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# American Indian Breast Cancer Project: Educational Development and Implementation

**FELICIA SCHANCHE HODGE AND JOHN CASKEN**

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## INTRODUCTION

The American Indian population faces many important health issues including cancer, injuries, diabetes, alcohol and substance abuse, violence, suicide, cardiovascular disease, and obesity. Cancer has become the second leading cause of death for Alaska Native women and is the third cause of death among American Indian women.<sup>1,2</sup> Due to a large Indian population residing in California,<sup>3</sup> and the fact that American Indian women have a high mortality and low survival rate in certain cancers,<sup>4</sup> California's American Indian population is an ideal target for cancer control efforts, particularly in the early detection and treatment of breast cancer.

Developing a breast cancer early detection and treatment education project for American Indians requires an understanding of American Indian illness beliefs, barriers to breast cancer screening, and the cultural constructs that inhibit or facilitate the utilization of screening protocols and treatment recommendations. This paper describes the steps taken in the development, implementation, and evaluation of the Pathways to Health project, a breast cancer education program targeting American Indian women in California.

## BACKGROUND

The Indian Health Service reports 309,238 American Indians living in California,<sup>5</sup> of which approximately 70,000 are women over the age of eighteen years. California boasts the largest concentration of American Indians in any state, according to the U.S. Census. Seventy percent live in major metropolitan areas, and the remaining 30 percent reside in rural counties on or

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near the state's eighty-five reservations. Health care services are limited despite the size of this population. Currently, no Indian inpatient facility exists in California. The small clinics are Indian-run and operated. The Indian Health Service (IHS) supplements these clinics by contracting for inpatient and specialized outpatient services. These services, however, are limited and have restricted eligibility requirements.

Cancer has recently become a major public health concern among American Indians.<sup>7</sup> Although breast cancer data specific to American Indians are difficult to obtain and interpret, current data suggest that the age-adjusted breast cancer incident rates are much lower among Indian women than among white women.<sup>6</sup> The Surveillance, Education, Evaluation Reports (SEER) data indicate that American Indians experience a cancer incidence rate for all sites which is half the rate of the white population (157.3 vs. 359.2).<sup>6</sup> Reported breast cancer mortality rates are also lower in this population. The age-adjusted breast cancer mortality for nine Indian Health Service Areas is 16.1 compared to the reported 26.7 rate for whites.<sup>4</sup> Considering the data available which indicate low breast cancer incidence and mortality rates, health care providers may conclude that breast cancer is not a problem among American Indian women. American Indian women may also conclude that they need not participate in breast cancer screening programs because breast cancer is not an "Indian problem."

These low incidence and mortality rates, however, may be misleading. First, there is no accurate database that reports cancer-related information for American Indians.<sup>4</sup> Second, studies have shown that current sources such as death certificates, Indian Health Service, and tumor registries have problems in racial misclassification and other reporting errors.<sup>4</sup> Third, there are increasing reports among Indian communities and Indian health clinics, and other trend data which indicate that breast cancer mortality rates are increasing.<sup>8</sup> Fourth, national data report that American Indian women have poorer survival rates from cancer of any racial group in the United States.<sup>9</sup> For all sites combined, American Indians experience a five-year survival rate of 35.2 percent, relative to 50.3 percent for whites. The disparity is even greater for breast cancer (49 percent relative to 76 percent in whites). This information supports the fact that breast cancer is a significant problem among Indian women and signals a need for the development of appropriate breast cancer control programs for American Indians.

