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Native Sisters Help Native American Women Overcome Obstacles to Breast Cancer Screening

Research to improve breast cancer screening among urban American Indian women

SUMMARY

In 1995–1996, Linda Burhansstipanov, MSPH, DrPH, at AMC Cancer Research Center in Denver, Colo., implemented and evaluated the effectiveness of Native American Women's Wellness through Awareness (NAWWA).

NAWWA is a culturally competent recruitment model aimed at increasing the number of underserved urban American Indian women participating in an early detection breast cancer screening program. The target population, Native American women 40 years of age and older, lived in the Denver metropolitan area or in the greater Los Angeles/Orange County area.

Key Findings

- "High"-level recruitment strategies involving steps and elements specific to Native Americans were much more effective than the typical "culturally sensitive" strategies used by most government programs.
  - Not only did program participation more than double when high-level recruitment strategies were used, but there was a significant drop in the number of women who canceled their scheduled appointments, and an increase in the number of women who called with questions or dropped into the clinic.
  - When low-level strategies were used, the percentage of "no shows" was between 50 and 80 percent.
  - During high-level interventions, this figure dropped to less than 20 percent.
- Among the high-level strategies tested, the Native Sisters Program, a "navigator program," was the most effective. Unlike other programs that provide a health care "navigator" only once breast cancer is discovered, this project used the Native Sisters throughout the recruitment and screening process.

- Dissemination about the project has been widespread through presentations to over 10,000 people at various meetings and conferences, an article in *Cancer* (October 15, 1998), and varied press coverage.

Funding

The Robert Wood Johnson Foundation (RWJF) provided $197,850 in grant funding after the development and testing phases to support the implementation and evaluation of culturally appropriate "low"-level and "high"-level recruitment models for breast cancer screening.

THE PROBLEM

Native American women have the poorest survival from breast cancer of any racial or ethnic group in the United States. From 1975 to 1984, only 49.7 percent had five-year survival rates, compared to 75.7 percent for whites, 70.3 percent for Hispanics, and 62.8 percent for African Americans. This is of concern because relatively effective screening tests exist that could contribute to improved survival if appropriately used.

The two primary reasons for poor survival are the diagnosis of the disease at later stages and poor access to culturally acceptable early detection services (e.g., mammography screening) and treatment. Since September 1993, urban Native Americans who live in the Los Angeles area have had access to mobile mammography screening through the American Indian Center (AIC).

During the first nine months, however, a total of only 17 mammograms were provided to Native American women, yet the AIC had an average female patient load of approximately 15,600. When mobile vans were used in other sites within Los Angeles, they averaged 50+ mammograms a day.

Since the AIC was well utilized for other health problems, it appeared that the low screening rate was not due to the lack of a culturally acceptable setting, but rather to the lack of a culturally acceptable recruitment protocol and breast cancer materials.

The goal of the Native Women's Wellness through Awareness (NAWWA) project was to increase the number of urban Native American women who participate in early detection breast cancer screening programs by changing their behavior through the implementation of a culturally competent outreach intervention.

The strategy for accomplishing this goal was to test a variety of recruitment techniques to determine which were the most effective. NAWWA involved collaboration among the AMC Native American Program of Excellence and the Denver Indian Center (DIC), both in Denver, Colo., and the Center for Healthy Aging (CHA), formerly known as "Senior Health and Peer Counseling, Inc.," in Santa Monica, Calif.

The development and testing were funded by a number of foundations, including the Hearst Foundation, Kenneth Kendall King Foundation, Blue Cross/Blue Shield Foundation (Denver), and the national Susan G. Komen Breast Cancer Foundation. RWJF funded the implementation and evaluation.

During the development phase, the survey questionnaire was developed and focus groups were held. The survey of 107 urban Native Americans found that almost half (42 percent) were full-blooded Indians and another 38 percent were half-blood or more, contrary to popular assumptions that the vast majority of urban-dwelling Native Americans are less than a quarter blood.

The surveys and focus groups also indicated that the real barriers to participation were not poverty related, but rather were psycho-social and sociocultural.

- **Psycho-social barriers** are related to misinformation, fear, and distrust, topics rarely dealt with in surveys. Different belief systems—a cancer diagnosis means certain death; an American Indian cannot "walk the spirit path" if a body part (e.g., breast) is missing; mammograms are painful and cause death; cancer is hereditary; Indians do not get cancer; and "If I have it, nothing can be done about it"—also limit the number of people willing to participate in breast cancer screening. In the 217 known Native American languages, no word for cancer exists. Instead, it is called "the disease that eats the body" or "the disease that has no cure."
- **Psycho-cultural barriers** require patience, understanding, and respect. These tend to be culturally, as well as tribally, specific, and are rarely evident in quantitative data collected by surveys. For example, cancer educational materials do not refer to Native Americans; thus, cancer does not occur in Native Americans; Native Americans have immunity to cancer; Native Americans do not get cancer; when a person does get cancer, that person is being punished by the Creator; cancer is spread by white doctors; to discuss cancer actually invites evil spirits or death into one's own body or family.

