promote screening and early detection through community-based awareness, education and trained community health workers that navigate women through medical screening and diagnostics and the health care system.
- Open doors to diagnosis and remove treatment barriers for those who are diagnosed through patient navigation and advocacy, insurance enrollment, and medical interpretation.
- Provide practical, spiritual and emotional support for women with cancer and for their families in homes, therapeutic group settings and the hospital during treatment.
- Provide cancer education to dispel myths and empower treatment decision-making.
- Create a linked and accessible continuum of services that works with the health care systems.



Continuum of Care

The Spanish-Speaking Women's Cancer Initiative's member organizations provide an array of services that are needed by the target population and that when lacking, have been associated with underutilization of cancer screening and treatment services, non-compliance with physician/health care provider recommendations, and loss to follow-up.⁽¹⁵⁾ SSWCI integrates a multi-faceted yet familial approach to providing support services and case management. The initiative addresses the relative lack of awareness of cancer and cancer prevention activities among low income and limited-English speaking women, integrates peer educators and facilitators in community outreach and navigation of the health care

system, and implements an ongoing marketing and outreach plan that is linguistically matched to the language nuances of various Latina communities in Contra Costa. All of these concurrent service methods can build and maintain an infrastructure to enhance the ability of Latino women to access culturally and linguistically appropriate health care services.

The programs and services of multiple agencies are linked to provide a continuum of linguistically and culturally competent cancer care and services ranging from community outreach and awareness to treatment and end of life support.

SSWCI Continuum of Care

Early Detection: Outreach, Education and Screening					Diagnosis: Diagnostics, Treatment, Coordination, Education & Support				
Community Awareness/ Outreach	Health Education	Screening	Navigating the Health Systems	Accessing Financial Support	Care Coordination Case Management	Cancer Education	Therapeutic & Emotional Support	Practical Support	End of Life Support
Community Outreach through trained Promotores	Community-based health education workshops; Breast self-exam, Nutrition, Wellness	Low or no cost exams in community based clinics; breast and pap tests	Support to access diagnostics and treatment services	Advocacy for health care coverage of medical services through public programs	Initial and on-going assesment of client needs	Disease education classes about cancers, treatments and self-care	In-hospital Support	Arranging respite care & child care	Hospice services
Awareness and education materials in Spanish	Training for Promotores	Lo or no cost mammography	Health plan and other insurance enrollment	Emergency financial assistance	Referral to support services and follow-up	Cancer treatment and recovery educational materials in Spanish	Support groups for clients and families	Help with household tasks	Nursing
Health fairs and community events		Mammography van	Appointment support	Eligibility process for financial support	Coordination with partners to assure needs are being met		Home visits	Wigs	Spiritual support
Spanish-language media Outreach			Liaison with health care providers		Advocacy for patient in health care system		Telephone support	Prostheses	Grief counseling
Policy Advocates Training			Medical interpretation		Liaison with providers and interpretation for clients on diagnosis and treatment			Transportation	
					Support during treatment and followup				

Roles of SSWCI Partners in Providing Services Within The Continuum Of Care

Each organization provides services to the community and to clients by drawing upon specific areas of expertise and strength. Duplication of services is avoided and services available to individual clients and communities are expanded.



La Clínica trains and supports Latina health promoters to reach out to the community to dispel myths about cancer, allay fears about medical services, provide interpretation and help women obtain screening and diagnostic services. La Clínica offers educational

workshops on breast health and other cancer prevention topics to the community as well as provides cancer screening and referral services. La Clínica staff helps women who have been diagnosed with cancer by providing benefits assistance, service coordination, and health services. Health educators work closely with medical providers and the staff of La Clínica's Pittsburg (East County) and Monument (Central County) locations to implement the SSWCI model.

Contra Costa County Patient Navigator Program provides "navigators" to help Spanish-speaking women access free or low cost breast and cervical cancer screening, diagnostics and treatment services offered by County Health Services. Two part-time navigators provide insurance enrollment, medical interpretation, education, and patient advocacy. A nurse case manager provides case management, patient assessment, and linkage to services within the Initiative and beyond.

American Cancer Society (ACS) provides transportation for eligible cancer patients to medical appointments under the guidelines of their Road to Recovery program, refers patients and their families to support programs, and provides educational materials in Spanish. In addition, ACS provides Spanish language patient services such as Look Good...Feel Better and Reach to Recovery, as well as wigs for those undergoing chemotherapy. A patient services assistant and volunteers will work with the SSWCI.

The Wellness Community provides education, emotional support and stress reduction through support groups to Spanish-speaking women with cancer and their families. Licensed bi-cultural therapists facilitate free weekly or monthly support groups in Spanish for individuals and family members. One-on-one case management with home visits, outreach, information and referral are also provided for women identified at Mt. Diablo Hospital (a local, private hospital). A program coordinator and two therapists/facilitators provide services to SSWCI clients.

Women's Cancer Resource Center (WCRC) works on-site at the Contra Costa Regional Medical Center where WCRC advocates are available to those undergoing screening, diagnostics and treatment. Services in Spanish are focused on practical support and include education, information, referral, patient advocacy, benefits assistance and emotional support. A full-time clinical case manager works with patients.