## METHODS

The Center for American Indian Research and Education (CAIRE) supports research, evaluation, education, policy development, planning, prevention, and community service activities. CAIRE serves American Indians and Alaska Natives nationally. In 1994, CAIRE received a three-year training grant from the National Cancer Institute to develop, implement, and evaluate a culturally sensitive breast cancer educational program targeting American Indian women in California. The goals of the project were to: (1) increase breast cancer prevention knowledge among primary care physicians, other health professionals, and American Indian women; (2) increase breast cancer early detection knowledge among primary care physicians, other health profes-

sionals, and American Indian women; (3) increase breast cancer treatment knowledge among primary care physicians, other health professionals, and American Indian women; and (4) to disseminate up-to-date professionally known information about prevention, early detection, and treatment of breast cancer to primary care physicians, other health professionals, and American Indian women. This paper reports on the portion of the Pathways to Health project that targeted American Indian women.

Three major activities were undertaken to develop and implement the Pathways to Health project targeting American Indian women and breast cancer. First, a series of six focus groups were held in an endeavor to identify cultural illness beliefs, to identify barriers and facilitators to breast cancer screening, and to provide feedback on the project's educational materials. Second, breast cancer educational materials were developed in response to the identified barriers, risk factors, illness beliefs, and specific informational needs of the targeted group. And third, a series of breast cancer educational workshops were offered to American Indian and Alaska Native women residing in California. The information obtained from the focus groups served as a framework for the development of key culturally sensitive messages and educational approaches used in the educational materials and workshops to increase knowledge and change breast cancer screening behaviors.

### **Focus Groups**

To identify the cultural response and milieu of breast cancer, the barriers to care, and the cultural aspects and beliefs surrounding breast cancer, we met with six groups of American Indian women. A total of sixty-five women attended a focus group and provided input on breast cancer in their communities. They were selected according to the following criteria: American Indian women (self-reported); over the age of eighteen years; and residing in the target communities. Initial contacts for focus group participants were made at local health clinics, and respondents were asked to provide names of other individuals in the community who fit the study criteria. The focus groups were held in San Francisco (n=15), Oakland (n=18), Santa Rosa (n=9), Round Valley Reservation (n=8), Berkeley (n=5), and the Hupa Indian Reservation (n=10).

An American Indian focus group leader conducted the sessions, guided by broad topic categories. The focus group phase used anthropological field methodologies to identify and describe knowledge, attitudes, and behaviors related to breast cancer screening and health care. This phase provided a preliminary look at health care beliefs and behaviors. The group discussion revolved around the following questions:

1. How important do you think breast cancer is in your community?  
Is it a problem among Indian women?
2. What are the barriers/facilitators to breast cancer screening (self breast exam, physician's exam, mammography)?
3. What are the cultural aspects surrounding breast cancer in terms of taboos and prohibitions?

4. What beliefs do you hold about breast cancer, your risk, surgery, treatment, etc.?

The focus group sessions were held at local Indian agency facilities, in a setting that was familiar and comfortable to the participating women. The sessions were coordinated and facilitated by a trained American Indian member of the community. Indian women over the age of eighteen years were invited by word of mouth to attend the focus group meeting. Flyers were also distributed in each of the four communities. An attempt was made to hold the sessions on a weekend or during evening hours to alleviate time barriers and to increase attendance. Food and drinks were offered to participants, as is the custom in many American Indian meetings. The meeting minutes were not tape recorded in compliance with participant request. Project staff recorded the focus group minutes by hand. The sessions lasted one to one and a half hours in length. The meeting minutes were transcribed and the data were analyzed.

Later in the year, the second round of focus groups took place. Approximately half of the original focus groups participated, responding to the educational materials provided in terms of: (a) media preferences, (b) communication styles, (c) presentation of materials, (d) literacy levels, and (e) cultural acceptability. The materials were assessed for their cultural acceptability, relevance and message appeal, level of comprehension, accuracy of information, and degree of credibility with the target population.

Information gathered from focus group meetings also assisted in the development of the workshop curriculum and the cultural approach used in the workshop. The curriculum included sessions on: (a) breast cancer risk factors, (b) breast cancer screening techniques, (c) breast cancer treatment and treatment options, (d) patient rights and second opinions, (e) communication techniques, and (f) cultural differences and strengths.

