



Early Stage Dementia Project ~ Nevada ~

Telehealth Early Phase Patient and Family Support Program (TESP) Manual

Alzheimer's Disease Supportive Services
Program Innovation

*State of Nevada,
Aging and Disability Services Division
August 2010*

Nevada Early Stage Dementia Project
Telehealth Early Phase Patient and Family Support Program (TESP)

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Project Title: Early Stage Dementia Project: Telehealth Early Phase Patient and Family Support Program (TESP)

Lead Organization: State of Nevada Aging and Disability Services Division (formerly Division for Aging Services)

Project Period: September 30, 2008 – March 31, 2010

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Executive Summary

Nevada's Early Stage Dementia Project, Telehealth Early Phase Patient and Family Support Program (TESP) provided rural residents access to specialized help for Alzheimer's patients and their care providers. Nevada's broad goal for this project was to improve function and delay institutionalization of rural dementia patients through telehealth initiatives. Nevada Aging and Disability Services Division (ADSD) partnered with the University Of Nevada Reno School Of Medicine, Center for Cognitive Aging and the Alzheimer's Association and later the Cleveland Clinic Lour Ruvo Center for Brain Health. This project was supported in part by grant number 90AI0019/01 from the Department of Health and Human Services, Administration on Aging. Additional support was provided by the Nevada Aging and Disability Services Division.

Nevada's activities for the 2008 Alzheimer's Disease Supportive Services Program provided rural, financially compromised individuals with early phase Alzheimer's disease access to interactive video classes for themselves and their care providers with an emphasis on Hispanic and Native American populations. The dedication of program partners provided an invaluable service to Nevada communities, individuals affected by dementia, and caregivers. Nevada continues its telehealth initiatives in rural areas through the dedication of program partners. The Cleveland Clinic has opened clinics in Elko, Winnemucca, and Battle Mountain and continues to provide telehealth services and maintains a strong relationship with the Alzheimer's Association.

ADSD serves seniors and individuals with disabilities at every step of the continuum by safe-guarding their rights, fostering their self-sufficiency, providing counseling and advocating on their behalf. ADSD focuses on specific areas identified as concerns of the older population through planning, as well as developing and coordinating resources. The Division strives to create and maintain an environment that enables Nevadans to be self-sufficient, independent and safe. Through federal entitlement funding, state money and program partnerships, the Nevada Aging and Disability Services Division continues to support family caregivers and the telehealth project and initiatives.

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Part I: About the Project

The project covered Northern Nevada counties and implemented telehealth and support for caregivers and individuals in the early stages of Alzheimer’s disease.



Source: Nevada Office of Rural Health (2006)

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Introduction

This manual serves as a guide for implementing Nevada's Early Stage Dementia Project, Telehealth Early Phase Patient and Family Support Program (TESP). For the period of September 30, 2008 through March 31, 2010, Nevada's goal was to improve function and delay institutionalization of rural dementia patients, through telehealth initiatives. This manual outlines the activities implemented in Nevada by the Aging and Disability Services Division (ADSD) and program partners throughout the Telehealth project.

The activities implemented in Nevada by the Aging and Disability Services Division (ADSD) and program partners throughout the Telehealth project are outlined in this manual, which is presented in two parts. Part One provides background information and Part Two describes how to implement the program.

During the implementation of the Nevada's Early Stage Dementia Project, Nevada was facing declining state budgets due to the developing recession. State money from Nevada's share of the Master Tobacco Settlement, which is used for Independent Living Grants and as state match, was diminishing. This limited Nevada's ability to enhance existing projects or compensate program partners for additional beneficial work in some communities. Eventually, state employees were mandated to take one furlough leave day each month to help compensate for the nearly \$3 billion deficit.

Nevada already had the capability for compressed video through its existing state infrastructure, allowing connections to rural areas for the telehealth initiative. Sites were selected based on area capability and connections to specific populations, such as low-income, rural residence of Hispanic or Native American populations. Rural residents were linked to specialized assistance from a nurse practitioner and Neurologist through the University of Nevada Reno School of Medicine's, Center for Cognitive Aging and later the Cleveland Clinic Lou Ruvo Center for Brain Health. In addition, the connections enabled the Alzheimer's Association of Northern Nevada Northern California to provide training and support to individuals affected by Alzheimer's disease and their care partners and families.

The Aging and Disability Services Division (ADSD) recognizes the importance of maximizing existing resources and has been continually identifying ways to ensure essential services are always available, even as funding levels diminish. The amount of available services to rural and frontier areas which have few resources is limited. To ensure services for Alzheimer's disease and support for their caregivers, televideo conferences were set up and coordinated by TESP partners.

Connecting individuals with Alzheimer's disease and their care providers, especially in rural areas, to a supportive network of medical and support specialists maximizes available resources and ensures efficiency for service delivery throughout Nevada.

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Project Overview:

The goal of this project is to improve function and delay institutionalization of individuals with dementia by improving the ability of individuals to negotiate the in-home caregiving role. This project expanded the existing telehealth infrastructure and provided responsive and effective services to dyads impacted by dementia. Early detection is important for a number of reasons: (1) medical treatment can slow disease progression; (2) patients are able to participate in self determination of future care; (3) education about resources and behavioral management can help families avoid crises, premature institutionalization, and reduce excessive medical utilization; and (4) improve family caregiver's ability to cope, thus, reduce the secondary effects of indirect cost of informal caregiving (e.g. time lost from work and medical and psychological risks to family members of caregiving).

Project objectives:

- Recruit individuals with early stage dementia through the Center for Cognitive Aging and other rural providers, including Spanish-speaking and Native American dyads impacted by early-stage dementia through Indian Health Services and Nevada Hispanic Services.
- Provide interactive video classes for dyads impacted by dementia.
- Provide interactive video question and answer sessions and onsite support group sessions for dyads through the Center for Cognitive Aging.
- Provide workshop classes onsite conducted by the Alzheimer's Association rural outreach coordinator.
- Provide telephone, interactive video, and face-to-face behavioral and counseling consultations for Spanish and English speaking caregivers and patients on an ongoing, as needed basis through the collaborative project partners.

Collaborative Partners

Program Partners for this project included: The University of Nevada Reno School of Medicine, Centers for Cognitive Aging; Cleveland Clinic Lou Ruvo Center for Brain Health (formerly Lou Ruvo Brain Institute); the Northern Nevada Chapter of the Alzheimer’s Association; and the Nevada Aging and Disability Services Division.

Program Partners	Lead Person
State of Nevada - Aging and Disability Services Division Management Analyst Grants Specialist	Jeff Doucet Shirley Alloway
Alzheimer’s Association of Northern Nevada Northern California Regional Director Program Director Outreach Coordinator Spanish Speaking Outreach Specialist	Angie Pratt Vicki Lebsack Stan Dowdy Laura Tellez
University of Nevada Reno School of Medicine, Center for Cognitive Aging Nurse Practitioner, Psychologist	Debra Fredericks, Ph.D, RNC, APN
Cleveland Clinic Lou Ruvo Center for Brain Health Neurologist Nurse Practitioner Director of Social Services	Charles Bernick, MD. Carol Meyer, APN, Susan Hirsch, MSW, LSW
Elko Alzheimer’s Clinic Rural Coordinator	Lisa Dinwiddie, RN, MS

Target Populations

The targeted populations for Nevada’s project were rural, financially compromised individuals with early stage Alzheimer’s Disease and their family caregivers. A special emphasis was given to Hispanic and Spanish-speaking populations and Native American populations for both caregiver/care receiver dyads. Target populations were mainly comprised of individuals in rural areas of Northern Nevada and included Reno, Carson City, Elko, Winnemucca, and Battle Mountain.

Eligibility

Eligible participants were individuals with mild cognitive impairment or early stage Alzheimer’s disease or other dementia and their care providers- both family caregivers and professional caregivers. Program partners targeted Hispanic and Native American populations to participate in the telehealth initiatives.

Anticipated Outcomes

Relevant to outcomes for the Innovative Grant – October 1, 2008 - March 30, 2009, the Alzheimer’s Association of Northern Nevada anticipated a success rate of 80 percent in each of the following areas:

1. Latino and Native American participants will report that the education/caregiving training they received increased their knowledge about Alzheimer’s disease (AD)/dementia and that they learned something new that applies to their situation.
2. Rural participants will report that the education and caregiving training they received increased their knowledge about Alzheimer’s disease/dementia and that they learned something new that applies to their situation.
3. Participants in the telemedicine program will report that the educational information they received via this program was useful and helped them more effectively manage the care and safety of the care recipient.
4. Telephone support group participants will report that the group increased their knowledge about dementia and helped them more be more effective in their work as a caregiver or support group facilitator.

Goals and Objectives

The goal of the Nevada project was to reduce the number of rural families spending down for Medicaid sponsored institutionalization by improving their ability to care for Alzheimer’s patients at home.

Nevada and program partners planned to meet the following objectives;

- (1) Early phase patients and individuals will be identified and recruited through the telehealth clinical services of the Center for Cognitive Aging and rural providers.
- (2) The Alzheimer’s Association rural outreach coordinator and Hispanic outreach coordinator will work with Indian Health Services and Nevada Hispanic Services to identify early phase Alzheimer’s patients and their families.
- (3) Interactive video classes will be presented by the Alzheimer’s Association for both caregivers and early phase patients.
- (4) Q & A support group sessions will be presented via interactive video by the medical and psychiatric specialists at the Center for Cognitive Aging.
- (5) Onsite support group sessions will be offered to both patients and caregivers, facilitated by the Center for Cognitive Aging’s telehealth nurse.
- (6) Onsite workshop classes will be conducted by the Alzheimer’s Association rural outreach coordinator.
- (7) Telephone, interactive video and face-to-face behavioral and counseling consultations will be provided for Spanish and English speaking caregivers and patients on an ongoing, as needed basis by the Alzheimer Association’s Hispanic Outreach Coordinator, Center for Cognitive Aging’s psychologist/clinical nurse specialist, and Rural Clinic Coordinator.

Background (About the Project)

Nevada's Early Stage Dementia Project, Telehealth Early Phase Patient and Family Support Program (TESP) was developed to provide rural residents with access to specialized assistance for Alzheimer's patients and their caregivers, both for diagnostic and support services. Nevada's goal was to improve function and delay institutionalization of rural dementia patients, through telehealth initiatives. Nevada's activities for the 2008 Alzheimer's Disease Supportive Services Program (ADSSP) provided rural, financially compromised individuals with early phase Alzheimer's disease (AD) access to interactive video classes for themselves and their care providers.