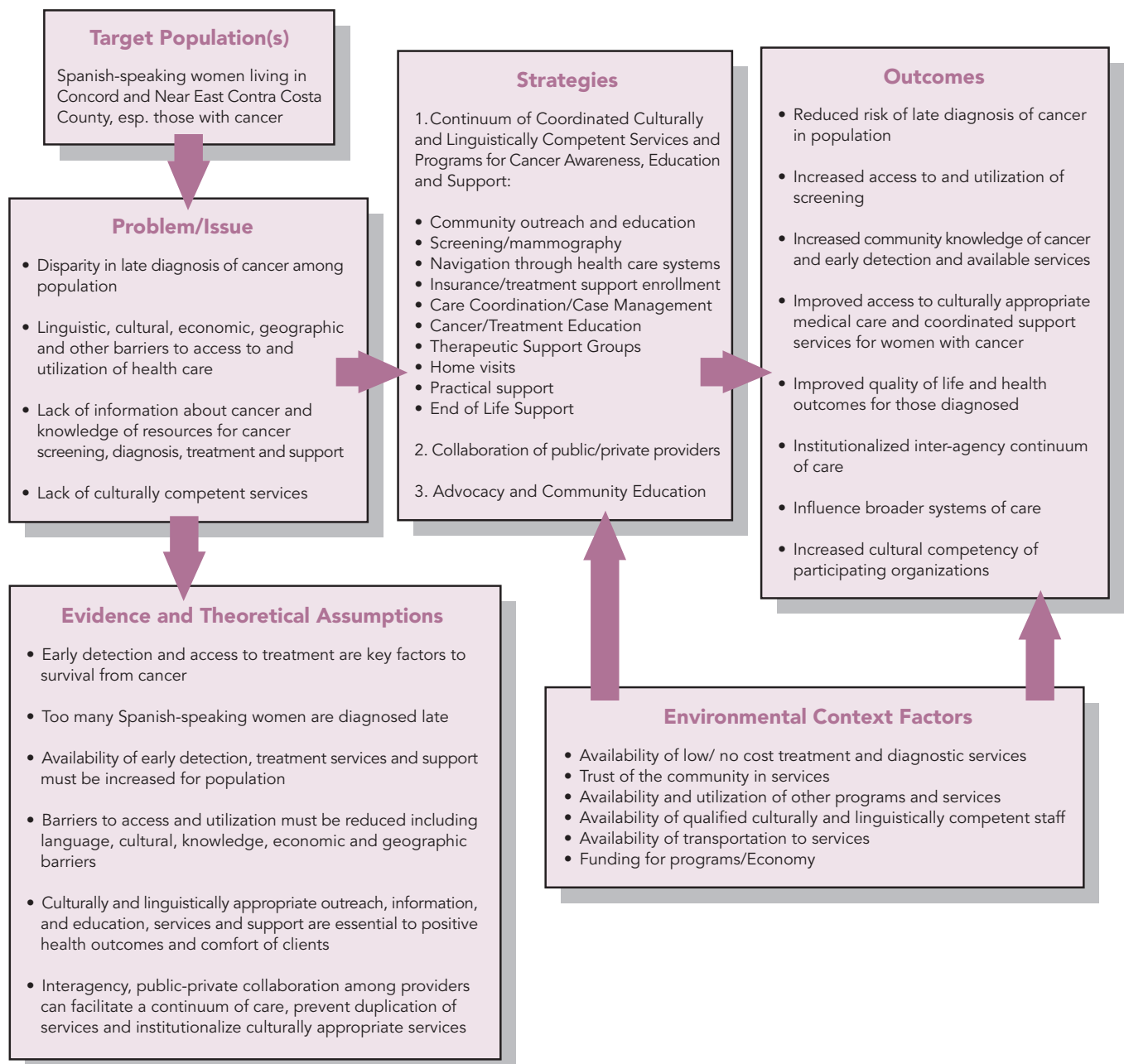
Hospice and Palliative Care of Contra Costa and Anna's Program Anna's Program provides in-home practical, emotional and spiritual support services for women with advanced cancer, including shopping, laundry, house-keeping and transportation. Hospice provides end-of-life support to allow people to remain at home or in a home-like setting. Social workers and volunteers provide services to SSWCI clients.



Key Evaluation Results

SSWCI Theory of Change

The following illustration provides a theoretical model for the Spanish-speaking Women's Cancer Initiative that describes the desired change process. The model outlines the problem addressed by the Initiative and to whom it applies. The model articulates the assumptions behind the approach, specifying key strategies to promote change and articulating which outcomes define success. It also identifies specific environmental factors that influence the ability (both positively and negatively) to achieve the desired change including community trust, availability of services and access to quality bilingual staff. The theory of change model provides a foundation for the evaluation plan and evaluative instruments.



Effectiveness of SSWCI Strategies in Reducing the Risk of Late Diagnosis

In order to reduce risk of late diagnosis of cancer among uninsured, underserved Spanish-speaking women in Contra Costa County, SSWCI implements strategies to increase community awareness, accessibility of screening and education about cancer.



SSWCI strategies seek to reduce cultural and system barriers and to promote early detection of cancer among Latino women through outreach by community members, educational workshops, increased access to screening for uninsured women and screening navigation by trained community health workers. Promotoras de Salud

educates women from the community in order to dispel myths about cancer and change preventive practices.

La Clínica has trained 89 Promotoras, approximately 30 annually. Outreach efforts have provided cancer information to 2,800 to 4,000 Latinos annually in central and east Contra Costa County. Since 2001, Patient Navigators have provided navigation to 6,742 Spanish-speaking patients for pap smears and breast examinations, at an increasing rate of approximately 3,500 annually in 2004. Collectively, the organizations have conducted 60 breast health workshops in Spanish.

Results from Promotoras de Salud Focus Group

The evaluation team conducted a focus group with 15 Promotoras to assess the value of this strategy in reaching a typically “hard to reach” population with information about cancer and wellness practices for early detection. The Promotoras de Salud program aims to promote the leadership skills of women and empower them to protect and promote their own health and the health of others in their community. The program works to overcome cultural beliefs and practices that may prevent early detection of cancer. Promotoras are provided 10-20 hours of health education and additional sessions to help them reach out to other Latinas in the community.

In the focus group setting, Promotoras discussed the value of the program in educating them and helping them provide information and support to other women in order to create a healthier community.

Participants learned correct information about cancer. Focus group participants spoke of the misinformation that formed their beliefs about cancer before they joined the Promotoras.

“I thought that cancer affected only older people or that cancer only happens to people with cancer in their families. I thought I knew everything.”

Through the program they learned that while cancer is serious, if it is diagnosed early it does not have to be a “death sentence” as many had believed. Overcoming cultural taboos about examining their bodies, many participants said they had learned how to examine themselves, and to teach others breast self-examination.

