CANCER IN RURAL AREAS

by Annie Gosschalk and Susan Carozza

SCOPE OF PROBLEM

- Cancer was the second leading cause of death in 1999.[36]
- Cancer is virtually tied with psychoses as the fourth most frequently first-listed diagnoses for hospital discharges nationally.[37]

GOALS AND OBJECTIVES

Cancer is second only to heart disease as a leading cause of death in the United States.[1] The direct and indirect costs in terms of premature death, disability, lost years of productivity, and medical expenditures make cancer a significant public health concern[2] to all population groups regardless of age, gender, race, or geographic region. Nonetheless, certain subgroups including the elderly, African Americans, and special rural populations may be at heightened risk of developing cancer as well as experiencing more negative outcomes.[3-5]

According to the Rural Healthy People 2010 survey, cancer tied with the focus area of nutrition and overweight for 10th and 11th ranks among the Healthy People 2010 focus areas that were rated as rural health priorities; it was nominated by an average of 22 percent of the four groups of state and local rural health leaders.[6] Cancer was most frequently rated as a priority by rural hospitals and least often by state agency respondents in comparison to local public health offices and rural health centers and clinics; this is a statistically significant difference. There were no significant differences in cancer nominations across the four regions of the country.[7]

The goal of the Healthy People 2010 cancer objective is to reduce the number of new cancer cases as well as the illness, disability, and death caused by cancer.[8] The objectives addressed in this review are as follows:

- 3-1. Reduce the overall cancer death rate.
- 3-11. Increase the proportion of women who receive a Pap test.
- 3-12. Increase the number of adults who receive colorectal cancer screening.
- 3-13. Increase the proportion of women aged 40 years and older who received a mammogram within the preceding two years.
- 3-14. Increase the number of states that have statewide population-based cancer registries.
- 3-15. Increase the proportion of cancer survivors who are living five years or longer after diagnosis.

PREVALENCE

Rural areas report a higher prevalence of chronic diseases,[9, 10] including heart disease and cancer, a finding that has been attributed, in part, to a rural population that is older, poorer, and less educated.[11] The disproportionate prevalence of chronic disease is reflected in the higher crude all-causes mortality rates reported for rural areas.[3, 10] However, adjusting the data for age, race, and sex distributions effectively eliminates any rural disadvantage for cancer.[10]

Rural areas report a higher prevalence of chronic diseases,[9, 10] including heart disease and cancer.

Nonetheless, notable exceptions exist among selected rural subpopulations in incidence and mortality. Of note are the cancer incidence and mortality rates for the Appalachian region.[12] The death rate in rural Appalachia (176.3/100,000) for all cancers is higher than all of Appalachia (173.1/100,000), and it is significantly higher than the national cancer death rate (166.7/100,000). Skin and

lip cancer mortality rates, as well, are higher in rural areas[10] and may be attributed to increased sun exposure of rural residents, particularly among farmers.[13]

In reviewing the literature, differences also exist between urban and rural populations in the stage of disease at first diagnosis. Cancer staging refers to the degree of tumor extension and growth[10] at first diagnosis. Early staging is considered an indicator of quality medical care and improves outcomes for many cancer types.[10] A number of state-level studies have analyzed the relationship between rurality (note, the definition of rural is not consistent among studies) and tumor staging and found rural residents to be at risk for late stage diagnosis. African Americans in rural areas are particularly at risk for late stage diagnosis, which significantly impacts cancer progression and outcomes.[4, 5, 14, 15] The findings are suggestive that rural cancer patients may be disadvantaged when compared to their urban counterparts.[4, 10, 16-18]

Differences exist between urban and rural populations in the stage of disease at first diagnosis.