The use of telemedicine technology was chosen for several reasons. Most rural areas of Nevada have access to a teleconferencing/compressed video system. In fact, there are more than 150 sites in Nevada connected to the teleconferencing system including rural clinics and virtually all rural hospitals. Moreover, use of technology to improve delivery of care is clearly the future of rural care, as it provides remote locations access to a multitude of professionals and specialists. Apart from using the advancing telecommunications platforms, there is virtually no other practical way to provide specialty health and supportive services to remote areas where great distances separate isolated towns.

Nevada Service Delivery

As a large state with only two main urban counties, Clark (Las Vegas) and Washoe (Reno), and a population dispersed throughout the rural and frontier remainder of the state, Nevada service delivery is a unique challenge. Numerous barriers exist to providing year-round services to many parts of the state, such as remoteness, geographic obstacles and severe weather conditions. This leaves many individuals deprived of basic services to help them lead independent, meaningful and dignified lives.

In the face of these service delivery barriers, Nevada is projected to have an Alzheimer's disease prevalence growth rate exceeding 80 percent among seniors age 65 and older, more than doubling its current population¹. Approximately 70 percent or 20,300 of Nevada's Alzheimer's patients live at home. Sustaining the patient and caregiver relationship, to delay or avoid institutionalization relies on bolstering the physical and emotional status of the patient to ease the caregiver burden. Nevada is estimated to have 87,000 Alzheimer's disease caregivers, constituting 47,171,212 hours of unpaid care. In many cases, caregivers have or no formal training or stress relief guidance. This results in less effective care for their loved ones. Even for older people whose incomes fall comfortably above the median income for households, the costs of home care, adult daycare center services, assisted living care or nursing home care can quickly exceed their incomes.

It is estimated that care for patients with Alzheimer's and other dementias cost Medicaid \$91 million dollars per year.² This is projected to increase significantly over the next decade. Nevada is expected to see a 100 percent increase in the number of its citizens with Alzheimer's disease over the next two decades. From the state's perspective, the bulk of Medicaid spending

¹ Alzheimer's Association. 2010 Alzheimer's Disease Facts and Figures. Chicago: Alzheimer's Association, 2010:1.

² Alzheimer's Association. 2010 Alzheimer's Disease Facts and Figures. Chicago: Alzheimer's Association, 2010:1.

for Alzheimer's disease involves reimbursement for long-term care. In fact, 70 percent of nursing home patients have AD, and many spend down their assets for care and become Medicaid eligible. Medicaid also funds home and community based care and prescription drugs for those who are financially eligible.

According to the National Center for Charitable Statistics, Nevada has fewer nonprofit organizations than other states of comparable size, and has the fewest nonprofit organizations (7,118) for states with populations over 1,500,000, except for Idaho (6,888). However, when applied to the aging network, these numbers are far more dismal. Due to minimal state resources, including non-profit organizations and ever shrinking state budgets, critical services are eliminated as the ability and the funding to deliver are removed.

But these numbers only tell part of the story, as family members are often affected as well; they assume the burden of caregiving, at the expense of their health and finances. Not only are close to half of caregivers clinically depressed, they also suffer from more illness, take more medicine and are more likely to be hospitalized than others their age. In addition, cultural and sensitivity issues may prevent many from seeking assistance. It is critically important to outreach into communities to encourage and address issues with AD, especially for those in the early stages, and to provide support and assistance for their care providers.

Alzheimer's Disease and Caregiving Costs in Nevada

According to the American Health Assistance Foundation (AHAF) - *Alzheimer's Disease Research*, Alzheimer's disease is the third most expensive disease to treat in the US, with costs of care estimated to be \$100 billion per year nationally. The Alzheimer's Association Desert Southwest Chapter estimates that more than 29,000 Nevadans currently suffer from Alzheimer's disease. Projecting to 2020, the number of persons in Nevada age 65 and older with Alzheimer's disease will grow to approximately 67,000. Persons with Alzheimer's disease generally live at home or in a community setting until the end stages, with family and friends meeting 75 percent of care needs (National Alliance for Caregiving/AARP, 2004; Ory et al., 1999). The reality of an aging society, compounded by the association of age with AD, will create significant growth in the number of informal caregivers and the need for home and community-based services.

Early detection of Alzheimer's disease is difficult, because symptoms are very subtle and often considered side-effects of normal aging; reliable objective biomarkers are yet to be discovered. Consequently, early detection depends upon a confluence of evidence, including memory testing. The most effective screening tests for early diagnosis include some sort of delayed recall of word lists with a recognition trial. Such screening is prohibitive for primary care offices due to the extensive training required for staff, time involved in administering the inventories and the high turnover of staff. The stigma associated with Alzheimer's disease may inhibit individuals from seeking testing from their primary physicians. Only about 50 percent of those in mild stages of the disease receive a diagnosis by their physician. The numbers may be even higher in rural areas of Nevada that do not have access to neurological expertise.

While there is no cure for AD, studies have consistently shown that early diagnostic and intervention, including medication management and caregiver support, can delay disease progression, functional decline and nursing home placement. Pharmacoeconomic studies of the commonly used medications for Alzheimer's disease have shown an average cost reduction of close to \$10,000 per patient over the course of the disease. In addition, if nursing home placement can be delayed for even six months, the Medicaid cost savings per individual for the

state would amount to close to \$24,000. Early diagnosis of Alzheimer's disease allows for related psychological and sociological issues to be addressed in a timely manner.

Opportunities for in depth and continuing education about the disease, and planning for care and related issues have been shown to make a difference in the course of the disease for both individuals with Alzheimer's disease and their care partners. As costs associated with providing care can be staggering, unpredictable and ever-increasing, unpaid caregivers are an invaluable resource in caring for loved ones with debilitating diseases. Early intervention benefits caregivers, as they are challenged to adapt to the stressful and protracted course of this incurable illness with little or no formal training or focus on their unique needs.

According to the Alzheimer's Association, "African-American and Hispanic populations are at higher risk for developing Alzheimer's. In fact, African-Americans are twice as likely to have Alzheimer's as whites, and Hispanics are about 1.5 times more likely than whites to develop the disease."³ Applying culturally and age sensitive outreach strategies into target populations helps to ensure appropriate and effective communication, thereby enhancing the likelihood of successful outcomes. These outreach efforts develop trust within the targeted communities. Developing leaders from individuals within the targeted community, who have first-hand experience with AD, will lead to new opportunities for initiating early stage supportive services, as well as reduce the stigma associated with diagnosis and treatment of AD. This outreach model and training, combined with the benefits of Telehealth for connecting families to specialized training and care, greatly enhanced the ability of rural families in providing care for their loved ones affected by Alzheimer's disease.

Alzheimer's Delivery

The telehealth project was developed to connect rural and underserved populations to medical and support specialists. Rural areas of Nevada have limited access to medical professionals and support programs, often taken for granted in more urban areas of the state. Existing familiar sites and organizations were used to connect the urban and specialized areas of Nevada to rural areas and underserved populations using compressed video.

Telehealth activities began to decline in July 2009, with the loss of the nurse practitioner initially involved in the project. Neurologists from Las Vegas began flying to Reno weekly to continue program development and support, and continued trips to Reno even after the nurse practitioner position was filled. The clinic referred clients to the Alzheimer's Association, as needed, for additional caregiver and patient support, beyond the diagnosis and medical perspectives. The partnership between the Cleveland Clinic Lou Ruvo Center for Brain Health and the Alzheimer's Association of Northern Nevada and Northern California continues to provide the continuity of services to Nevadans affected by Alzheimer's disease and their care providers.

³ Alzheimer's Association. http://www.alz.org/alzheimers_disease_facts_figures.asp. Chicago: Alzheimer's Association, 2010:1.

Strengths of a Telemedicine System

- The system is an efficient and feasible method for providing clinical care for patients with dementia.
- Use of equipment is generally good; people are able to communicate through the system.
- By having rural sites, people are likely to get care sooner, to access care more consistently over time and to generally be engaged in efforts that may improve patients' quality of life.
- The burden on caregivers may be eased by the existence of this system.
- As technology improves, the capacity of the system improves, and existing problems can be resolved.

Program Partners

Initially, project partners for telehealth activities consisted of the Aging and Disability Services Division (formerly the Division for Aging Services), the University of Nevada Reno School of Medicine Center for Cognitive Aging, and the Alzheimer Association. As the Lou Ruvo Brain Institute was developed, the grant was transferred from the University to the Lou Ruvo Brain Institute, along with the specialized staff familiar with the program. In February 2009, a partnership between the Lou Ruvo Brain Institute and the Cleveland Clinic was announced forming the Cleveland Clinic Lou Ruvo Center for Brain Health. This partnership enabled Alzheimer's disease medical specialists to provide rural communities with expertise and patient review, and enhanced colleague review and consulting utilizing the resources of the Cleveland Clinic.

Program Partners	Lead Person
State of Nevada - Aging and Disability Services Division Management Analyst Grants Specialist	Jeff Doucet Shirley Alloway
Alzheimer's Association of Northern Nevada Northern California Regional Director Program Director Outreach Coordinator Spanish Speaking Outreach Specialist	Angie Pratt Vicki Lebsack Stan Dowdy Laura Tellez
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Elko Alzheimer's Clinic Rural Coordinator	Lisa Dinwiddie, RN, MS

Alzheimer's Association staff equipped, energized and ultimately empowered individuals, families and communities to provide compassionate and effective dementia care through specialized outreach and training sessions. Alzheimer's Association staff include:

Angie Pratt, Director, Alzheimer's Association of Northern Nevada: Utilized resources from the Alzheimer's Association to support project initiatives.

Vicki Lebsack, Program Director Northern Nevada: Provided oversight of programs and services for families in the 12 northern counties of Nevada and works with staff and volunteers to deliver quality programs consistent with the Chapter-wide standards and the Association's mission.

Stan Dowdy, Rural Outreach Coordinator: Provided outreach to Native American tribes.

Laura Tellez, Spanish-Speaking Outreach Specialist: Provided outreach to Hispanic populations.

The University of Nevada Reno School of Medicine, Center for Cognitive Aging staff later transferred to the Lou Ruvo Center for Brain Health included:

Deborah Fredericks, Ph.D: Provided non-medical psycho/social services evaluation.