The program has made a contribution to their health. Promotoras learned about the value of regular screening which is not a common practice among Latinos. *“In the Latino Community we do not schedule regular check ups with a doctor; we only go to the doctor when we need to go, or when there is an emergency.”*



Alicia *Based on Alicia's previous experience, it was natural for her to be attracted to Promotoras de Salud. Alicia is an immigrant from El Salvador who has always been interested in helping and supporting people at risk in the Latino Community. "I worked in El Salvador in literacy campaigns and as a legal adviser. I chose to work with farm workers." Through the program, Alicia reported that she learned a great deal about cancer and in turn has been able to pass her knowledge along to others. When she began participating in the training at La Clínica, she did not know much about cancer and what she did know was largely incorrect. Alicia thought that women who developed breast cancer are those who breastfed their children. She also believed that women who pounded on their chest were more susceptible to cancer. The classes at Promotoras de Salud radically changed her ideas. Through the classes she learned that cancer had nothing to do with the theories she had, but instead that cancer could happen to anyone. Additionally, she learned that as soon "as a woman feels a little ball in her breast, she must immediately go to a doctor because this is a serious warning sign." Alicia said, "The program has helped me tremendously. The process has been great and it has given me much energy and hope. The women in the program are passing their strength to me. I feel very proud of this process."*

Participants in the focus group have applied their new knowledge in the community in a variety of ways. As one participant said, *"What we learn we apply to ourselves first and then we teach others."* Promotoras participated in door-to-door community outreach activities, conducted workshops and presentations, distributed flyers and brochures (produced by La Clínica), and talked to neighbors and friends at churches, schools and other community sites. The Promotoras enjoyed the freedom that La Clínica gave them in conducting their outreach activities and suggested a community event to promote cancer screening and distribute information. Promotoras are proud of their accomplishments in the community.

Other suggestions for improving the Promotoras program include:

- Hold monthly meetings to exchange and share experiences, ideas, and feelings among themselves
- Produce a calendar of monthly community activities
- Provide a small financial support or stipend as an incentive
- Work in teams

Effectiveness of SSWCI Strategies in Improving Access to Cancer-related Care

SSWCI has implemented a continuum of culturally and linguistically appropriate medical care and coordinated services that support quality of life for Spanish-speaking women diagnosed with cancer. Utilizing a collaborative case coordination approach and services design, each year the SSWCI provides support to 85 -120 Latino women diagnosed with cancer. Services provided annually include the following:

- The American Cancer Society responds to approximately 300 transportation requests annually to medical appointments from SSWCI clients.
- The Wellness Community currently provides 40 support

groups annually serving 60 cancer clients and their families. Staff also provides lead case management and intensive support to 30-40 clients each year. 200-250 SSWCI clients and family members attend the Celebración de la Vida annually.

- Women's Cancer Resource Center provides in-hospital and in-home support to approximately 85 Latino women annually who are undergoing cancer diagnostics and treatment. Staff implements 8-12 cancer education workshops in Spanish annually, attended by 100 unduplicated clients.
- Anna's Program and Hospice are providing services to approximately 50 Spanish-speaking women annually.

Results From Client Survey and Focus Groups

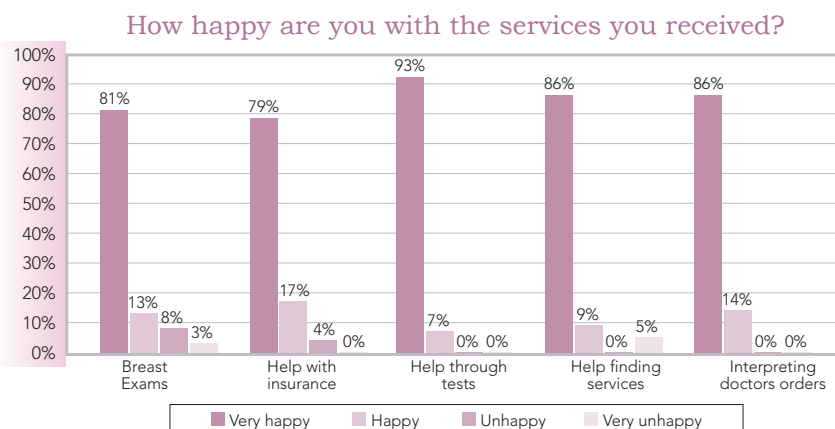
In order to learn clients' perspectives about SSWCI, C.A.L. Research collected quantitative and qualitative data from clients who received services from the collaboration. A random sample of thirty-four current and past clients (approximately 25% of those served over 2.5 years) participated in the focus groups and completed brief written questionnaires about their experiences with cancer and SSWCI. Surveys were written in Spanish and

administered verbally by evaluation staff to those clients who requested assistance. All clients and members of the evaluation team were Spanish speakers.

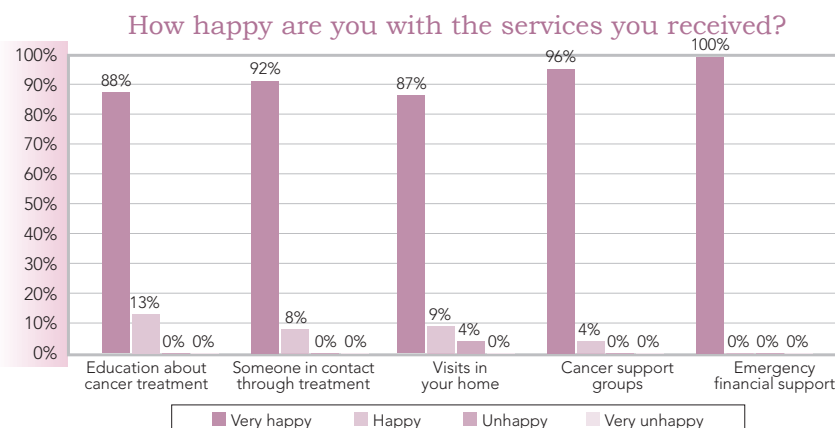
Participants reported learning about the services of the SSWCI through a variety of avenues. 56% learned of the services through Promotoras, 26% were referred by the doctor, 15% respectively heard of the programs from a friend or at a community event.

Client Satisfaction with Services

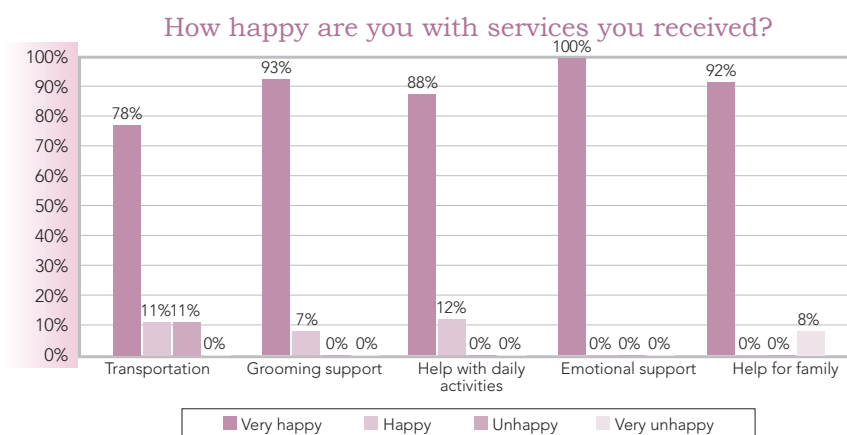
Participants were asked to identify the services they received from SSWCI and the degree to which they were "happy" with those services on a 4-point scale from "very happy" to "very unhappy". 81% of those who receive breast screening were "very happy" with the services, 79% of those receiving services were "very happy" with the help they received in acquiring health insurance, 93% were very happy with support received during diagnostic testing, 86% were very happy with support finding other services and 86% were very happy with support provided to help them understand their physician's orders. One person mentioned being very unhappy with the lack of adequate transportation services.