Among the reasons suggested for this disparity in diagnosis and treatment is that rural areas have a disproportionately high percentage of high-risk groups. Rural residents, who are typically older,[19] less educated, and poorer than urban residents, have less access to or utilization of early cancer detection programs.[20, 21] Rural people also regularly experience variation in the quality, availability, and accessibility of services when evaluated against their urban counterparts.[4] Limited access to quality medical care facilities and particularly cancer prevention programs[4] may negatively affect health outcomes for cancer patients. Studies have also analyzed the impact of insurance and socioeconomic status on cancer, screening, diagnosis, staging, and treatment. Residents in low-income areas (defined as those receiving Medicaid) and the uninsured are at a greater risk of late-stage diagnosis.[21-24]

IMPACT

According to the Centers for Disease Control, 1,284,900 new cancer cases were expected to be diagnosed in 2002, and more than 555,600 people were expected to die from cancer.[1, 25] The number of new cases does not include a projected 1.3 million cases of basal and squamous cell carcinoma of the skin.[26] Overall, cancer mortality has decreased during the period 1993 to 1999 for men and women, while incidence has stabilized during the period 1995-1999.[27]

The National Institute of Health estimates that $180.1 billion was spent in 2000 on direct and indirect cancer-related costs (e.g., medical expenses, lost years of productivity).[2] In 1999, there were an estimated 8.9 million people alive with a history of cancer.[25] The probability of a person recently diagnosed with cancer being alive in five years is 59 percent.[26] However, this number represents an average for *all sites*. Five year survival rates vary considerably depending on cancer type.

Rural residents who are also older, represent minority populations, or are low-income use fewer screening services, thus contributing to late stage at diagnosis and, subsequently, poorer survival rates.[4, 10, 17, 28]

BARRIERS

A number of behavioral and social factors have been identified as related to an increased risk of a variety of cancers. Smoking, excessive alcohol use, other modifiable behaviors associated with cancer risks,[29] and limited knowledge of cancer and the importance of early detection and regular screening are among the areas often addressed through health education efforts to raise awareness and change behavior.

There are a number of other potential barriers that are particularly salient to accessing cancer services in rural settings. These include:

- poorer access to health care services, including specialists;[4, 5, 10, 16]

- limited geographic access to new, effective therapies and technologies;[5, 10, 16]
- minimal transportation options for either cancer screening or treatment;[16, 30]
- limited knowledge of cancer, particularly the importance of early detection through regular screening;[31, 32] and
- prohibitive cost of cancer screening and treatment.[20, 30, 31, 33]

Social factors, such as living in poverty and having limited education, are far more difficult to address but often more significant in terms of contributing to the risk of cancer.

The failure to more fully address both cancer prevention and treatment among the rural populations represents a significant obstacle to diminishing cancer mortality at a national level.[16]

PROPOSED SOLUTIONS

Solutions or interventions are intimately tied to access to health care resources. Many of the solutions most often advanced in the literature are dependent on access to primary care and clinical preventive services—often a challenge in rural areas. Among the solutions most frequently articulated and potentially feasible in rural settings include:

- providing cancer education within the community, particularly emphasizing the importance of early detection through regular cancer screening;[31, 34]
- encouraging primary care providers to comply with current screening regimen within each area of cancer, making use of simple screening devices that possibly already exist in their practice;[34]
- encouraging the use of sun block, hats, and staying inside or in shade during peak sun hours;[2, 13, 31, 35] and
- developing and sponsoring smoking cessation programs within the community.[2]

SUMMARY AND CONCLUSIONS

Mortality rates for various cancers vary by demographic attributes including age, race, sex, and residence, creating a diverse pattern of cancer survival not reflected in mortality rates. The clear conclusion to be made from the literature and data reviewed is that rural residents demonstrate a lesser adjusted rate of cancer than urban residents; this comparative advantage, however, may be offset by higher death rates of rural residents diagnosed at later stages of disease. Even though the adjusted incidence rate of cancer is lower in rural areas than in urban, the factors related to barriers to care increase the likelihood of negative outcomes.

Despite positive strides in reducing cancer incidence and mortality, the prevalence of cancer is expected to increase as the population ages. While urban and rural America are both faced with meeting the health care needs of an aging population, the impact may be especially challenging for rural areas with a disproportionate number of elderly in combination with limited resources. Ultimately, combating cancer requires a multi-dimensional approach aimed at improving access to health services, including the imperative need for early cancer screening and detection, and improving patient knowledge of modifiable risk factors.

MODELS FOR PRACTICE

The following models for practice are examples of programs utilized to address this rural health issue.

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MODELS FOR PRACTICE
FOCUS AREA: CANCER

Program Name: Kokua Program (Hui No Ke Ola Pono)
Location: Wailuku, Hawaii
Problem Addressed: Cancer
Healthy People 2010 Objective: 3
Web Address: http://www.HuiNo.org

SNAPSHOT

The Kokua program provides breast and cervical cancer education presentations through outreach, enrollment with individuals, 'ohana' (family), or with various organizations.