Charles Bernick, M.D: Developed collaborative relationships with rural physicians, consulting on early detection strategies for family care practices. Taught classes on diagnosis and medical management of early Alzheimer's disease, and provided consultative services to all partners.

Lisa Dinwiddie, MS, RN: contracted with Center for Cognitive Aging to provide data collection by telehealth site facilitators and facilitated local support groups for caregivers and taught classes on rural resources and skill-based caregiving strategies.

Susan Hirsch, MSW: provided support to the project through Cleveland Clinic Lou Ruvo Center for Brain Health in coordination with Dr. Bernick.

Part II: Program Implementation

Project targeted Hispanic and Native American populations in Northern Nevada Counties.



Source: Nevada Office of Rural Health (2006)

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Implementing Early Stage Dementia Project - Telehealth Early Phase Patient and Family Support Program (TESP)

Infrastructure for the Telehealth Project

Nevada's existing infrastructure provided access to accommodate compressed video throughout the state, including rural areas. Nevada has more than 150 sites connected to the teleconferencing system including rural clinics and virtually all rural hospitals. Each area must have existing infrastructure and necessary network connections to accommodate the compressed video.

Existing facilities must be able to accommodate and access the compressed video feeds, therefore, some sites required upgrades to their existing networks. In addition to the technology infrastructure needed to accommodate the compressed video, each site must have all hardware required to communicate with partnering sites. Due to occasional issues with technology, local staff should be familiar with the setup and connections of the equipment, and be prepared to accommodate individuals should problems occur. Additional resources to meet the needs of participants are also required to assist during each session, such as:

1. Headphones for individuals who are hard of hearing or may have a hearing impairment.
2. Translators for target populations or presentations implemented in specific languages.
3. Anti-Glare screen to reduce or eliminate glare from lights.
4. Additional items specific to the covered topics, handouts, discussion objects, etc.

Outreach To Participants

Outreach efforts were targeted to Hispanic populations and Native American populations. Participants were identified through outreach efforts, referrals, and by forming relationships with target populations. Potential participants may have already had some sort of relationship with program partners, have been referred through another organization, or come to the program through publicized outreach efforts.

The Alzheimer's Association of Northern Nevada Northern California hired a Hispanic Outreach Coordinator for outreach to Hispanic populations. A key concept when hiring for this position was to identify and hire an individual with connections to the community and a dedicated, outgoing personality.

The Hispanic Outreach Coordinator had existing roots in the community, having lived in the Northern Nevada for the past 15 years. Using innovative and out-of-the-box thinking, the Hispanic Outreach Coordinator was able to connect with individuals in the community at coffee shops, bars, restaurants and other unusual meeting locations.

Some of the locations for outreach efforts include Dayton, Carson City, and Virginia City. Overall, Nevada's efforts were successful in reaching families in need of vital information, which was provided information in their native language by individuals of their culture.

In addition to a Hispanic Outreach Coordinator, The Alzheimer's Association of Northern Nevada Northern California also hired a Rural Outreach Coordinator who coordinated outreach activities in rural areas for Native American populations. Outreach into Native American communities has been difficult throughout Nevada. Building upon previous experiences, the Alzheimer's Association approached this community and began forming relationships with individuals and tribal leaders. Other lessons learned in reaching out to Native American populations included the need to:

1. Respect cultural differences when forming relationships with tribal elders.
2. Enter the community with a flexible attitude and listen rather than attempting to teach the population.
3. Build relationships over time with continued efforts; immediate results should not be expected or elicited.
4. Invite community partners to work with you, or ask community elders to teach you what is needed.
5. Plan to have follow-up relationship building trips and calls.

To further reach this population and develop stronger and lasting relationships, one future consideration, is to hire a Native American Outreach Coordinator. To ensure effective outreach into Native American Populations, an individual with existing connections to the targeted community should be hired. In addition, the individual should connect with tribal leadership with the identified lessons learned in mind. Developing the relationships and showing successes with families in the population will strengthen credibility and help to develop community acceptance.

During outreach to these communities, the outreach purpose was often less important to the participants than the socialization aspect before and after. Though there were several successes in outreach to the targeted populations, efforts continue to include these populations in Nevada activities. Utilizing the established foundation will increase future successes with these and other populations.

However, this project struggled in its ability to attract Hispanic and Native American populations, due to their strong affinity for established relationships. However, this problem is not generationally consistent. Younger individuals in these populations were less opposed to using technology. More studies will have to be made to determine the actual age discrepancy. Doctors, and the title of "doctor," were highly respected and trusted in these communities. Limited access to health facilities in the rural areas (Elko, Ely, Fallon, Lovelock Yerington and Winnemucca) may contribute to the respect of medical professionals due to the scarcity of the medical and health commodities.

Therefore, an additional lesson learned from the Telehealth project is that cultural differences affect outreach and acceptance of technology. Though it was not implemented during this project, program partners have now begun using the lay health worker, "Promotora" concept to outreach into specific cultural populations. The lay health worker or "Promotora" model helps to develop lay leaders in target populations who can assist individuals in the target communities. The key to this outreach is to develop a trusting relationship with individuals in the target communities.

Program Partners

Collaborative partners were identified and selected based on their ability to provide a continuity of care to individuals affected by Alzheimer's disease and their care providers in the targeted population. Each program partner was experienced in providing services to individuals with affected by Alzheimer's disease and had developed an established relationship and reputation with the community.

The State Unit on Aging - The Aging and Disability Services Division

The Nevada Aging and Disability Services Division (ADSD), one of six divisions within the Nevada Department of Health and Human Services, has a primary focus of providing statewide outreach and services for Nevada elders. These services are provided either directly by Division staff or in collaboration with numerous partners around the state. In delivering and funding services, the Division considers a multitude of factors including, state geographic and demographic data, at-risk seniors, public input regarding service needs and levels of available funding from various resources. ADSD provides exceptional and compassionate services to Nevada's older citizens and provides funding for numerous programs in Nevada to serve individuals and families affected by Alzheimer's disease.

ADSD works collaboratively with several grantees and community partners for service delivery through a wide variety of projects. These partners are recognized for their successful strategies, achieved through state and federally funded grants.

Alzheimer's Association of Northern Nevada Northern California

The nationwide mission of the Alzheimer's Association is to eliminate Alzheimer's disease through the advancement of research, to provide and enhance care and support for all affected, and to reduce the risk of dementia through the promotion of brain health.

The Alzheimer's Association began as an alliance of family members and professionals dedicated to helping people with Alzheimer's disease and related dementias and their families through education, advocacy and support. The Northern Nevada Chapter of the Alzheimer's Association started nearly 20 years ago; opening its first office in 1994. In 2002, the Northern Nevada Chapter merged with the Northern California Chapter along with six other chapters under a major realignment in order to expand capacity to reach more people and deliver programs more effectively. This merger created efficiencies of scale across the board and a broad new culture of sharing information, ideas, services and personnel. Technology and networking systems have helped staff and volunteers extend their reach and enhance the high quality of services while still leveraging the expertise of the individual local area offices. Today the Northern Nevada office services 12 counties in Northern Nevada, including Washoe, Humboldt, Elko, Pershing, Lander, Eureka, White Pine, Churchill, Storey, Douglas, Lyon and Carson City -- through its Regional Office based in Reno and its rural outreach office in Carson City.

The Alzheimer's Association is the primary provider of education, family care consultation, community referrals and support groups for people affected by Alzheimer's disease and related dementias. Through a set of core services and special programs, the Association informs and supports families, both initially, as they struggle to accept and understand the Alzheimer's disease diagnosis, and throughout the 8-10 year progression of the disease. Through

public awareness, advocacy and education, the Alzheimer's Association changes the way people think about Alzheimer's disease and encourages earlier diagnosis, treatment, and compassionate care. Additionally, the Alzheimer's Association offers accurate, timely information and education for health care professionals and the public, and support of research focused on the cause, treatment and prevention of Alzheimer's disease and related disorders

The Alzheimer's Association was the obvious selection as it has the support at the national level and recognition from community partners and individuals. The Alzheimer's Association, with its existing training material, is the recognized source for caseworkers, hospitals, and individuals with Alzheimer's disease. Established in 1989, the Alzheimer's Association continues to be the primary provider of dementia education, information, care consultation, community referrals, support groups and respite coordination in Northern Nevada. Its mission is to eliminate Alzheimer's disease through the advancement of research, to provide and enhance care and support for all affected, and to reduce the risk of dementia through the promotion of brain health. Alzheimer's Association programs have continued to evolve in direct response to the needs of families as well as health care professionals. For every person with dementia that is served, an average of three other individuals, usually family members, are helped as well.

In Northern Nevada the Alzheimer's Association operates from an office in Reno and in the Carson City Senior Center with programs serving the population in the 12 Northern Nevada counties. Core programs reflect a group of services found to be the most effective in reducing the negative impact of caregiving. Programs elements are supported by findings from the longest running study on caregivers, "Spouse Caregiver Intervention Study" (Mittleman, et al., 1995), a scientifically rigorous trial that showed a combined use of key program components to be extremely effective in maintaining the well-being of caregivers and in delaying or avoiding the necessity of institutionalization. The Association, through its national research program, has access to the most up-to-date, accurate information on research findings and new treatments before they are released to the public. As such, it is well positioned to bring this valuable information and training to the public.

The University of Nevada Reno School of Medicine, Center for Cognitive Aging

The University of Nevada Reno School of Medicine, Center for Cognitive Aging, has specialized, well versed staff who are passionate about Alzheimer's disease and related dementia, including a neurologist and a nurse practitioner involved in Nevada's project. The Centers for Cognitive Aging was established 12 years ago through partial funding from the Aging and Disability Services Division and is dedicated to providing patient care, research and education on Alzheimer's disease. The Centers for Cognitive Aging has on staff neurologists, neuropsychologists, social workers, research coordinators, nurses and clinical nurse specialists--all with specific expertise in Alzheimer's disease. The following services have been provided at their onsite clinics for over 10 years: diagnosis & medical management, social service referrals, competency evaluations, case management/future planning, support groups and workshops for families, behavioral consultation and counseling for individuals and families, education for professionals, and high functioning patient groups.

Cleveland Clinic Lou Ruvo Center for Brain Health

The Lou Ruvo Brain Institute was developed as a statewide institution targeting care and translational research in AD, Parkinson's disease, Amyotrophic Lateral Sclerosis, and

Huntington's disease. The Lou Ruvo Brain Institute was particularly interested in developing new models of diagnosis and care in AD and actively pursued partnerships to further develop and strengthen community impact. There has been tremendous support from the medical community for these organizations.