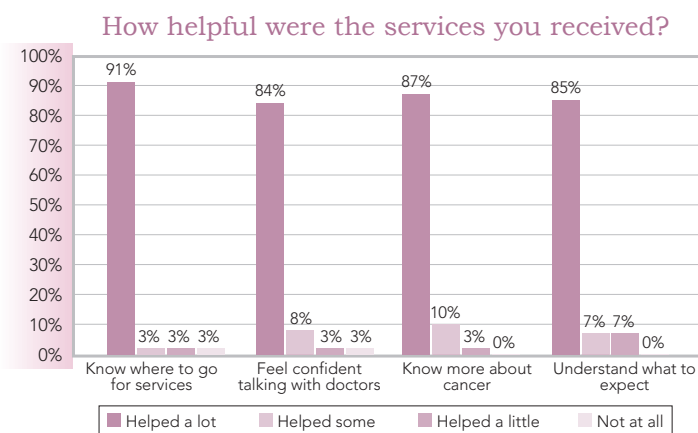
The vast majority of respondents (88% - 100% of those who received cancer treatment education, case management, home visits, support group, or emergency financial support services) were "very happy" with the services they received.



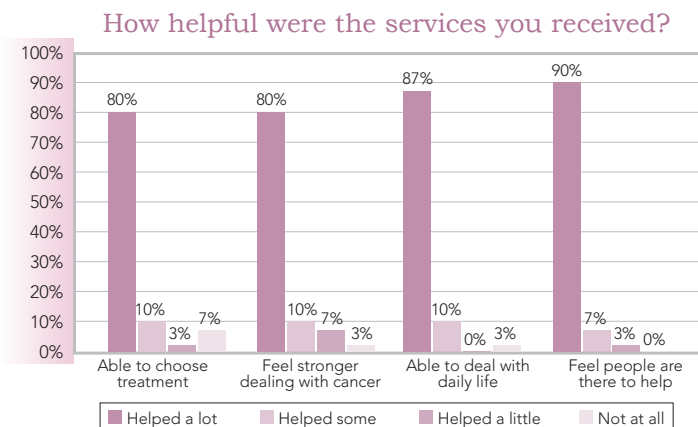
A smaller majority (78%) were “very happy” with the transportation services provided through ACS and other sources. From 88% to 100% of respondents were “very happy” with grooming help (wigs, prostheses), emotional support, help with daily activities, support for their family members and other services they mentioned.



Participants were asked to identify the services they received from SSWCI and the degree to which they believed the services were “helpful” in supporting them through their cancer treatment on a 4-point scale from “helped a lot” to “not at all helpful”. The vast majority of clients (80% or more) believed the programs helped them “a lot” to know where to access services, feel more confident speaking with their doctors, have knowledge about their disease and know what to expect from the treatment and the disease.

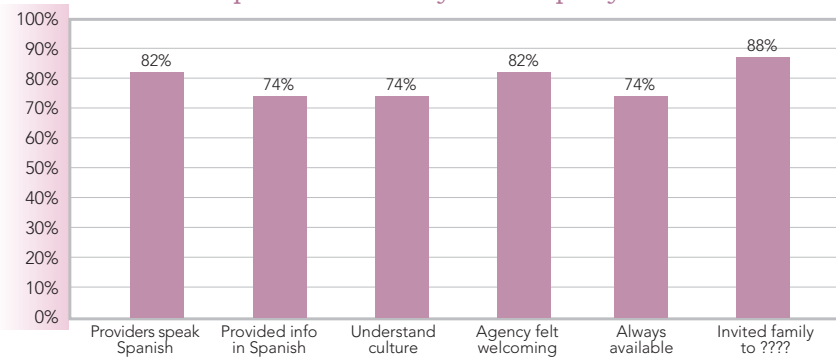


Eighty percent of respondents felt that the services helped them to be better able to participate in determining their treatment and to feel stronger in fighting their disease. 87% felt more able to continue with their daily life and 90% had a sense that there were people available to help them.



Participants were asked to assess the cultural competence and understanding of service providers in the SSWCI, including their language capability, cultural understanding and ability to support participants through their treatment. 74% to 88% found the services to be culturally and linguistically accessible.

Were the services provided in a way that helped you feel comfortable?



Overall, respondents reported that in general they were very satisfied with the services they received through SSWCI. Participants would recommend others seek these same services if they were diagnosed with cancer. The reason given for recommending SSWCI to others included:

- "I received good services. They were very helpful"
- "Helped me to feel better and have great hope"
- "Saves lives"
- "Supportive in very difficult times. They provided lots of moral support."
- Others "can learn about resources and other important information"
- "Helps to fight depression"
- "Gives you confidence"
- Staff / workers motivate you
- Services are accessible

Only four clients (12%) said that there were some services missing such as transportation and assistance with obtaining in-home medical care or housekeeping help. Participants offered suggestions on ways to improve the services provided by the SSWCI. These included:

- More bilingual personnel in the hospitals and waiting rooms
- More family activities
- More community outreach in churches, adult education schools and the community about the services
- Support groups during evening hours

Voices from the Client Focus Groups

Clients from all three focus groups talked of experiencing similar barriers and difficulties obtaining health services. In many cases, lack of health insurance and regular care often delayed detection of the disease. The challenge of managing the insurance systems created further delays in obtaining treatment.

"While I was waiting to resolve the problem with my health insurance my cancer spread to my lungs and bones."

The lack of insurance increased the economic burdens for most women in this study. Some clients lost their private medical insurance when they lost their jobs due to their illness.