Also, in the development phase, the groundwork was laid for implementing a "low"-level recruitment strategy that incorporated protocols that are typically implemented by local, state, and federal agencies when they attempt to increase the recruitment of underscreened women.

THE PROJECT

Implementation and Evaluation

The project's target population was Native American women 40 years of age and older living in the Denver metropolitan area and the greater Los Angeles/Orange County area. The low-level intervention was implemented and measured in both Denver and Los Angeles. The materials and dissemination methods were similar to those typically used

by state and federal agencies to recruit Native Americans into research, screening programs, and clinical trials.

The low-level intervention consisted of the basic necessities for breast cancer screening, including recruitment materials that presented logistical information about screening and incorporated Native American logos and clip art, culturally acceptable screening settings, such as the Denver Indian Center, generic informational materials, and promotion in Indian-specific newsletters and publications.

The low-level intervention was implemented in Denver from February 1995 through October 1995; and in Los Angeles from February 1995 through April 1996. The average number of Native American women screened throughout the low-level intervention in Denver was 3 women per month; in Los Angeles it was 2.3 women per month.

Next, a variety of "high"-level recruitment strategies were implemented and their effectiveness measured against each other and the low-level recruitment interventions. The high-level recruitment strategies included additional steps and cultural components that addressed poverty and psycho-social and sociocultural barriers identified by Indian women in the surveys and focus groups.

They included free transportation and child care; dissemination of cultural materials; using elder outreach workers to recruit women; referral-fee vouchers for participants who recruited other women; Native American Breast Cancer Traditional Circle gatherings; trained "Native Sisters" who acted as health care "navigators" throughout the recruitment and screening process, accompanying women to clinics for screenings and follow-up tests; appointment reminder cards and letters; and "outcalls" to recruit participants 40 and over.

The high-level intervention was introduced in Denver in October 1995. During the first six months of its implementation in Denver, the Los Angeles site continued to use low-level intervention to determine if other events could be responsible for an increase in screening behavior. The high-level intervention in Denver almost doubled the number of women who participated in screening, raising it from 3 to 5 per month.

The high-level intervention was introduced to the Los Angeles site in May 1996 and more than doubled the number of women who were screened each month, from 2.3 to 5.6. Also, an increasing number of women who had health insurance requested screening through NAWWA, which indicated that there was a cultural component of NAWWA that influenced screening behaviors and was not correlated with poverty.

There also was a significant drop in the number of women who canceled their scheduled appointments during the high-level intervention. During the low-level intervention, the percentage of no shows was between 50 and 80 percent. During the high-level

intervention, the figure dropped to less than 20 percent, and, in addition, the number of women who called with questions or dropped in continued to grow.

FINDINGS

- **Four high-level strategies proved most successful in increasing the rates of participation:**
  - The Native Sisters Program, which provided health care system "navigators".
  - Appointment reminder calls.
  - Culturally relevant informational and promotional materials.
  - Outcalls, where a pre-written telephone script was used for unsolicited telephone recruiting.
- **Among these strategies, Native Sisters was the most effective because having a health care "navigator" throughout the recruitment and screening process helped increase participation by establishing a level of trust.** However, lower-cost training of "Native Sisters" needs to be developed in light of a high turnover rate that was often due to unforeseen family demands.
- **Making these positions salaried rather than voluntary might help to stabilize them.**
- **The Recruitment Voucher System, which provided a $10 payment to participants for each woman they referred for screening, met with very little initial success.** It may be reintroduced to allow anybody in the community to receive $10 for referring a person for screening.

This project also has increased general awareness, interest, and involvement among the Native American community in Denver and Los Angeles regarding health care issues, including nutrition, prevention, and the different types of screening they should have throughout their lives.

Communications

Dissemination of material through book chapters, journal articles, press coverage, and presentations has been widespread, including articles in *Cancer, Cancer Practice,* the *Journal of Cancer Education,* and a number of NIH publications.

To date, the director of the AMC, Linda Burhansstipanov, and other AMC staff have addressed over 10,000 people at various meetings and conferences—50 percent were health care professionals and the other half lay people—including presentation of a paper during the *6th Biennial Symposium on Minorities, the Medically Underserved and Cancer* held in Washington, D.C., on April 27, 1997. (See the Bibliography.)

AFTERWARD

Dr. Burhansstipanov has left the AMC and is now with the Denver Indian Center. She would like to leverage her work by obtaining funding to develop training materials that would make it easier for other groups to develop similar recruitment programs for a whole range of health care issues.

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