In February 2009, a partnership between the Lou Ruvo Brain Institute and the Cleveland Clinic was announced, thereby forming the Cleveland Clinic Lou Ruvo Center for Brain Health. In a facility designed by the internationally renowned architect Frank Gehry, the following programs are offered: diagnosis and treatment of neurocognitive disorders, caregiver therapy and support services, family social services, neuroimaging services, research and preventive brain health services. To implement these services, the collaboration between the Cleveland Clinic and the Lou Ruvo Center for Brain Health brings together a team of clinicians, researchers, surgeons, therapists, imaging specialists and other experts to improve diagnosis, treatment and advance knowledge of cognitive loss syndromes. The facility offers patients a continuum of care, infusing education and research into all aspects of service. Efforts are also directed at prevention and supporting further research in an attempt to slow and eventually stop diseases that rob society of its memory.

The Cleveland Clinic Lou Ruvo Center for Brain Health was conceived and is being operated as a not for profit state-of-the-art medical facility for the early diagnosis and treatment of neurocognitive diseases. The newest methods of treatment, clinical trials and ongoing research provide the best known care available. A comprehensive approach to caregiving is an integral part of the Cleveland Clinic Lou Ruvo Center for Brain Health's program. History and research has shown that these diseases have significant impact on the families of patients. The Cleveland Clinic Lou Ruvo Center for Brain Health places an emphasis on providing an array of therapeutic services and educational programs to support caregivers and increase their capacity to respond to the needs of their loved one. The Ruvo Center is a place that offers valuable resources as well as treatment, offering hope and help to patients and their families.

The Telehealth project requires interaction and coordination between all partners, even though each partner can act autonomously. Program partners, especially for televideo sessions, maintain contact with each other to coordinate activities. Additionally, with numerous sites available for project activities, program partners were able to assist consumers through coordination with other services available and for future actions needed for follow up assistance.

To assist program partners in the delivery of the program, Aging and Disability Services Division staff visited the program several times a year and communicated through email and phone as necessary.

Once a quarter, the Alzheimer's Association facilitated telehealth session to individuals in the rural areas who were interested in topics related to Alzheimer's disease. Video sessions were hosted at the Center for Cognitive Aging facilities. Through the coordination of program partners, the following components were offered at each session.

- **Consultative and Question & Answer Sessions:** Sessions were offered in English and Spanish. Faculty were experts from both the Alzheimer's Association and Center for Cognitive Aging.
- **Medical and Behavioral Care Consultation:** The Hispanic outreach coordinator provided ongoing consultation by telephone, onsite, or compressed video to families on an as needed basis. The Center for Cognitive Aging's, later the Cleveland Clinic Lou Ruvo Center for Brain Health, Rural Clinic nurse and the Reno clinic's psychologist and clinical nurse

specialist also provided ongoing consultations to English speaking individuals and families, Native American families and Tribal service providers via phone, compressed video or onsite.

Partner Roles

To provide the needed oversight, ADSD maintained communication with partners and was available as necessary to assist with issues that might arise. ADSD staff maintained communication with program partners and made several facility visits each year to program partners, initially in Reno, in Northern Nevada and later in Las Vegas, in Southern Nevada. During scheduled trips to Reno, Nevada, ADSD staff conferred with Alzheimer's Association staff and the nurse practitioner to help improve the project outcomes. The nurse practitioner interacted with patients on a continuous basis, first through the University of Nevada, Center for Cognitive Aging location, and then through the Cleveland Clinic Lou Ruvo Center for Brain Health.

Aging and Disability Services Division

The Aging and Disability Services Divisions' role for the Telehealth Early Phase Patient and Family Support Program was to monitor the project and ensure all requirements set forth by the Administration on Aging were completed. To ensure coverage for the project, ADSD assigned two staff to monitor and ensure project requirements were implemented and on target: a resource development specialist and a management analyst. The resource development specialist is responsible for monitoring and providing oversight for state grants and works in conjunction with other specialists throughout the state: two in Las Vegas; one in Carson City; one in Reno; and one in Elko. The management analyst is responsible for project oversight and report development. Working in tandem, the resource development specialist and the management analyst oversaw the telehealth project and ensured program partners had the tools and materials needed to complete the project.

Alzheimer's Association of Northern Nevada Northern California

The Alzheimer's Association role in the telehealth initiative was to provide support for individuals affected by Alzheimer's disease and their care providers. Through targeted efforts within the Hispanic and Native American populations, the Alzheimer's Association developed and enhanced existing relationships. Additionally, the Alzheimer's Association has made great inroads with the Native American community. To further support the patient and care provider, the Alzheimer's Association, using its reputation and experience, along with developed training material, was able to provide support and guidance to the patient and care provider in a group and individual setting. The Alzheimer's Association provided family and care provider training and one on one support as needed via the compressed video feed.

The goals of the Alzheimer's Association include:

1. Hired a rural outreach coordinator and Hispanic outreach coordinator to work with Indian Health Services and Nevada Hispanic Services to identify early phase Alzheimer's patients and their families.
2. Present interactive video classes for both caregivers and early phase patients.

3. Conduct onsite workshop classes by the rural outreach coordinator.
4. Provide telephone, interactive video and face-to-face behavioral and counseling consultations for Spanish and English speaking caregivers and patients on an ongoing, as needed basis by the Hispanic Outreach Coordinator.

The Northern Nevada Regional Office presently has eight (8) support groups in the rural communities. Support Groups are available in communities throughout Nevada, led by trained facilitators, to enable families to share information and experiences, build new skills, and offer peer support and ideas about issues related to dementia. Education programs, for both small and large groups, are designed to increase awareness about the disease and help families increase knowledge and skills to enhance the care of persons with dementia. In addition, The Alzheimer's Association also offers Early Stage Support/Education Programs, designed specifically for dyads of persons in the early stage of Alzheimer's and their care partners.

The University of Nevada Reno School of Medicine, Center for Cognitive Aging - Cleveland Clinic Lou Ruvo Center for Brain Health

The Center for Cognitive Aging (later the Cleveland Clinic Lou Ruvo Center for Brain Health) and rural providers identified and recruited early phase patients and individuals through its telehealth clinical services. It also presented Q & A support group sessions via interactive video by the medical and psychiatric specialists and hosted sessions with patients and their care providers to provide medical expertise for support. The nurse practitioner and the staff neurologist identified patient needs and formulated progression plans. Onsite support group sessions were offered to both patients and caregivers facilitated by the telehealth nurse. Telephone, interactive video and face-to-face behavioral and counseling consultations were provided for Spanish and English speaking caregivers and patients on an ongoing, as needed basis by the psychologist/clinical nurse specialist, and Rural Clinic Coordinator.

The Project Associate Director, Lisa Dinwiddie MS RN, disseminated project schedules and services to rural referral sources, including Indian Health Services, Hispanic Services, nurses, social workers, physician offices, guardians, senior centers, and all other agencies that provide services to rural seniors. The Project Associate also trained and supervised the collection of data by telehealth site facilitators. Additionally, the project associate worked with the Medical Director to maintain collaborations with rural physician offices and provide training and consultation for their staff in identifying at risk and early phase clients. The Project Associate facilitated local support groups for caregivers and taught classes on rural resources and skill-based caregiving strategies.

Educational Sessions

Educational sessions were designed as both diagnostic and training to provide the continuity of care for patients and their care providers. Individuals with mild cognitive impairment were observed by the nurse practitioner and the neurologist for signs of progression. Additional support needs were identified as sessions progressed to determine a more certain diagnosis. To further support the patient and care provider, the Alzheimer's Association, using its reputation and experience, along with developed training materials, was able to provide

support and guidance to the patient and care provider in group and individual settings. The Alzheimer's Association provided family and care provider training and one on one support as needed via the compressed video feed. The Center for Cognitive Aging hosted sessions with patients and their care providers to provide the medical expertise for support. The nurse practitioner and the staff neurologist identified patient needs and formulated progression plans. Program partners reported information for project outcomes directly to the ADSD management analyst as needed and as requested. In addition, the project partners also reported unduplicated client counts into the Social Assistance Management Information System (SAMS). Program partners, in addition to funding for the ADSSP project, received state funding through Independent Living Grants (ILG), from the master tobacco settlement agreement, for comparable projects to leverage and maximize the benefits of the program. With the addition of awarded ILG dollars from the state, program partners were able to improve existing services and service delivery and purchase needed equipment to enhance efforts.

One of the visions for this project was to provide teams that would utilize the telehealth videoconferencing capabilities to enhance education and support programs for rural residents statewide. Topics were addressed and publicized as follows:

- ***Alzheimer's and Safety:*** A guide to planning and preparation.
- ***Alzheimer's 101:*** Learn the basics of Alzheimer's disease. This program provides information regarding the symptoms, diagnosis, progression, and current treatments for the disease.
- ***Alzheimer's Research Updates:*** Phenomenal progress in research is being made every day. Learn about current research that is being done to find a cure for Alzheimer's disease.
- ***Behaviors: Responding to Reality or Perceptions:*** Learn how to interpret behaviors and explore creative techniques useful when responding to behaviors exhibited by people with dementia.
- ***Communication: A Meeting of the Minds or of the Hearts?*** Identify and practice communication skills that help to establish and/or strengthen relationships with people who have dementia.
- ***Holiday Survival Kit:*** The holidays can be a joyful time with family and friends. If you are caring for someone with dementia, the holidays can also bring special challenges. This session will provide helpful information and strategies to enhance the holiday experience for both the individual with dementia and those who care for him/her.
- ***Legal and Financial Planning for Alzheimer's Disease:*** Learn about the documents needed and financial considerations for future care planning.
- ***Maintain Your Brain:*** What can you do to keep your brain healthy and active? How can you assist individuals with dementia in preserving their strengths and skills? How can you reduce your risk of getting a brain disease, such as; Alzheimer's disease? How can you help individuals with dementia to possibly delay the progression of dementia? Find out in this workshop.
- ***Partner With Your Doctor:*** This workshop was designed for persons with memory problems and their care partners. Participants will learn techniques to: improve how you talk with your doctor, improve how a care partner and patient work together, lower your stress by organizing yourself and ensure the patient gets the best health care possible.
- ***Taking Care of You:*** Learn how to identify the symptoms of caregiver stress and discuss effective coping skills.