"They did not want to take care of me at the hospital when I was diagnosed with cancer because I lost my health insurance."

In other cases, clients had partial health insurance coverage, but did not have the resources to cover the co-payments and other costs. Lack of knowledge of programs open to them and the difficulty in understanding the resources available for women with cancer prevented women from seeking the full level of care they need. Sometimes, their financial situation became so difficult that they were afraid to seek medical services because they did not have money to pay for them.

Lack of personnel who can translate for them when they go to the doctor was a problem for many participants. Some clients had received translation services, but others had not. In order to communicate with the doctor some of the women took family members with them, but they felt that they could not fully express their feelings in front of family members.

A number of clients felt non-public health care providers discriminated against them due to their economic situation and their ethnicity. They believed that the quality of the care they were given was less than that provided to non-Latino women or women with private health insurance. Below, one participant describes her difficulty with obtaining a diagnosis due to lack of health insurance.

Rosa *When Rosa began feeling severe breast pain, she went to a local private hospital. She knew something was wrong and asked for a mammogram, but she was denied service because she did not have health insurance. After living in pain for three more months, Rosa returned to the doctor, but again was denied services. Unfortunately, she was not told about or referred to mammography services provided free to uninsured women or to the community clinic for screening. Only when her husband was able to cover her under his insurance was she seen at the hospital and ultimately diagnosed with advanced breast cancer.*



SSWCI helped women overcome barriers and fight cancer. Participants talked about the value of the information provided by SSWCI to help them and their families understand and deal with cancer treatment. They mentioned educational workshops, nutrition and meditation classes and grooming classes as extremely helpful to them.

Participants felt that the Initiative helped them continue and maintain their treatment.

"When I did not make it to a doctor's appointment, someone called and set up another chemotherapy appointment immediately."

Participants spoke of how the SSWCI support groups and educational programs provided a sense of community and restored their hope in recovery.

"The program is a support base for me because I share my experience with other people that are suffering like me."

"I started living again since I joined this program. It helps me tremendously to talk with other women. I learned how to enjoy good things in life"

SSWCI helped participants change their attitude and feel more positive. According to many participants, being diagnosed with cancer has been a life-changing experience. They talked of living their lives now with a sense of plenitude and a commitment to give their best. They have learned how to better value themselves.

"We have learned how to feed our spirit with good things"



Support provided for families was important to participants:

"My daughter suffered a lot when I was diagnosed with cancer, but now that she comes to the groups with me she sees me in good spirits and consequently she is doing much better too."

Participants spoke of the accessibility and capacity of the staff to support them through their treatment.

"They (SSWCI staff) are sensitive, loving, and they have a great sense of humor that helps us deal with our realities."

"Someone is always available us."

"A nurse and a counselor came to my home when I was alone and just needed someone to talk to."



Linda Linda was referred to the Patient Navigator Program by Mount Diablo Hospital's Breast Clinic when she was diagnosed with breast cancer and had to undergo a radical mastectomy. Linda said that her cancer diagnosis came as a huge surprise. As a result, she was sad and frightened; she did not know what to do, who to talk to, and she had no knowledge of what to expect after the operation. She felt totally ignorant of all aspects of the illness and was confused about going through chemotherapy, or if she would need more surgery in the future. According to Linda, her Patient Navigator talked a lot with her about what to expect and gave her as much support as she needed. Linda said, "I appreciated specific support in the areas of treatment, surgery, prescriptions and doctor appointments."

One major problem for Linda was the lack of economic resources - "If I do not work, I have no one to support me. I am practically alone in this country and the financial terror was tremendous." Her Patient Navigator enrolled her in the BCCTP (Breast Cervical Cancer Treatment Program) program that offers insurance for undocumented women to receive treatment for cancer and cancer-related secondary effects. Linda is a strong person, but nevertheless, felt very depressed after her operation. A staff member from The Wellness Community provided Linda with post surgery support by visiting her at home and spoke with her about her options for cosmetic rehabilitation, including a breast reconstruction operation. Linda began participating in support group meetings where she met other women going through similar situations. As time passed and she was able to recuperate a bit, she passed her optimism and courage to others in the group, and shared her experiences with them. Linda considers herself a very fortunate person. She said that thanks to the SSWCI, she can see her life with much optimism. Linda feels empowered by the program. In April, she had the breast reconstruction operation and is doing well. Linda now feels strong enough to help other women in her same situation. "It was a life changing experience and thanks to the SSWCI and the support I received, I want to share my experience with other clients and support them more." She continues to support SSWCI by acting as a spokesperson and advocate for the services.

Effectiveness of SSWCI in Sustaining Collaboration and Systems Change

SSWCI works to improve the quality of services for underserved, Spanish-speaking women through a dynamic and strong collaboration of agencies linked to form a continuum of services. They partner with health care providers and community-based organizations to reduce barriers to care and promote institutional responsiveness to the cultural and linguistic needs of Latinas. To assess effectiveness of SSWCI in addressing the cancer-related needs of Latinas in coordination with health care systems and community organizations serving Latinas, C.A.L. Research surveyed health care providers and community organizations. Secondly, the evaluators surveyed SSWCI's partner agencies and conducted

interviews with each organization to assess the strength and sustainability of the collaboration and the degree to which systems change had occurred within participant organizations in order to more effectively address the needs of Latinas.