Information from these focus groups was also used to develop a survey instrument which was administered to 352 adult American Indian women at four sites. The pre-test questionnaire was administered when workshop participants arrived at the beginning of the workshop, and the post-test was administered at the end of the workshop.

## FOCUS GROUP RESULTS

The findings from the focus group interviews identified the following areas to be considered in developing and implementing educational and training programs:

### **Belief in Breast Cancer Risk**

The American Indian women participating in the focus groups did not feel that breast cancer was of particular significance in their communities, and, therefore, prevention and treatment were somewhat useless. Although several had friends and relatives who either had been diagnosed with breast cancer or had died of breast cancer, as a whole the group members felt they were at low risk of breast cancer. Indeed, many considered other problems such as

poverty, alcoholism, and diabetes of greater significance. Several women noted that since there were so many problems to confront in the American Indian community, breast cancer was lower on the scale of everyday concerns. The belief that breast cancer did not occur frequently and that other problems warranted greater concern is troublesome, as it supports the low cancer screening rates evident in this population.<sup>10</sup>

### **Barriers to Cancer Screening and Treatment**

The focus group results highlighted numerous barriers that interfere with cancer screening and treatment efforts. These barriers include, but are not limited to, culturally inappropriate recruitment protocols, lack of culturally appropriate cancer-prevention and control materials, inaccessible science and research educational training opportunities, language and communication problems, poverty, transportation, cancer causation beliefs, lack of Native health providers, and unavailability of health facilities. The types and impact levels of such barriers vary among Native communities in different regions of the state and country.

Cultural barriers, specifically, contribute to underutilization of medical care. Modesty, taboos, and traditional healing practices are important elements of the cultural belief system among urban and rural Indians. Beliefs about modern medical procedures, such as radiation, for detecting and treating cancer may be barriers. The female patient may also be offended by what she might consider to be an abrupt or impersonal manner. Being treated with respect and courtesy by health care staff was identified as an important feature to successful health care practice. This included the provider taking the time to explain procedures and not rush patients in and out of the office.

Many Indian women were frightened by the treatment for breast cancer. Fear of surgery and of radiation and chemotherapy were identified. Although there were significant fears identified with dying, fears of its repercussions were also voiced, as responsibility for surviving children and other families members were of concern. To many, a diagnosis of cancer was a diagnosis of death that would produce an overwhelming financial hardship and distress within the immediate and extended family.

Several women stated, and many agreed, that cancer was not talked about in their families. When their grandmothers, mothers, or other relatives died of cancer, it was never discussed. Cancer was not openly talked about as a disease, and its treatment, or the long-term effect of the disease, was not acknowledged.

### **Culturally Sensitive Issues**

American Indians live in a bicultural world combining both indigenous and Eurocentric cultural patterns. These cultural characteristics and differences are important in understanding the influences that affect their interaction with the health care delivery system. To many American Indians health care means more than dealing with illness and pain; it reflects the basic worldview and cultural values of the group, which in turn influences health and illness behavior. It is believed that healing takes place not only in the body but also

spiritually and that it includes the family and community. These cultural characteristics also affect the acceptance of preventative medicine particularly with respect to breast cancer screening, and are important factors in designing an intervention that is acceptable to the American Indian population.

Family and community are of high importance for many American Indian women and family needs take precedence. Only after the children's and family's needs are met will women tend to their own health care needs, especially in regard to health screening exams. Time orientation also is different, with the focus on the present rather than the future. It is said that it is important to take care of today as tomorrow may never come. However, this does not mean that they do not value prevention or the important role it plays in keeping healthy. Rather it is necessary to explain the impact that actions taken today have on the health of individuals and families in the future. Health care workers need to recognize the American Indian's orientation to the present and to short-term goals. This orientation makes screening more difficult. Modesty and the value of privacy is important, particularly with discussing breast-self exams and the actual breast examination. It is important that the procedures be explained beforehand and that care is taken to keep the patient draped as much as possible. The examiner should try not to expose both of the patient's breasts at the same time. Additionally, female health care workers should always be present during a breast examination by a male practitioner. Most important, American Indian patients should feel that they are treated with care and courtesy and that their traditional beliefs are accepted and valued.