- ***Understanding Memory Loss:*** Learn about the differences between “normal” aging and dementia.
- ***The Latest Research on AD:*** Learn about the latest research being undertaken by researchers throughout the world and in the United States.

Selecting Telehealth Sites

Sites were selected based on their ability to host televideo calls. Initially, some upgrades to existing infrastructure were needed to accommodate the compressed video. Other considerations for implementation sites include ease of access for patients and their care providers, access to support staff in the area, recognition of the facility in the area, and accommodation and privacy for televideo settings.



Source: Nevada Office of Rural Health (2006)

Lessons Learned

Many lessons were learned during this project initiative involving the telehealth program and interaction between program partners, specific to communication, coordination and continuity.

Coordination: To ensure program partners had access to the clients and care providers during sessions, each partnering agency needed to be informed of the interaction and coordinate with the host sites. From the participant perspective, this coordination was essential in providing the continuity of care to individuals affected with Alzheimer's disease and their care provider. Though some components for telehealth trainings could be completed autonomously, the coordination at the patient level was the most beneficial in providing the supportive structure necessary for patient and care provider.

Communication: Excellent communication between all program partners, including the Aging and Disability Services Division is essential to successful program performance, project outcomes, and successful adaption of the program. Overall project communication must be frequent and consistent to identify and prevent or eliminate potential barriers and other issues.

Continuity: The program initiative must be consistent in its application, throughout the time frame established. Services must continue without breaks or delay, as revitalizing services is often more difficult than simply maintaining services and visibility. During this project initiative, the loss of the nurse practitioner and the transition to the Cleveland Clinic, resulted in project delays. Though additional program partners (including the Alzheimer's Association and the Rural Coordinator) were able to compensate as available to continue activities, a loss of momentum for the program resulted. When the transition completed, the Cleveland Clinic revitalized the program with its commitment and establishment of additional rural clinics in Elko, Battle Mountain, and Winnemucca.

Lessons learned from two years of monitoring:

- The IT staff, though generally invisible, is on the front line to ensure that the proper equipment is provided, that it functions adequately and that all are trained in its use and maintenance.
- The responsiveness of staff to potential issues and technical difficulties can make or break an appointment. Occasional equipment or technical issues may occur and the availability of staff for prompt resolution is essential.
- When the equipment is used for educational programs, brief lectures followed by discussion and opportunities for all to interact are better received than long lectures, as it is difficult to sit and "watch" a lecture on the monitor.
- All participants should be briefed in use of the equipment.
- A written guide for use and maintenance of the equipment should be provided to all telemedicine sites.
- Equipment can be improved with the addition of earphones for those who may have difficulty hearing.

Challenges of a telemedicine system:

- As technology and capacity improve, requirements for more staff will increase. Therefore future costs to maintain the system will likely increase.
- Equipment must be up-to-date, and easy to use and maintain.
- There is an ongoing need for orientation and training.
- The equipment is a factor in every appointment; it is not invisible.
- Consultants and coordinators will always have some responsibility for the equipment; it is another tool in the interaction.

Lessons Learned in the Targeted Communities.

The telehealth program did not appeal to many individuals in the targeted populations. Through this differs slightly across generations, the overall impression was the preference for direct connection to subject experts especially for caregiver supportive topics. This may be based on a stronger affinity for establishing relationships. In general from Nevada's experience, the telehealth initiatives were not attractive for Hispanic and Native American populations, though this is not generationally consistent. Younger individuals in these populations were less opposed to using technology, though more studies will have to be made to determine the actual age discrepancy.

Cultural differences from outreach relating to the acceptance of technology influenced the attractiveness of the telehealth initiative. Though it was not implemented with this project, program partners have begun using the lay health worker, "Promotora" concept to outreach into specific cultural populations. The lay health worker or "Promotora" model helps to develop lay leaders in target populations who can assist individuals in the target communities. The key to this outreach is to develop a trusting relationship with individuals in the target communities. As these relationships are built and leaders in the community are able to speak with other members of the targeted community the telehealth initiative may provide a larger impact to the target populations.

The Promotora Model; Community Health Worker

Effective outreach has been an obstacle for Nevada's outreach into several populations. The Alzheimer's Association hired an outreach coordinator to pursue effective outreach strategies into minority populations, specifically Hispanic and Native American populations in rural areas. During the project, one outreach model that could have improved the effectiveness of outreach into these populations is the promotora model or community health worker. The "community health worker" model of education, developed from the promotora model, trains chosen "lay leaders" (as opposed to health professionals) to train others in their community about Alzheimer's disease and early detection. The "community health worker approach" has proven to be highly effective in working with minority populations to help educate these populations about the signs of Alzheimer's and early detection of the disease.

The Volunteer Promotora / Community Health Worker concept represents a low-cost innovation to early detection outreach that will enable continued outreach sustainability beyond the duration of the grant. The Alzheimer's Association, outreach coordinator developed a presence and reputation in the proposed target areas through community level interactions. The outreach coordinator, through outreach efforts into the target communities, was able to connect

with individuals in the community, provide information and guidance, and forge strong community bonds to enable more effective outreach. With the development of lay leaders in these target communities, the results of the program outreach model will significantly improve and spread throughout the target communities.

Two articles which illustrate the success of this model are attached in Attachment A and Attachment B. Please note that both examples identified the model as “Community Health Workers” and do not appear to be using the terminology “lay health workers”. We suggest referring to this as Promotoras/ Community Health Workers Program.

Some key points from the article, to serve as quick summaries include:

**Evaluation of *Salud Para Su Corazón*
(Health for Your Heart) — National Council of La Raza *Promotora* Outreach Program
Health for Your Heart**

- Result showed that the average number of families per promotora was seven, with a range of 2 to 13 families per promotora. (page 4 – Results)
- The most common locations of contact were home, community centers, church and schools. (page 4 - Improving heart health of families)
- “Based on the *promotores* interviews conducted in 2003, five of the seven sites reported that more than 90% of the participants referred for screening in 2001 were actually screened, and one of the sites reported that 100% of the participants referred were screened. Another site reported that it did not have this information”. (page 6)
- “The capacity of *promotores* to function as health educators and advocates has important implications for health promotion and disease prevention, given recent evidence that physicians spend less than 10 minutes per patient delivering educational messages (15)”. (page 7)

The Effectiveness of the Promotora (Community Health Worker) Model

- Very specific as to what the Promotora would do at each phase. Please refer to page 66 under intervention.
- Incentives were used - “The Environmental Health/ Home Safety Tool Kit”. (page 68)
- “The promotoras involved in this project continually demonstrated that they were successful in gaining the trust and confidence of the clients, who allowed them into their homes. The practice of someone entering a person’s home and assessing it for health and safety matters can be perceived as intimidating and potentially embarrassing. The practice of an outsider observing a person’s household product storage methods is often deemed to be unacceptably invasive or intrusive (Roddy et al., 2004-2005), yet the matter was successfully overcome by the promotoras in this project. The promotoras’ ability to gain the trust and support of the clients is a significant reason behind the success of this program. They have the ability to inform and educate in a manner that clients perceived as supportive; this is a key issue when conducting a program of this nature”. (Page 70).

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Appendix A: Satisfaction Survey Elko

UNIVERSITY OF NEVADA SCHOOL OF MEDICINE

ALZHEIMER'S DISEASE DIAGNOSTIC AND TREATMENT CENTER

SATISFACTION SURVEY

Elko Clinic

Patient's Name: _____ Today's Date: _____

Family or Friend's Name(s): _____

1. **If** you recall, please mark all staff you have seen during your visits:

___ Charles Bernick, MD

___ Lisa Dinwiddie, MS, RN

___ Arnold Greenhouse, MD

___ Debra Fredericks, PhD, RNC, APN

2. When you telephoned the office, were you treated courteously?

___ Yes ___ No If no, please explain _____

3. On your first visit, did you feel that you spent enough time with the Doctor/Staff?

___ Yes ___ No If no, please explain _____

4. Were all your questions answered to your satisfaction?

___ Yes ___ No If no, please explain _____

5. During your follow-up visit(s), was the diagnosis explained to you in a manner that you understood?

___ Yes ___ No If no, please explain _____

6. **If** you saw the Doctor/Staff via video-conferencing, were you pleased with the technology?

___ Yes ___ No If no, please explain _____

7. Would you recommend our services to others?

___ Yes ___ No Comments: _____

8. Do you have any suggestions or comments that would assist us in providing better care for you and your family?

___ Yes ___ No If yes, please explain (you may continue on the back of this form).

THANK YOU FOR YOUR TIME!

PLEASE RETURN IN THE SELF-ADDRESSED STAMPED ENVELOPE

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Appendix C: Rural Dementia Telemedicine Initiative (RDTI) Form 2b

Family Member/Patient Advocate Educational Program Evaluation

Program Title _____ Date _____

1. The overall quality of the educational program was

_____excellent

_____good

_____fair

_____poor

2. The objectives were of interest to me.

_____yes

_____no

Comments:

3. Please give one or two examples of something that you learned today that will be helpful in the care that you provide your family member:

4. In general using the telemedicine system for educational sessions and discussion groups is

_____excellent

_____good

_____fair

_____poor

PLEASE TURN OVER

The telemedicine program will appreciate your feedback. Regarding educational sessions and discussions over the telemedicine equipment:

The telemedicine does the following very well:

The telemedicine program could do more of:

The telemedicine program could do less of:

The telemedicine program should change:

Appendix D: Email Response to Project Details

- **Interactive Video Classes: What are the mechanics of the interactive video classes? (equipment needed, process, etc.)**

Each site has a room equipped with a Picture Video Conferencing System including a monitor, camera, microphone, and a remote control. The remote control is able to adjust the camera so the people in the room are viewed clearly on the monitor. In each room, individuals are viewable to all participating parties. For clients with hearing impairment, headphones are provided to better assist patients in hearing the provider from the remote location. The system is fully conversation between sites occurs in real time. A power point presentation is loaded into the computer from the teaching site and the instructor manually switches between the slides and his/her image that the students in remote sites see on their monitor. The system is voice activated so, when a remote classroom has a question, they simply speak up and the monitor at the instructor's site changes to the image of the site that spoke. There are numerous equipped sites throughout Nevada.

- **Target Population Numbers: Is there an estimate for the number of early stage persons the program anticipates serving?**

Less than 5% of proposed clients are considered "early stage" since people in the rural communities tend to ignore the signs of dementia until it is at the end of the beginning stages.