Hui No Ke Ola Pono is a private, non-profit, health enhancement agency. It is a community-based 501(c)(3) organization that serves uninsured or underinsured Native Hawaiian, Pacific Islander, and Filipino women. The agency is accredited by the Commission of Accreditation for Rehab Facilities (CARF). The Kokua Cancer Program is one of many programs of Hui No Ke Ola Pono; other programs are prenatal education, diabetes self-management, and nutrition. The Kokua Program provides breast and cervical cancer education presentations through outreach, enrollment with individuals, 'ohana' (family), or with various organizations. Services provided include clinical breast exams (CBE), Pap tests, mammogram screening, blood pressure screening, glucose screening, cholesterol screening, transportation, and case management that consists of following up through resolution of abnormal results or diagnosis and treatment. The geographic service area is the island of Maui covering 727 square miles, with a total population of 117,644. There are 33,093 Native Hawaiians and part-Hawaiians in Maui County. Maui's geography is varied and poses significant problems when planning for networking and outreach, and it constitutes an accessibility problem for residents.

THE MODEL

Blueprint: The Kokua Cancer Program is a collaborative partnership among six organizations, which include: Hui No Ke Ola Pono, (Maui's Native Hawaiian health care system); Maui Community College Health Clinic, which consists of a nurse practitioner who supplies CBE and Pap tests; American Cancer Society, which grants educational material on breast cancer, cervical cancer, and cancer resources via the Internet; Maui Medical Group Radiology, which makes mammogram screening available; Maui Radiology Consultants, which also provides mammogram screening; and Cancer Research of Hawaii, which offers cancer information services that provide staff training on breast and cervical cancer, outreach strategies, and skill updating. All six partners are original stakeholders in the Kokua Program. The program is supported in part by a three-year $600,000 Federal

Rural Outreach Grant (1999–2002) to provide breast and cervical screening for Native Hawaiians, Pacific Islanders, and Filipino women.

Kokua's paid staff consists of a registered nurse who is also a health educator and clinical case manager, a program coordinator, two outreach health care workers, and a clerk receptionist. Hui's Medical Director and program medical doctor donate their time for clinical and case management to the Kokua Program. The volunteer staff for the Kokua Program consists of seven gatekeepers to access the Native Hawaiian community, Pacific Islander community, Tongan community, and Filipino community. These gatekeepers provide information to the program staff on the communities' culture, beliefs, norms, traditions, customs, history, and language and also volunteer as interpreters.

Health Care Workers (HCWs) provide education upon clinical intake and through the enrollment process. HCWs provide presentations at various organizations, such as Hawaiian civic clubs, Hawaiian churches where Pacific Islanders attend, senior adult organizations, health fairs, women's prisons, women's rehabilitation centers, homeless shelters, and community events. HCWs provide transportation to clients from their residence to enrollment, Pap test, and mammogram screening appointments. Medical problems that are identified as a result of the clinical assessment/screenings are referred out to a primary care physician. All clients are provided enabling and entitlement services, such as transportation, applications for Social Security, MedQuest (the state's Medicaid program), and emergency funding for health needs.

Making a Difference: The program's goals are measured against two Healthy People 2010 outcomes and outreach targets: 1) increase to 70 percent the proportion of female clients aged 40+ who have had a clinical breast exam and a mammogram within the preceding two years and who have been instructed in self breast exams; and 2) increase, to at least 95 percent, the proportion of female clients age 18 and older who have ever had a Pap test and increase to at least 90 percent those who received a Pap test within the preceding three years.

Outreach: The program is based on the Hawaiian value "Kokua" (helping each other). The focus of the program is to outreach and educate women who have not participated in regular screenings. One outreach strategy is to use 'ohana' (family) style outreach to three or four women of the same family or friends helping the women feel more comfortable. This works for the Pacific Islanders also.

Enrollment: A clinical intake and education approach are used as a bridge between traditional Hawaiian culture and medicine and Western medicine. This is accomplished by providing health education in a "talk-story" manner that demystifies Western clinical practices. In Hawaii, "talk-story" is an important social convention for sharing information informally, finding

common ground, and getting to know each other. The staff have established close relationships with this target group of women and have gained their trust.