Results of Survey of Community Organizations and Health Care Providers

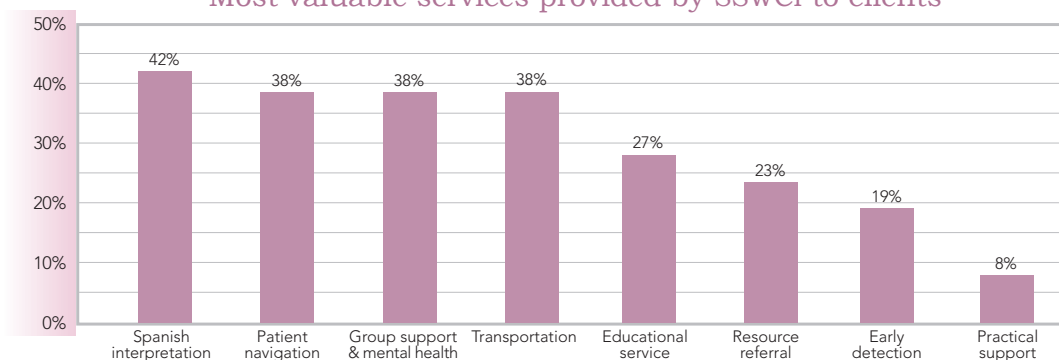
C.A.L. Research developed and mailed a 25-item self-administered questionnaire to 134 health and social services providers in central and east Contra Costa County with a 20% response rate. The survey assessed knowledge of the services provided through SSWCI and perception of the cultural competence and effectiveness of SSWCI in increasing access to health care and improving cancer-related services and a system of care for Latinas. Respondents were primarily health care providers and administrators in public and private health care systems including community clinics (46%) and hospitals (38%). 23% of respondents were from community-based organizations and other community partners. The respondents' knowledge and or "connection" to the SSWCI included having SSWCI agency staff work in their clinic, collaboration in developing educational programs, attending functions sponsored by the SSWCI, providing referrals to SSWCI agencies, and personal/professional interest in "working with communities with needs."



Community Partner Perception of the Effectiveness of SSWCI

Spanish Speaking Women's Cancer Initiative addresses client/patient needs. Respondents were asked to determine the most valuable services provided by SSWCI in addressing needs of their Latina patients/clients. The most frequent responses, among those in a list of needs, were Spanish interpretation (42%), patient navigation (38%), group support/mental health (38%), and transportation to care/services (38%). Other responses included educational services (23%), early cancer detection services (19%), and practical support (8%).

Most valuable services provided by SSWCI to clients



Respondents' whose patients/clients have used the services of the SSWCI, noted that their patients/clients were helped in the following ways:

- "Access to existing services has increased"
- "[Patients] have more support during their treatment,"
- "[There is] access to culturally and linguistically competent care"
- "[Patients are] better informed about their disease" and they "more actively participate in their own cancer care"
- "They are better able to manage their disease"
- "Clients now know more about cancer and early detection".



Respondents were asked a series of questions related to the effectiveness of SSWCI programs and staff in addressing needs of the target population and improving the system of care for their patients and clients. The 5 point scale included "strongly agree," "agree," "disagree," "strongly disagree," and "don't know."

- 84% of respondents "strongly agree" or "agree" that the programs through the SSWCI contribute to service access for Spanish speaking women in Contra Costa County. 16% did not know.
- 76% of respondents "strongly agree" or "agree" that the SSWCI enhances case management and communication to providers about Spanish-speaking client needs. 14% did not know.
- A combined 70% "strongly agree" or "agree" that the SSWCI has contributed to collaboration and cooperation among providers serving Spanish-speaking clients. 30% did not know.

- 73% of respondents combined "strongly agree" or "agree" that the SSWCI contributes to a continuum of care for Spanish-speaking women with cancer while 27% of them did not know.
- 73% of respondents "strongly agree" or "agree" that SSWCI staff members are knowledgeable about cancer, 4% disagree and 23% did not know.
- 58% of respondents indicated, "strongly agree" or "agree" to the statement, "SSWCI staff members are knowledgeable about behavioral interventions that are practical for Latina patients." 4% disagree and 38% do not know.
- Consistent with the large percentage (70%) of respondents who either "strongly agree" or "agree" that the SSWCI contributes to collaboration and cooperation among providers serving Spanish-speaking women with cancer, 66% of respondents indicated that they either "strongly agree" or "agree" that the SSWCI agencies' staff members are easy to work with for inter-agency referrals. 34% did not know.
- 70% of respondents "strongly agree" or "agree" that SSWCI agencies' staff members are culturally competent to work with Spanish-speaking cancer patients; 30% did not know. 66% of respondents either "strongly agree" or "agree" that the staff members are linguistically competent to work with that group of patients; 34% did not know.



Assessment of Organizational Change and Collaborative Effectiveness

Organizations within the SSWCI Collaborative have grown in ways important to facilitating the mission to provide a culturally and linguistically competent continuum of care and cancer-related services to Latino women in Contra Costa County. The Collaborative has demonstrated several key factors that are commonly needed for a successful partnership including leadership, communication, community development, and sustainability. Organizations have developed new competencies to facilitate quality service delivery to the population. As a result, the SSWCI has successfully created a nearly seamless system of care for Spanish-speaking women in Contra Costa County who are in need of cancer-related health services.



Individual agencies have made changes in several areas including:

- Adopting culturally and linguistically competent practices in service delivery and community outreach
- Diversifying staff throughout the organization and hiring well qualified bilingual/bicultural staff;
- Increasing overall organizational outreach to and focus on Latinos; and
- Understanding existing service barriers for Latinos and addressing those barriers.

While La Clínica has traditionally served a largely Latino population with bilingual and bicultural staff, other SSWCI agencies generally had not served this population. Since the outset of SSWCI, Hospice and Anna's Program has increased their Spanish-speaking clients from 1-2 to 51

last year. The Wellness Community conducted no Spanish-language support groups before 2002 and now conducts four. Both agencies have tripled the number of Spanish-speaking staff. American Cancer Society has undertaken a broad-based planning effort to increase outreach and support for Latinos throughout the Bay Area and the nation. County personnel made valiant and successful efforts to obtain funding to continue the Patient Navigator Program despite cuts in all non-essential services during a serious County budget deficit.

There also have been significant collaborative efforts and agreements that have positively affected cancer-related services for Latinas in Contra Costa County, including:

- Articulated a commitment to diversity and to creating a comfortable multicultural partnership where each organization is an equal partner and all opinions and voices are heard and valued
- Formalized infrastructure to collaboratively set policy, plan and execute the programs:
 - A strategic plan to focus on-going effort through 2008
 - SSWCI budget allocations to agencies and SSWCI activities determined through collaborative discussion
 - Monthly executive-level meetings held
- Established interagency direct service team processes for client care coordination and program activity collaboration:
 - A common intake, referral and case coordination form developed for use with clients to assure the full support offered through SSWCI.
 - Direct Service staff meet monthly to review cases and develop strategies to conduct activities
 - Outreach activities such as health fair participation are planned jointly
 - Responsibility for educational and other events is shared
 - Cross-training conducted among and within agencies regarding available services
- Increased integration into the community through collaboration with other community groups and organizations
- Participation in community action groups, neighborhood collaboratives, and Latino organizations
- SSWCI brochures in Spanish and English developed and collaborative outreach to community-based organizations, health care providers and media conducted

- Shift from individual agencies reporting on progress and applying for funding (for the SSWCI) to collaborative reporting and applications for funding
- Increased trust among all agencies that each member agency will provide high quality culturally competent services
- Formal and informal support that allows for sharing information and knowledge. This professional support system helps staff members alleviate feelings of isolation and provided agencies with a new resource pool
- Organizations remain committed to the Initiative despite changes in agency leadership or funding from the Community Health Fund

SSWCI has been able to develop and implement a well-functioning collaborative that has generated positive outcomes for monolingual Spanish-speaking women in Contra Costa County. As a collaborative, they have created a flexible working environment where authority is shared, each person is challenged to do their best and to provide high quality services, and all are involved in the process of improving the quality of life for their clients and for the community at large.