Northern Nevada Alzheimer's Association anticipates serving 430 clients for Care Consultations, Support Groups and Education. 10 of these clients are expected to have early stage Alzheimer's disease or related dementia.

The Lou Ruvo Brain Institute serves approximately 95 clients per month and anticipates serving 20-25 early stage persons.

- **Evaluation: Is there any more specific, updated information on the creation of "methods for monitoring project progress and assessing project outcomes?" Also, plans for cost analysis?**

Every client is given an opportunity to assess educational programs at the conclusion of each program. These evaluations can be mailed or completed orally with each person over the telemachine. The evaluation measures the degree to which the program objectives were clear and met, the presenter's knowledge of the material, the presenter's style of teaching, the comfort of the meeting area, the quality of the audio/visual aids, the degree to which the program increase their knowledge, the likelihood of recommending the program to others, and their overall satisfaction. (Poor, Fair Good, Very Good, Excellent)

For Support Groups: Once a year, every support group attendee is asked to complete an evaluation. The evaluation measures whether participants think their knowledge of AD has increased, participants ability to handle being a caregiver, participants ability to prepare for the future, participants ability to take care of themselves, participants understanding of their ability to turn to others for help, and participants overall satisfaction with the group. (all of the above are measured by does not help, helps a little, helps a lot or don't know). In addition, participants get to rate their experience as to the place they meet, the topics they discuss, the responsiveness of the group to their needs, their likelihood of coming back to the group and their likelihood of recommending the group to others and their overall satisfaction (Poor, Fair, Good, Very Good, Excellent)

For Care Consultations with Respite: Twice yearly, evaluations are sent requesting information on the following questions:

1. Do you feel the quality of care your loved one received was adequate.
2. Please Explain.
3. How has the respite assistance helped decrease some of your caregiving responsibilities?

They also indicate whether their stress levels have decreased (not at all, somewhat, greatly); whether they feel in better health (not at all, somewhat, greatly); and whether the respite has helped improve their overall mood (not at all, somewhat, greatly).

- **Products and Dissemination: Clarification of products and dissemination plan requested.**

The program will be advertised in a tri-yearly newsletter which reaches 7,000 households in Northern Nevada with approximately 1,352 mailed to rural areas. Another 1000 of these newsletters will be distributed for education services, support groups, and at annual care conference. Information and findings will be disseminated through this newsletter and during public outreach efforts including at the annual care conference.

Partners will submit a poster presentation for a national conference and may even be chosen as a presenter. A paper on the findings will be submitted for consideration in reviewed professional publication.

Partners will also disseminate an analysis of the project to the Division. The Lou Ruvo Brain institute is planning to schedule a think tank meeting of professionals across the nation providing telehealth care services in rural communities.

Attachment 1: Lay Health Workers Help Increase Cancer Screenings Among Low-Income Hispanic Women



Lay Health Workers Help Increase Cancer Screenings Among Low-income Hispanic Women

22 Mar 2009

[Click to Print](#)

The intervention of lay health workers can be beneficial in increasing breast and cervical cancer screening among low-income Hispanic women, reports a new study.

Participants in this study were women 50 and older who were non-adherent to mammography or Pap test screening guidelines. Researchers developed an educational intervention ("Cultivando La Salud"/Cultivating Health), which was administered by lay health workers. After follow-ups, researchers found that screening completion was higher among women in the intervention group than in the control group for both mammography and Pap test screening.

The study's authors concluded, "Our study provided further evidence that the lay health worker model can increase breast and cervical cancer screening among low-income Hispanic women."

"Effectiveness of Cultivando La Salud: A Breast and Cervical Cancer Screening Promotion Program for Low-Income Hispanic Women"

The American Journal of Public Health is the monthly Journal of the American Public Health Association (APHA), the oldest and most diverse organization of public health professionals in the world. APHA is a leading publisher of books and periodicals promoting sound scientific standards, action programs and public policy to enhance health.

[American Journal of Public Health](#)

Article URL: <http://www.medicalnewstoday.com/articles/143107.php>

Main News Category: Breast Cancer

Also Appears In: Women's Health / Gynecology, Cervical Cancer / HPV Vaccine,

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Attachment 2: Preventing Chronic Disease

PREVENTING CHRONIC DISEASE

PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY

VOLUME 2: NO. 3

JULY 2005

ORIGINAL RESEARCH

Evaluation of *Salud Para Su Corazón* (Health for Your Heart) — National Council of La Raza *Promotora* Outreach Program

Héctor Balcázar, PhD, Matilde Alvarado, RN, MSN, Mary Luna Hollen, PhD, RD, Yanira Gonzalez-Cruz, MPH,
Verónica Pedregón

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PEER REVIEWED

Abstract

Introduction

In 2001, the National Heart, Lung, and Blood Institute partnered with the National Council of La Raza to conduct a pilot test of its community-based outreach program *Salud Para Su Corazón* (Health for Your Heart), which aims to reduce the burden of morbidity and mortality associated with cardiovascular disease among Latinos.

Methods

The effectiveness of *promotores de salud* (community health workers) in improving heart-healthy behaviors among Latino families participating in the pilot program at seven sites was evaluated. Data on the characteristics of the *promotores* in the *Salud Para Su Corazón* program were compiled. *Promotores* collected data on family risk factors, health habits, referrals and screenings, information sharing, and program satisfaction from 223 participating Latino families (320 individual family members) through questionnaires. Paired *t* tests and chi-square tests were used to measure pretest–posttest differences among program participants.

Results

Results demonstrated the effectiveness of the *promotora* model in improving heart-healthy behaviors, promoting community referrals and screenings, enhancing information sharing beyond families, and satisfying participants' expectations of the program. The main outcome of interest was the change in heart-healthy behaviors among families.

Conclusion

The community outreach model worked well in the seven pilot programs because of the successes of the *promotores* and the support of the community-based organizations. Successes stemmed in part from the train-the-trainer approach. *Promotora*, as implemented in this program, has the potential to be integrated with a medical model of patient care for primary, secondary, and tertiary prevention.

Introduction

Recent epidemiological studies have demonstrated that Latinos may not be as protected from mortality events associated with cardiovascular disease (CVD) as postulated in earlier studies (1). Compared with non-Hispanic whites, Mexican Americans, who represent the largest percentage of the U.S. Hispanic population, experience equal or greater rates of CVD mortality (2,3). This disparity is paralleled by the increased prevalence of associated risk factors (e.g., obesity, diabetes, lack of physical activity) for CVD in this and other Hispanic populations (4). The response to combat CVD and its risk factors among Hispanics necessitates the development of culturally

The opinions expressed by authors contributing to this journal do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions. Use of trade names is for identification only and does not imply endorsement by any of the groups named above.

www.cdc.gov/pcd/issues/2005/jul/04_0130.htm • Centers for Disease Control and Prevention 1

competent programs that include community outreach strategies that target underserved and underinsured Hispanic populations. The *Salud Para Su Corazón (SPSC)* (Health for Your Heart) program is one example of a community-based outreach strategy that aims to reduce CVD risk factors and ultimately reduce the burden of mortality associated with CVD among Latinos.

SPSC was developed in 1994 by the National Heart, Lung, and Blood Institute (NHLBI) of the National Institutes of Health (NIH) as a community-based health promotion model for heart health among Latinos (5-9). The integration of the *promotora de salud* (community health worker) model distinguishes *SPSC* from other heart health programs. The use of community health workers has proven to be a cost-effective intervention strategy for expanding health access and health care services to underserved and underinsured minority communities, including Latino communities (10).

In 2001, the NHLBI partnered with the National Council of La Raza (NCLR), the nation's largest Hispanic grassroots organization, to establish a national pilot dissemination of *SPSC* programs. The partnership sought to test the *promotora* model for promoting heart health and reducing CVD risk factors within seven Latino communities across the country. *Promotores de salud* and community-based organizations (CBOs) teamed up to deliver the culturally competent *SPSC* health promotion intervention.

The *SPSC-NCLR* initiative to test the *promotora* outreach model had three components: 1) a planning and development phase, 2) an implementation phase, and 3) an evaluation phase. The description of the planning and development phase has been published elsewhere (11). The objectives of the implementation and evaluation phases for the *SPSC-NCLR* initiative were to 1) monitor changes in heart health knowledge, attitudes, and skills of *promotores*; 2) track the delivery of program curriculum and educational sessions by *promotores* to Latino families; 3) deliver a series of community-educational activities; 4) assess perceptions of CBOs associated with the *promotora* model to build community capacity; and 5) evaluate changes in heart-healthy behaviors reported by Latino family participants. This article describes the *SPSC-NCLR* pilot dissemination approach, focusing on the implementation and evaluation phases of the initiative, and describes the effectiveness of *promotores* to

improve heart-healthy behaviors among participant Latino families.

Methods

The *SPSC-NCLR* pilot dissemination approach

The theoretical framework guiding the *SPSC-NCLR* initiative integrated two major elements: community outreach processes and participatory research methods. This integrated approach guided the development, implementation, and evaluation of the train-the-trainer *promotora* model.

Development of the *promotora* model

The development phase of the *SPSC-NCLR* initiative consisted of a needs assessment survey of CBOs, which was used for selecting the seven participating sites. These participating sites were CBOs that had *promotores* working for them. The Table provides the names and locations of the CBOs. A detailed description of the development of this model is described elsewhere (11).

Implementation of the *promotora* model

The implementation phase at each site consisted of 1) *promotora* training activities, 2) activities to recruit participant Latino families, and 3) a 6-month intervention delivered by *promotores*.

***Promotora* training.** A series of well-defined and structured *promotora* training activities was conducted and supervised by the *SPSC-NCLR* team for all seven sites. The activities involved the development of participatory process and capacity building to support the adequate delivery of the interventions (11).

Recruitment of Latino families. Recruitment was primarily the responsibility of the *promotores*. They recruited families using advertisements developed by their own CBOs, and they enrolled participants from community centers, health centers, schools, and other community and neighborhood sites. *Promotores* approached individual family members and invited them to participate in the program. All family members were invited to participate in the program; however, the mother was the most likely participant (91% of the time).