Completing the Screening: One-stop screening is achieved by scheduling the CBE, Pap test, and mammogram screening on the same day. The convenience of one-stop screening is attractive, especially because women find it hard to take off work, find childcare, etc.

Providing transportation eliminates geographical barriers. Clients are picked up and transported, scheduling five and six women at a time. The 'ohana' style scheduled screening for family and friends, with same day Pap test and mammogram screening, helps eliminate fear and shame.

Makana (gifts) are given as incentives after the women complete the Pap test and mammogram screening. The first year of the program, t-shirts with the program's logo were given. The second year, a tote bag with the program's logo was given.

Tracking and Case Management: The Health Pro Database is used to manage the client roster, results, and tracking of clinical encounters. A program/case management algorithm was developed to show the flow of clients from education and outreach through basic case management and, if needed, resolution or treatment and intermediate case management with the case management team.

Performance Measurement: The program has also established outreach target goals for Hawaiian, Pacific Islander, and Filipino women.

Beginnings: Pre-grant meetings and a series of focus groups composed of underserved women set about to address the questions of defining barriers to cancer screening in the region. A survey was developed to gauge clients, the community, and program partners. A Maui Cancer Research Team performed a study to determine motivational factors and specific barriers to breast and cervical cancer screening.

Challenges and Solutions: Barriers encountered include: cultural beliefs regarding health, language, fear, shame, mistrust of Western medicine, financial, accessing health care services, limited knowledge of available health resources, and geographic isolation in remote rural areas.

The majority of the population in the service area mistrust Western medicine. The staff provides culturally sensitive services and clinical counseling by focusing on outreach services, which integrate modern medical care with traditional Hawaiian values, beliefs, and practices.

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MODELS FOR PRACTICE
FOCUS AREA: CANCER

Program Name: Real Men Checkin' It Out
Location: Columbia, South Carolina
Problem Addressed: Cancer
Healthy People 2010 Objective: 3
Web Address: http://www.scdhec.net

SNAPSHOT

The South Carolina Department of Health and Environmental Control's (SCDHEC) Office of Minority Health (OMH), under contract with the U.S. Department of Health and Human Services Office of Minority Health (DHHS OMH), developed and implemented Real Men Checkin' It Out, a community-driven, culturally appropriate education and communication initiative addressing prostate cancer in the African-American community. Real Men Checkin' It Out provides prostate cancer screening, follow-up and educational sessions, technical assistance, training services, one-to-one screening, one-to-one follow-up, and culturally appropriate social marketing outreach initiatives.

THE MODEL

Blueprint: There has been limited attention directed toward men's health issues in the area of primary prevention. Within the last decade, prostate cancer emerged as a major health problem and a critical health issue in South Carolina. The prostate cancer mortality rate in South Carolina is one of the highest in the nation. African-American men are particularly at risk for the disease, with black males being two times more likely to die from this cancer than their white counterparts.

Real Men Checkin' It Out is a two-phase demonstration project. Phase I focused on community prostate cancer education and awareness through various community-based grantees in one county. The current Phase II of the project expands activities to include prostate cancer screening through specific partnership grants with Historically Black Colleges and Universities (HBCUs) in three counties.

The project activities target at risk African-American/black men ages 40–70. The project also focuses on African-American/black men (21–39) who are less at risk; African-American/black females (ages 21 and over); and young adults (ages 17–20) as secondary target groups for reaching and providing

information and education to the priority targeted African-American/black males.

The goal of Real Men Checkin' It Out is to educate African-American men about prostate cancer and to ensure the provision of appropriate screening and follow-up services by engaging the state's HBCUs located in Orangeburg, Bamberg, and Richland Counties—two of which are rural counties. The emphasis for the current initiative (Phase II) is screening. Benedict College, Claflin University, and Palmetto Health in collaboration with Allen University, and Omicron Phi Chapter, Columbia South Carolina of the Omega Psi Phi Fraternity, Inc., implemented the project activities.

The goal of Real Men Checkin' It Out is to educate African-American men about prostate cancer and to ensure the provision of appropriate screening and follow-up services.

The staffing required for Real Men Checkin' It Out includes a South Carolina OMH director who provides oversight and direction for the project, a health disparities consultant who serves as the program coordinator, an epidemiologist who provides guidance with data and evaluation, a media consultant who assists with an awareness campaign, and an administrative assistant who provides administrative support.