Lessons Learned in Building Sustainable Collaboration

1. Recruit and utilize an experienced outside facilitator. Using an external facilitator allowed agencies to communicate effectively and constructively with one another and assisted these agencies to move from simply being individual agencies that work together, to a cohesive unit that provides a spectrum of services for Spanish-speaking women in Contra Costa County. The funder recommended support for facilitation from the outset of a collaboration as well.
2. Seek multi- year funding. SSWCI representatives believed that the luxury of time provided by multi-year funding was important to the successful planning and implementation of this collaborative model. Without the time necessary for agencies to build trust and develop solid working relationships, collaboration is not able to grow and partnering remains at the networking level. Also, recruiting and hiring of appropriate staff to work in limited-English, underserved communities may take up to six months or more. Relationship-building also must be nurtured among these staff to support a seamless system of support for clients and prevent duplication of services and competition.

3. Start small with a variety of agencies. Beginning the partnership with a small group of individual agencies with distinctive expertise and service areas helps build a rationale for teamwork, enables relationship-building, and reduces competition among agencies.
4. Connect with existing community resources. The SSWCI has created links with existing community resources such as Concord's Monument Community Partnership. Creating these community linkages has enhanced their outreach efforts, supported location of SSWCI services in the community and raised the community's level of awareness about the SSWCI and its services.
5. Recognize the time commitment required for collaboration. The time required to support collaborative efforts and manage reporting and planning requirements for funders is significant. Building partnerships requires developing shared mission, vision, and understanding of the needs of the community and how best to use the resources at the table to address those issues. To work together, people must come together to address issues, resolve conflicts and stimulate the creativity of the team members.

Lessons Learned in Serving the Target Population

1. Understand impact of cultural differences in disease intervention. Cultural norms and beliefs among Latino women that can impact cancer detection and treatment must be sensitively addressed. In traditional Latino families the woman seldom if ever puts her needs first and may neglect her own health in order to care her husband and her children's needs. Norms for modesty may prevent women from regular breast examination and screening and pap tests. Husbands may not understand the impact of the disease and the requirements for successful treatment and continue to expect their wives to support the family in every way traditionally expected. The SSWCI addresses these challenges on multiple levels, including but not limited to: encouraging participation of women, their husbands and their children in support groups where they can learn about the disease and the importance of treatment, nutrition, rest and support from others; Patient Navigators, who assist women to navigate the health care system and explain procedures and medical information that the patients do not understand; emergency stipends (up to \$600) and in-home practical

support services that provide some help for those who are very ill and alleviate some of the burden when women are not able to work in the same way as before.

2. Poverty impacts survival. There are additional environmental stresses that can be detrimental to a cancer patient such as multiple families living together in overcrowded homes and apartments due to the high cost of living in Contra Costa County, transience due to seasonal work, the need to continue to work during treatment, lack of adequate health insurance to pay for drugs and other care needed, limited eligibility for public support due to immigration status, and poor access to transportation and other support. SSWCI works to alleviate some of these barriers, but cannot significantly address the larger social issues related to poverty and immigration status.
3. Lack of cancer knowledge and misinformation is prevalent. In the Latino culture (as in many cultures) there is a lack of understanding about the benefits of preventive health practices such as breast examinations and pap smears. Without proper health education many view cancer as a “death sentence.” This sense of fatalism can mean that they do not discuss their concerns or act to prevent the progress of the disease. Erroneous beliefs about who can get cancer and when contribute to late diagnosis. The SSWCI is working to raise awareness, dispel myths and educate the Latino community about cancer detection and treatment services. Promotoras and the Patient Navigators often go out into the community to local grocery stores and community gathering places to meet and talk with Latina women. The agencies attend health fairs and cultural events where they can reach community members. The Women’s Cancer Resource Center (WCRC) with the support of the other partners provides classes for women who are undergoing cancer treatment. These classes provide information to support adherence to treatment protocols, empower decision-making and promote recovery.
4. Recruiting qualified staff is challenging. The recruitment and hiring of high quality bilingual/bicultural staff has taken a fair amount time for some of the agencies. Not only did they have to look for competent and dedicated applicants, but also these individuals needed to be able to live on a small non-profit salary, which can often be difficult due to the high cost of living in the Bay Area. The few bilingual, bicultural professional

level staff are in high demand. By sharing recruitment information and qualified applicants, agencies have been able to recruit highly qualified staff. Commitment on the part of the organizations to expand bilingual staff has strengthened as has the number of bilingual staff in programs throughout their organizations.

5. When planning, take into account systemic barriers and community contexts that will affect service delivery and effectiveness. The most difficult systemic barrier that the SSWCI has faced is the lack of adequate transportation for clients to health care and other services. Contra Costa County covers a large geographic area and due to urban sprawl many of the newer communities are in very remote sections of the County. The majority of SSWCI clients do not drive, which makes it almost impossible for some of them to make and keep their appointments. Other alternatives such as public transportation or taxi are not viable solutions due to cost, hours of availability, distance, and travel time with multiple transfers required to reach the hospital and clinics. Lack of adequate resources to address this barrier has created a strain on direct service staff and reduced the ability of clients to participate in services. However, the cost and logistics of providing transportation to more than a few clients is daunting given the transportation infrastructure available in the County. SSWCI has located support groups in the communities to the degree possible, they arrange car pools for educational events, drive clients to critical appointments, and conduct services in client’s homes. American Cancer Society is able to provide some van service to medical appointments, but the lack of linguistically competent volunteer drivers has been a barrier. Voluntarism is not a cultural tradition in the Latino community and efforts to recruit volunteers have been only minimally successful.