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Intervention. The intervention implemented at all seven sites included a series of educational sessions from the NHLBI heart-health curriculum called *Your Heart, Your Life*. *Promotores* delivered seven of eight curriculum lessons in 2-hour sessions within a 2- to 3-month period for the first part of a 6-month intervention. The eighth lesson on diabetes was optional. Sessions occurred either several times a week, once a week, or every other week. *Promotores* used a variety of educational materials including workbooks, *fotonovela* stories, easy-to-read booklets, and videos. The intervention also included home-visit or telephone follow-up contacts to reinforce the educational activities learned in the program. More detailed information about this family heart-health education program using *Your Heart, Your Life* has been reported in a recent article (11). Additional activities under the contracts for the CBOs and their *promotores* included referrals to health care providers for health screenings of blood pressure, blood cholesterol, blood glucose, and measures of weight and waist circumference.

The SPSC-NCLR program reached 223 Latino families served by 33 *promotores* at seven locations across the United States. The majority of the families served by the program resided in California, Illinois, New Mexico, and Texas and were of Mexican origin. Latino families of Central and South American origin were also represented in the communities of Chicago, Ill; Escondido, Calif; and Providence, RI.

Evaluation of the *promotora* model

The evaluation framework focused on the content of the program, how it was implemented, and its results. To evaluate the extent to which the SPSC-NCLR program effected change in awareness, knowledge, and behavior, data were collected using an evaluation tool called *¡Cuéntamelo!* (Tell me about it!) at three levels: 1) the CBOs, 2) the trained *promotores*, and 3) the participating families. Designed to guide and assess program implementation, *¡Cuéntamelo!* captures process and outcome data with several instruments. Data sources include questionnaires completed by *promotores*, families, and CBOs as well as interviews. A full description of the instruments comprising *¡Cuéntamelo!* (11) as well as evaluation data provided by participating CBOs (12) are published elsewhere.

This evaluation consisted of analyzing data collected from 33 *promotores* and 223 families (including a total of

320 individual family members) across all seven Latino communities. The evaluation focused on the characteristics of the *promotores* participating in the pilot program; the impact of the intervention on improving heart-healthy behaviors among family participants; the levels of referrals and screenings resulting from the program; the extent to which family participants shared their newly gained knowledge with others; and degree of participant satisfaction with the program.

Data analysis

Questionnaires were designed to facilitate data entry into a computer database using Epi Info 2002 (Centers for Disease Control and Prevention, Atlanta, Ga). The SPSS statistical software program (SPSS Inc, Chicago, Ill) was used to do a variety of analyses, which included calculating frequencies of responses to each question, computing averages and scores, and comparing responses across families and *promotores*. Paired *t* tests and chi-square tests were used to test for pre-post differences in family habits. Average improvement scores based on pre-post tests and their 95% confidence intervals were also calculated. Data analysis is presented for all sites combined based on several factors: 1) 91% of participants were women; 2) the mean age of participants for each site ranged from 30 to 51 years; 3) data on country of origin were not available for subgroup analysis; and 4) sample size was limited for some sites.

The main outcome variable of interest was the change in heart-healthy behaviors among family contact persons. A pre-post research design without a control group was used because the outreach programs were pilot programs and because of financial and logistic limitations. Families participating in the *Your Heart, Your Life* educational sessions completed a survey on practices of heart-healthy behaviors both before and after the sessions. The average time between the completion of the curriculum and the posttest was 3 months. A 35-item self-report 4-point scale for assessing family habits (0 = never, 3 = always) was used to assess heart-healthy behaviors.

The family habits scale included many items that assessed the frequency with which families engaged in a variety of heart-healthy practices, such as exercise and eating a low-sodium diet. Two groups of physical activity questions were asked. For the question "What does the family do to be more active?," the possible responses included such activities as walking, dancing, riding a

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stationary bike, working in the garden, aerobic dancing, or playing soccer. The second group of physical activity questions focused on such activities as getting off a bus one or two stops early and walking and using stairs instead of elevators. Families could choose to answer “never,” “sometimes,” “usually,” or “always.” Responses were converted for each of the items representing a desirable behavior to a 0–3-point scale with “never” equaling 0 and “always” equaling 3, assuming there were equal distances between responses. Subscores were calculated by adding responses to individual items on the same topic. An overall score using responses to all items was also computed. For ease of interpretation, scores were converted to a 0–100-point scale in which a high score reflected a higher frequency of always practicing a desirable behavior. Content validity and reliability of these subscales have been reported elsewhere (11,13) and shown to have good reliability (Cronbach $\alpha > 0.60$) (13).

Results

Promotores

A total of 33 *promotores* delivered the intervention. The average number of families per *promotor(a)* was seven, with a range of 2 to 13 families per *promotor(a)*. The Table presents the number of *promotores* working with participant families, the total number of families, and the mean number of families per *promotor(a)* at each site.

Most *promotores* were women aged 20 to 67; the average age was 41. About 65% of the *promotores* were born outside the United States. Of the 33 *promotores*, 5% reported having attended only primary school or less, 18% reported having some high school education, 28% reported having a high school diploma or GED, 30% reported having some college or technical school education, and 18% reported being college graduates. Overall, most *promotores* reported being bilingual. As would be expected, the preferred language varied depending on whether the *promotores* were born in the United States; a greater proportion preferred English or English and Spanish if they were born in the United States. Most *promotores* (78%) had worked as lay health educators before participating in the SPSC-NCLR program, with experience ranging from 6 months to 20 years.

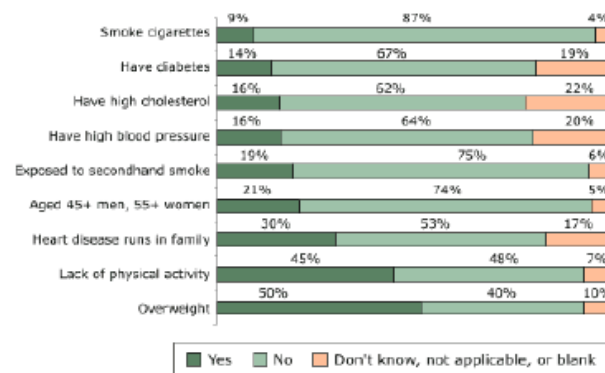


Figure 1. Heart disease risks reported by individual family members (n = 320) participating in the *Salud Para Su Corazón* outreach program. Data collected by *promotores* using questionnaires, 2001.

Improving heart health of families

The location for conducting family education sessions varied slightly depending on the topic; the most common locations were family homes (35%) and community centers (32%). Other locations (e.g., church, school) were also used for about 27% of the family education sessions. Fewer than 5% of the family education sessions were conducted in health centers. The surveyed families received an average of about seven educational sessions out of the possible eight. Almost all families (89%) were given information on at least seven topics, including diabetes.

Promotores asked the main respondent for the family, usually the mother, to provide the estimated number of individuals in the family at risk for CVD. Among the main respondents for the 223 families, 57% reported that no one in their family was at risk for CVD; 42% reported that they had at least one family member at risk.

Figure 1 shows CVD risks reported by individual family members. When *promotores* asked individual family members to report on a list of risk factors, 80% of the 320 individuals surveyed had at least one risk for heart disease. The mean number of risks per family member surveyed, excluding those who reported having no risks, was three. The overall mean number of risks, including the individuals who reported having no risks, was two. The two most common risks factors for CVD among all individuals surveyed were being overweight (50%) and a lack

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of physical activity (45%). Only 9% of the respondents reported that they smoked, a low percentage compared with other factors.

Changes in pretest and posttest scores for the families' practices of heart-healthy behaviors are presented in Figure 2. Families showed improvement in heart-healthy behaviors. Paired *t* tests of the increases in average overall scores and for each topic were statistically significant ($P < .001$). For the 190 families that completed both surveys, the average pretest overall score was 41% and the average posttest overall score was 59%, representing an average improvement in the total score of 18% (95% confidence interval [CI], 16%–21%).

The greatest improvement was observed for the items on practices related to cholesterol and fat, with an average pretest score of 43% and an average posttest score of 69%, an improvement of 26% (95% CI, 23%–30%). On topics such as "What is the family doing to be more physically active?" an average improvement of 13% was found (95% CI, 9%–16%). An improvement of 17% (95% CI, 14%–21%) was found for the physical activity topic. An average improvement of 21% (95% CI, 18%–24%) was found in practices related to weight reduction and control. Improvements were also observed on items related to salt and sodium consumption.

Figure 3 describes the distribution of responses across the four possible response categories. Chi-square tests of changes in the distribution were statistically significant ($P < .001$), even though this test does not correct for a potential underestimation of the effect due to the correlation between pretest and posttest scores for individual respondents.

Community referrals and screenings

Of the 223 families surveyed, *promotores* referred 74% to health care providers for blood pressure screening and 81% for blood cholesterol screening. They also weighed and measured the waist circumferences of family members for 77% of the families. Among the 101 families that received the educational session on diabetes, 70% were referred for a blood glucose check. According to the data collected by *promotores* through the group education questionnaires, *promotores* referred participants in 89% of the 56 classes taught on cholesterol for blood cholesterol screening and referred participants in 86% of the 37 classes taught on

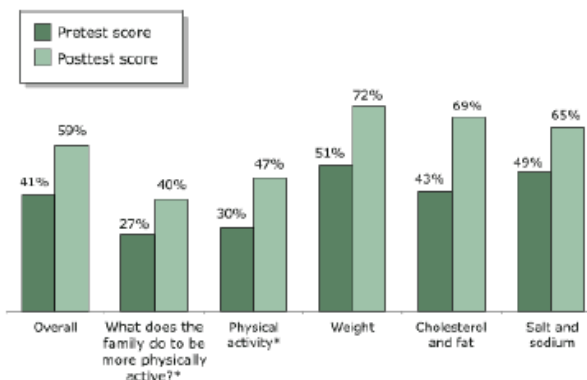


Figure 2. Average scores, by topic, for heart-healthy habits among families (n = 190) participating in both the pretest and posttest as part of the *Salud Para Su Corazón* outreach program. Score percentages calculated based on maximum score of 100. Asterisk (*) indicates that data refer only to mother. $P < .001$ for paired *t* tests on all topics. Data collected by *promotores* using questionnaires, 2001.