OMH provides administrative and programmatic staff support to assist with the coordination of project activities with the grant recipients (partners). Each partnership/grantee has a non-paid project coordinator. Individuals from the grantees and other organizations, which include nurses, administrators, counselors and instructors, etc., provide other in-kind or donated services. Volunteer staff is from the faith community, media, and civic and fraternal organizations who provide support to implement the outlined project activities.

Making a Difference: The plan incorporates three separate categories/ stages of evaluation to address the process of implementation, provision of technical assistance/support, and outcome assessment. The process evaluation seeks to address:

- the types of activities that will be carried out by the prostate cancer initiative and by whom,
- the timely manner in which activities were initiated/performed (contractor),
- the barriers that were encountered and how were they overcome,
- to what extent the actual cost of project implementation is in line with initial budget expectations.

The process evaluation tools include: Real Men Checkin' It Out Time-Line, Program Activity Check List, and Budget Proposal vs. Actual Budget.

The performance evaluation provides feedback on OMH's execution of its role as contractor for the initiative. The evaluation seeks to address: to what

extent did OMH provide technical assistance/support, the effectiveness and efficiency of services/trainings provided by the contractor, and to what extent were resources identified to sustain activities beyond the project period. The evaluation tools for the performance evaluation include: Grantees Focus Group, Real Men Training Evaluation, and Resource Guide.

The outcome evaluation provides data on the community response to the initiative and the effectiveness of the education and screening components. The evaluation addresses the receptiveness of the community toward the initiative, to what extent community members were willing to be screened, was the initiative viewed as a successful venture by the community and program implementers, and obstacles/challenges in implementing the program and/or gaining community buy-in. The outcome evaluation tools include: Education Seminar Evaluation, Log Sheet for PSA Screening, Community-Based Organizations (CBOs) Evaluation of Initiative, and Grantees Focus Group.

Beginnings: In 1998, the South Carolina Department of Health and Environmental Control's Office of Minority Health, under contract with the U.S. Department of Health and Human Services Office of Minority Health, developed and implemented Real Men Checkin' It Out, a community-driven, culturally appropriate education and communication initiative addressing prostate cancer in the African-American community. The program recently received additional funding to continue its efforts and to expand the Real Men Checkin' It Out prostate cancer education community initiative.

Within the last five years, several organizations in South Carolina have given attention to prostate cancer, focusing on both education and screening. While these efforts have played an important role in addressing this disease and identifying the lack of education and screening as critical gaps in early intervention, they have not taken into consideration the need to seek community involvement in the development and implementation of acceptable educational programs for the target population. A culturally appropriate, public-health-based educational outreach approach was needed to enhance current efforts.

Challenges and Solutions: Initial funding supported a one-year demonstration project, and additional funding was received in 2001. Between the two-year break in the funding cycle, the community, including churches and fraternal organizations, either funded or voluntarily carried out the project activities. If additional funding becomes available, SCDHEC-OMH will apply to continue this prostate cancer initiative. SCDHEC-OMH will also assist in identifying other funding opportunities for the current grantees as well as other organizations to sustain and implement the existing prostate cancer project.

The most difficult challenges for the program have been timely submission of initial Requests for Proposals, identifying physicians to participate, and recruitment of men for screening.

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MODELS FOR PRACTICE
FOCUS AREA: CANCER

Program Name: Women's Way
Location: Mandan, North Dakota
Problem Addressed: Cancer
Healthy People 2010 Objective: 3
Web Address: http://www.health.state.nd.us/localhd/CDHU

SNAPSHOT

Custer Health, a local public health unit serving five counties in North Dakota, is affiliated with Women's Way—the North Dakota Breast and Cervical Cancer Early Detection Program. Women's Way has a statewide network system where the state health department, local public health units, and health care providers work together to provide breast and cervical cancer screening for eligible women. The program provides counsel on screening guidelines for breast and cervical cancer, education, and case management for women enrolled in the program to ensure that the women are screened. Custer Health's service area is considered rural and has one of the state's reservations within its boundaries. Minority women, primarily the Standing Rock Indian Reservation women, are a focus for the program. Thirty percent of all women enrolled with the Women's Way program from the Custer Health service area are American Indian.