### **American Indian Illness Beliefs**

It is important to note that many tribes do not hold the same beliefs about health and illness. Most health beliefs are, however, closely linked to the tribe's religious beliefs. American Indians embrace a much more holistic approach to health than do most Euramericans. Health is considered not only a physical but a spiritual state; a person is made up of body, mind, and spirit. Wellness is the harmony of these three components, whereas sickness is caused by disharmony and a state of imbalance. The following figure illustrates the cultural values held by many American Indians:

**Figure 1.**  
**American Indian Cultural Values for Developing a  
Breast Cancer Screening Program**

- Health beliefs linked to cultural values of religion and spirituality.
- Modesty, taboos, and illness beliefs linked to tribal beliefs.
- The importance of family and community.
- The importance of women and their role in caring for the family.
- Time orientation to the present.
- The value of health for the well-being of the tribe and community.

## DEVELOPMENT OF EDUCATIONAL MATERIALS

The focus groups described above provided important information for designing the Pathways to Health breast cancer education materials and for implementing the breast cancer screening workshops. First, the focus group findings identified a common theme: the importance of family and of health to the American Indian women in regard to the role they played as providers and caretakers for their immediate and extended families. Second, the focus group results pointed to a pessimistic view toward cancer, with early detection not seen as meaningful since it was felt that little could be done to prevent or treat the disease. It also showed that Indian women responded well to programs that included health workers from their own communities and clinics. Thus, the Pathways to Health materials emphasized how early detection techniques were important in saving lives and keeping families together. All Pathways to Health material included Indian designs and information specific to the Indian women, such as how to improve communication with their health care providers and how to involve the family in the prevention and treatment of breast cancer. Furthermore, all Pathways to Health workshops included panel members and workshop assistants who were members of the targeted community, and the workshops were held at American Indian community sites.

The Pathways to Health project produced three educational products for American Indian women at risk of breast cancer: a video, a treatment manual, and a resource guide. The following provides information on the development and production of these three products.

### **Pathways to Health Video**

The focus group interviews identified a preference for visual educational materials as opposed to written pamphlets or booklets. The production of the Pathways to Health video took two major steps. First was the planning stage, during which the actors and participants were identified, the video theme and messages were selected, and the story board was created. It was important that credible American Indian actors participate in the video, and so we recruited Indian women who had breast cancer, who had experience with a relative's breast cancer, who had a high personal risk for getting breast cancer, or who had experienced a breast biopsy or other breast cancer screening or treatment protocol to provide testimonials. Additionally, we identified an American Indian leader to assume the "talking head" role, delivering the much needed information and message regarding breast cancer screening to the women. Our video message encompassed the importance of screening, of Indian women in their role of caretaker and homemaker, and of health care. "Survival techniques" included tips on communication with providers, obtaining needed support, record keeping, and obtaining second opinions.

The testimonials heard from local Indian women recalling their experience with screening, their relative's experience with breast cancer, and the cultural milieu and barriers to care supported the video's theme of the importance of Indian women and their role in their community and family. Upon



completion of the fifteen-minute video, the contents were reviewed by focus group members to consider the cultural acceptability, level of comprehension, length, and degree of credibility with the target population.

### **Pathways to Health “American Indian Women’s Breast Cancer Guide”**

The Pathways to Health “American Indian Women’s Breast Cancer Guide” provides information to the American Indian women on breast cancer risk and treatment, the patient-physician relationship, patient rights, Indian Health Service health care, services, alternative resources, and breast cancer information resources such as cancer support organizations, insurance information, physician data query programs, and recommended readings. The appendices contained the names and addresses of California’s health and welfare agencies, references, glossary, and acronyms.