Summary of Findings

SSWCI has made significant progress in addressing many of the barriers to care for Latinas with cancer. They provide them with support services in their own language that help them navigate the health system, connect with the appropriate health care and insurance, and support their treatment and recovery processes with education, emotional and practical support. They have begun to raise cancer awareness in the community and promote regular screening that leads to early diagnosis of cancer. They have built a sustainable, effective collaborative

approach that avoids duplication of services and increases availability of services to fill high level cancer-related needs of the population. The various agencies involved in SSWCI work well together and share the same vision and commitment.

Survey results indicate that SSWCI is addressing the specific needs of the Latina clients and patients and

successfully linking with health care systems and providers to assure that disparities in access to services are reduced. They have increased the availability of culturally and linguistically competent cancer-related services that are valued by the community and the health care system. One of the greatest strengths of SSWCI is the on-going effort to create culturally competent services through highly qualified bilingual, bicultural staff and volunteers and organizational change. Staff members speak the same language as the clients and are committed, experienced professionals sensitive to the needs of women with cancer. Existing programs have been redesigned to address cultural differences.

According to the funder, the initiative has succeeded in creating a safety net, where collaborating agencies assist each other and are determined to continue working together. The collaboration has created an opportunity for the agencies to provide access to needed services to a large number of people from a diverse community that lacks adequate access to health care. The funder

acknowledges that while funding is very necessary for the success of a collaboration such as the SSWCI, it requires more than that. It also requires "the right attitude" and the "willingness to commit" to providing health care to a population in need. The collaboration created a plan that is built on "simple" common sense", but changes must be "institutionalized" - meaning that the initiative exists not just because of grants to sustain the work, but because that it is "the work these agencies do." There is significant evidence that SSWCI agencies have internalized these programs and their collaboration with each other.

SSWCI partners identified several challenges that the Collaborative faces in meeting its objectives, including:

- A chronic lack of adequate transportation for clients
- A lack of financial and other resources for clients
- Difficulty in recruiting bilingual staff and volunteers
- Overcoming cultural barriers and the community's lack of cancer knowledge and their resistance to screening
- The difficulty of leveraging funds on an individual agency level
- Maintaining a consistent presence in the collaborative due to the intense time commitment required.

The Collaborative has increased their awareness regarding these barriers and has actively worked to overcome them. However, community infrastructure problems such as lack of adequate transportation and financial support and resources for clients still remain as obstacles to overcome.



SSWCI could enhance their ability to improve their services by continuing and expanding multicultural and other training. Increased outreach to the community and to providers about the services could improve awareness of SSWCI services. Other community awareness efforts including media outreach could complement the work of the Promotoras and the direct service team to increase



knowledge and screening among community members. While most health care professionals in the community were familiar with individual agencies in SSWCI, services could become even more integrated if providers could

begin to see the collaboration as a single entity. Lack of adequate public transportation is not specifically a weakness of SSWCI, but the collaboration could more explicitly develop strategies to address this problem for clients.

Finally, although the participating agencies have improved their data collection methods, there is still room for improvement in that area. The funder acknowledged that developing and funding an evaluation strategy from the outset would have enabled a clearer assessment of systems and population level changes. County-wide baseline data is not readily available to measure progress toward improving incidence of late detection. Tracking screening at La Clínica and the County community clinics over time could provide an indication of improvement in preventive behaviors among the population. Centralized data collection could provide a clearer picture of the unduplicated clients served through cancer support services and educational activities.

The Spanish-Speaking Women's Cancer Initiative is a replicable program based on research and emerging best practices for addressing disparities in health for underserved populations caused by poverty, language and cultural differences, and lack of access to health care. The program is clearly serving the needs of Latinas for cancer awareness, education and support services.

- (1) National Institutes of Health (NIH). Addressing Health Disparities: The NIH Program of Action. (n.d.) Retrieved February 10, 2004, from <http://healthdisparities.nih.gov/whatare.html#top>
- (2) Contra Costa Health Services Department: <http://www.cchealth.org/cchealthPages/pages/whp/>
- (3) California Health Interview Survey: www.chis.ucla.edu
- (4) American Cancer Society. Cancer Facts & Figures for Hispanics/Latinos 2003. American Cancer Society, Atlanta, GA, 2003.
- (5) American Cancer Society. (August 20, 2003). American Cancer Society Examines Cancer Trends in Hispanic / Latino Americans. Retrieved February 10, 2004 from <http://www.charitywire.com/charity6/print 04297 .html>
- (6) Smedley BD, Stith AY, Nelson AR (Eds). Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care. Institute of Medicine 2002.
- (7) Breast and Cervical Cancer: Gaps in Services to Women Prepared by the California Breast and Gynecological Cancer Treatment Task Force August 2002
- (8) American Cancer Society. (August 20, 2003). American Cancer Society Examines Cancer Trends in Hispanic / Latino Americans. Retrieved February 10, 2004 from <http://www.charitywire.com/charity6/print 04297 .html>
- (9) Luquis, R.R., and Cruz, I. V., (2002, November). Knowledge, behaviors, and concerns about breast cancer among Hispanic women. Poster session presented at the 130th Annual Meeting of the American Public Health Association.
- (10) Institute of Medicine. (1999). The unequal burden of cancer: An Assessment of NIH research and programs for ethnic minorities and the medically underserved pp.162-169.
- (11) National Institutes of Health. Addressing Health Disparities: The NIH Program of Action. What are health disparities? Available at: <http://healthdisparities.nih.gov/whatare.html>.
- (12) U.S. Census Bureau, American Community Survey Office. American Community Survey, 2002.
- (13) Monument Corridor Community Profile. Martinez: Contra Costa Health Services, 2004.
- (14) U.S. Census Bureau, American Community Survey Office. American Community Survey, 2002.
- (15) Saha, S., Arbelaez, J.J., and Cooper, L.A. (2003). Patient-physician relationships and racial disparities in the quality of health care. American Journal of Public Health, Vol. 93, No. 10, 1713-1719.



SSWCI Collaborative Partners

American Cancer Society, California Division, Inc.
Anna's Program and Hospice and Palliative Care of Contra Costa, Inc.
Contra Costa Health Services Department Patient Navigator Program
La Clínica de La Raza - Fruitvale Health Project, Inc.
The Wellness Community
Women's Cancer Resource Center

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