Women's Way has a statewide network system where the state health department, local public health units, and health care providers work together to provide breast and cervical cancer screening for eligible women.

THE MODEL

Blueprint: Women's Way is a statewide federally funded program that pays for breast and cervical cancer screening. Women's Way is the North Dakota component of the National Breast and Cervical Cancer Early Detection program. They work with all area clinics and have a volunteer network system that is referred to as outreach or recruitment. On the state level, there are many partners such as American Cancer Society, the Governor's wife, Blue Cross Blue Shield, and the Avon Corporation. Custer Health, the umbrella organization, serves five counties in North Dakota and provides services via the Women's Way program. Women's Way has had great success with this program throughout the service area, but in particular in the Standing Rock Indian Reservation in Sioux County. Women's Way works with the Indian Health Services and Tribal Health throughout the reservation.

At Custer Health, there are approximately 60 hours per week of paid time divided among three staff people. An Avon grant pays for an additional part-time nurse (16 hours per week) on the Standing Rock Indian Reservation.

All Custer Health public health nurses work with the program enrolling women into the program at the community level. Their time is all donated to the program. Custer Health has approximately 75 volunteers in the Women's Way program serving the five county areas. Some volunteers may work four to six hours per month, and others may donate one to two hours per year.

The Women's Way program serves all women ages 18 through 64 who are either uninsured or underinsured and meet the financial guidelines for the program. The primary minority group in the state is American-Indian women, and this is the focus of the program. Women's Way pays for breast and cervical cancer screening for eligible women. Women's Way provides case management of women enrolled in the program to ensure that they receive appropriate and timely screening, which includes a diagnostic work up and treatment if needed. Women's Way also counsels women on screening guidelines for breast and cervical cancer. They educate women on breast and cervical health, including teaching women how to do a breast self-exam, assisting women with scheduling appointments for breast and cervical cancer screening, and serving as a community resource regarding breast and cervical cancer screening. The program works directly with clients by enrolling them into the Women's Way program and teaching them about screening guidelines and women's health issues. Women's Way then refers clients to their provider to schedule appointments for breast and cervical cancer screenings. The clients undergo follow-up and continue through the screening process, including assistance with scheduling diagnostic work if needed. The program promotes annual screening, contacting women annually to re-enroll if eligible and re-schedule appointments and screenings.

Making a Difference: Women's Way sets goals every year, based on the population of potentially eligible women. Their goal is to serve 10 percent of potentially eligible women within the service area and then measure the number of women served on a monthly basis. The data manager with the state health department for the Women's Way program provides each local public health unit with this information. Women's Way also tracks the number of women served locally. Currently, about 19 percent of eligible women are being reached by the program.

Beginnings: The Women's Way program started in North Dakota in 1993 at four pilot sites, with screening of women beginning in September 1997. Custer Health was not a pilot site and came into the program April 1997. Women's Way began enrolling women into the program November 1997. The program was fully implemented by spring of 1998, with enrollments occurring in all five counties in the service area. Currently, Women's Way serves 420 women in the service area. A total of 575 women have been in the program since its initiation in 1997.

Challenges and Solutions: Women's Way has encountered several challenges with the program. State and local Women's Way staff continuously work to sustain the program by networking with CDC at the national level, and health care providers and the community at the local level.

Due to the ruralness of the area, availability of mammogram screening is a significant barrier. There is no mobile mammography throughout southwest North Dakota, thus some women may not get a mammogram at all during the course of the year. Many women have no transportation to go 50 to 150 miles for a mammogram. Time off work may also prohibit them from going that distance for a mammogram.

This is especially true for the women of Standing Rock. With support from an Avon grant, transportation is arranged for women to travel from Fort Yates to Bismarck for mammography. This enables 170 women to have access to mammography who otherwise would not have had access to the service. This is certainly not enough for everyone, but it is a start. Women's Way is encouraging local providers to bring a mobile mammography unit into the area, which would increase access.

Trust in the program and staff working with the program is another challenge, especially for the women of Standing Rock. Women's Way has been working in the Standing Rock community for four years, and it is slowly seeing more women willing to come in to the local clinic for screening and inquire about the program. With the addition of the Sioux County nurse, the county in which the Standing Rock Indian Reservation is located, the Women's Way program continues to build trust among the community members.

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