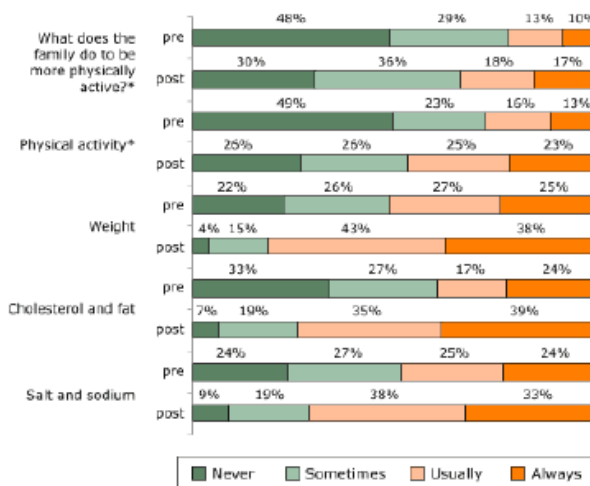


Figure 3. Distribution of responses on family heart-healthy habits among families (n = 190) participating in both the pretest and posttest as part of the *Salud Para Su Corazón* outreach program. Asterisk (*) indicates that data refer only to mother. Data collected by *promotores* using questionnaires, 2001. Percentages do not add to 100% because of rounding.

diabetes for blood glucose screening. *Promotores* also measured the weight and waist circumferences in 34% of the 32 classes taught on maintaining a healthy weight. No data were collected for blood pressure screenings.

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Based on the *promotores* interviews conducted in 2003, five of the seven sites reported that more than 90% of the participants referred for screening in 2001 were actually screened, and one of the sites reported that 100% of the participants referred were screened. Another site reported that it did not have this information. To ensure that the participants would be screened after taking the class, some of the *promotores* opted for providing transportation to a clinic after the class, while others decided to bring a nurse to the session to do the screening. In other locations, *promotores* kept track of the percentage of participants who were screened by asking them for the screening results during follow-up visits. In still other locations, *promotores* arranged for free screening of class participants in an effort to increase the number of people getting screened for the different heart risk factors. The interaction between *promotora* and screening activities on reducing CVD risk factors was not explored because of limitations in data collection.

Reaching beyond families

According to the data collected from 223 families, SPSC-NCLR reached other people beyond the original participant families. Responses to questions on information sharing revealed that family respondents were likely to share information they learned about heart-healthy behaviors with friends in their neighborhood, friends in other cities, friends in their country of birth, relatives in their country of birth, or people at work. The results showed that family respondents were just as likely to share information about one topic as another, with the exception of smoking (Figure 4). Fewer than 33% of families shared information with friends in other cities, friends in their country of birth, relatives in their country of birth, or people at work. The lower proportion of families that shared information about smoking, compared with other topics, may reflect the fact that most respondents reported being nonsmokers.

Participants' evaluations of SPSC-NCLR programs

Family participants expressed a very high level of satisfaction with the program. Overall, of the 207 families participating in the survey on satisfaction, 96% were very satisfied with the program. Accordingly, the level of satisfaction with specific aspects of the program was also very high (Figure 5). For example, the majority of the families surveyed (95%) rated the information they received

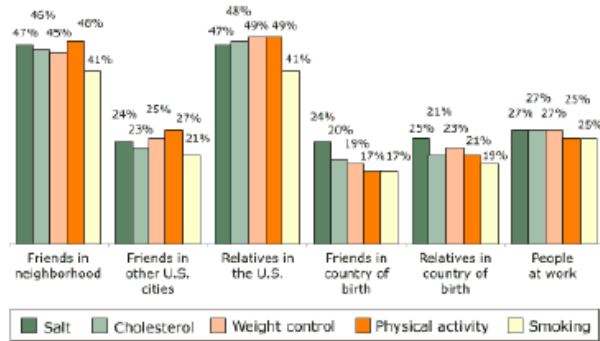


Figure 4. Audiences with whom families participating in *Salud Para Su Corazón* outreach program (n = 223) shared educational information received, by topic. Data collected by *promotores* using questionnaires, 2001.

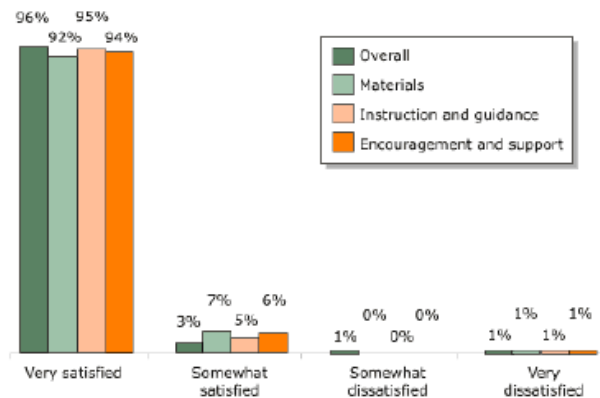


Figure 5. Percentages of families satisfied with guidance provided by the *Salud Para Su Corazón* outreach program (n = 207). Data collected by *promotores* using questionnaires, 2001.

through the program (instruction and guidance) as very important, including information on cholesterol and fat, blood pressure, weight control and serving information, physical activity, smoking, and salt and sodium.

Discussion

Successes

The community outreach model worked well in the seven pilot programs because of the successes of the

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promotores de salud and the support of the CBOs (12). With their skills, commitment, and enthusiasm, the training program and health education curriculum proved effective, translating into success for the SPSC-NCLR initiative. Overall, the results of the evaluation show that the initiative resulted in significant accomplishments at all three levels: *promotores*, families, and CBOs (12).

The successes realized in promoting heart health stems in part from the train-the-trainer approach. It nurtured the competency of the *promotores* to ensure success of the intervention. The train-the-trainer approach empowered *promotores* in their work by broadening their range of instructional approaches and heart-health knowledge. Based on self-reports by *promotores* and families, after completing the SPSC training, *promotores* were able to obtain the knowledge and skills necessary to recruit community members to participate in the program, to pass on the knowledge they had gained, and to support community members in accomplishing lifestyle changes that promoted better heart health. *Promotores* also expanded awareness of the project in the community, solicited additional funding, developed public service announcements related to the teaching materials, or did all of these. Despite facing a number of challenges, including limited funding and the need to prove the value of their work and that of the SPSC-NCLR program to some health care professionals, they successfully established partnerships with a variety of local organizations and programs, including clinics and health care providers, churches, schools, radio stations, health professional associations, restaurants, and pharmaceutical companies.

Promotoria, as implemented in the SPSC-NCLR program, has the potential to be integrated with a medical model of patient care for primary, secondary, and tertiary prevention. Using the *¡Cuéntamelo!* evaluation tools, *promotores* successfully identified risks for heart disease at the levels of both families and individuals, referring individuals for screening and providing community members with the knowledge and skills that they needed to improve their heart health. The capacity of *promotores* to function as health educators and advocates has important implications for health promotion and disease prevention, given recent evidence that physicians spend less than 10 minutes per patient delivering educational messages (15).

The ability of *promotores* to effect behavioral change is evident among the families they served. Evidence sug-

gests families participating in the SPSC-NCLR program made positive changes in heart-healthy behaviors. Families showed an improvement of 18% on self-reported heart-healthy behaviors. It seems that *promotores* succeeded at improving heart-health awareness and creating a cultural environment for learning heart-health information to promote changes in lifestyle behaviors among family members. Changes in heart-health behaviors have been consistently observed for similar *promotora* educational programs, adding credibility to the *promotora* approach (16,17).

According to the CBO survey (11,12), these local organizations supported the SPSC-NCLR program for two main reasons: the program supported the organization's mission of enhancing health education and prevention in Latino communities, and the program facilitated partnerships and provided access to additional human and financial resources. Furthermore, the adaptability of the SPSC-NCLR program facilitated its implementation at all seven sites. Even though all the sites applied the same SPSC-NCLR program training and materials (including the *¡Cuéntamelo!* tools), each site adapted some aspects of the program based upon their needs, the resources available, and the characteristics of the community. For example, some sites focused on conducting group education sessions; others focused on home visits for family education. Thus, SPSC-NCLR appears to be a flexible and adaptable program for use in a variety of settings and with different types of Latino communities (5,13,17,18).

Recommendations

Four recommendations are identified to improve the implementation and evaluation of the SPSC-NCLR program. First, it might be useful to explore how to facilitate health screening and follow-up care for individuals whom *promotores* identify as being at risk for heart disease. The second recommendation follows from the difficulties reported by *promotores* in using videos as educational materials. These difficulties resulted from a lack of video equipment on site. It might be useful instead to use socio-dramas based on the video scripts as supplemental educational tools or to replace the video entirely. The use of the videos could also be tested for its effectiveness in promoting awareness and changing behavior. Third, a distance-training and continuing-education module of *promotora* training can be considered, using a Web-based curriculum. It would be interesting to examine whether this form of

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training is effective; it might have implications for international use. Finally, a formal evaluation of the SPSC-NCLR program requires a quasiexperimental design or a clinical trial with pretest and posttest comparisons. It should involve evaluation of a series of sociodemographic and acculturation indicators, in addition to biological parameters, including changes in blood pressure, blood cholesterol, and body mass index. Finally, a formal evaluation should include more distal or secondary outcomes such as screening rates, sales of low-fat foods, and similar aspects in the community at large to indicate whether heart-healthy behaviors are becoming a community norm.

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Author Information

Corresponding Author: Héctor Balcázar, PhD, University of Texas Health Science Center at Houston, School of Public Health, El Paso Regional Campus, 1100 N Stanton St, Suite 100, El Paso, TX 79902. Telephone: 915-747-8507. E-mail: Hector.G.Balcazar@uth.tmc.edu.

Author Affiliations: Matilde Alvarado, RN, MSN, National Heart, Lung, and Blood Institute, National Institutes of Health, Bethesda, Md; Mary Luna Hollen, PhD, RD, University of North Texas Health Science Center at Fort Worth, School of Public Health, Department of Social & Behavioral Sciences, Fort Worth, Tex; Yanira Gonzalez-Cruz, MPH, National Hispanic Council on Aging, Washington, DC; Verónica Pedregón, University of Texas Health Science Center at Houston, School of Public Health, El Paso Regional Campus, El Paso, Tex.

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Table

Table. Sites and Numbers of Participants and Promotores for *Salud Para Su Corazón* Program

Site of <i>Salud Para Su Corazón</i> Program	No. Promotores	No. Participating Families	No. Families per Promotora
Centro San Bonifacio, Chicago, Ill	10	76	7.6
Centro San Vicente, El Paso, Tex	1	2	2.0
Neighborhood Health Care, Escondido, Calif	4	38	9.5
Hands Across Cultures, Española, NM	3	36	12.0
CHisPA, Providence, RI	4	10	2.5
Council for the Spanish Speaking, Stockton, Calif	5	32	6.4
Migrant Health Promotion, Las Colonias, Tex	6	29	4.8
Total	33	223	6.8

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