The guide is printed in an attractive booklet format with American Indian artwork strategically placed throughout. The authors were careful to maintain a sixth- to ninth-grade reading level (not taking into account medical terminology). A glossary of terms and a description of acronyms appear at the end of the booklet. Each chapter is outlined at its beginning in bold letters and bulleted sentences. The summary at each chapter’s beginning is shaded in a light beige color to highlight the points.

### **Pathways to Health Resource Guide**

The Pathways to Health Resource Guide assists American Indian women with breast cancer or at risk of breast cancer and their families to identify treatment centers, Indian health care clinics, screening centers, social service agencies, hospitals, and other resources such as the National Cancer Institute and various websites. The resource guide is divided into three sections for easier review: the first section highlights Northern California counties north of San Francisco; the second section covers the central portion of the state and lists the resources by those counties found between San Francisco and Los Angeles; and the third section contains information by counties for Southern California.

The focus groups were again valuable in their review of the educational materials in terms of media preferences, communication styles and patterns of speech, and the presentation of materials in terms of font size, artwork, and readability. Literacy levels were maintained at a sixth- to ninth-grade level, and cultural acceptability of the materials was assessed. In summary, the educational materials developed were pilot-tested to ascertain their cultural acceptability, relevance, message appeal, level of comprehension, accuracy of information, and degree of credibility with the target population.

### **Pathways to Health Workshop Curriculum**

In the second year of the project, American Indian women residing at two urban and two reservation settings were invited to participate in one of four

breast cancer educational workshops offered by the Center for American Indian Research and Education (CAIRE). Formal one-day workshop sessions curriculum included information on the following:

**Breast cancer risk factors:** Information was provided on the risk American Indian and Alaska women face with regard to breast cancer. Current literature was presented, and panel members discussed issues regarding perceived low risk, obtaining adequate information on breast cancer, and ways to keep women and their families healthy through appropriate screening.

**Breast cancer screening techniques:** The hows and whys of breast cancer screening techniques were presented. Topics surrounding radiation, the safety of the screening techniques, and the importance of screening were presented.

**Communicating with providers:** The patient-provider relationship was presented in terms of the responsibility of patients to present information to the provider about their health and to listen carefully and to follow prescribed medical protocols. The responsibility of the provider was to listen carefully to the patient and to identify and treat the ailments of the patient. Memory techniques, such as taking notes or taping conversations, and support aids, such as involving the family in major decisions and having a friend or family member accompany the patient to the office visit, were discussed.

**Treatment options and second opinions:** The various treatment options—from biopsies to modified and radical mastectomies were discussed. The relationship to the stage of cancer diagnosed and the treatment option recommended was highlighted. In addition, workshop participants were encouraged to consider obtaining a second opinion on their cancer diagnosis and treatment plan. How to get a second opinion, what to say to the physician, how to find an appropriate physician for a second opinion, and how to assess the recommendations were reviewed.

**Patient rights:** That patients have well-defined rights in the medical arena was new information to many of the workshop participants. Delineating exactly what patients have a right to expect, such as access to their records and a right to informed consent, was presented.

The Pathways to Health video for American Indian women was presented at each of the workshops along with the printed resource booklet and patient's guide. Sufficient educational materials were mailed to each Indian health care clinic in the state for further dissemination.

Three hundred and fifty-two American Indian women residing at four targeted sites participated in the Pathways to Health workshops. Participation was limited to American Indian and Alaska Native women between the ages of eighteen and eighty. The workshops were held in various locations: at tribal facilities, Indian agency conference rooms, and at a local hotel meeting

room. The Pathways to Health workshops highlighted American Indian professional panel members. The project was staffed with American Indian trainers and workshop assistants who were members of the targeted community. In addition, the workshops were held at American Indian community sites identified as acceptable sites for the target population.

Pre- and post-test questionnaires administered at the beginning and at the end of the workshop aided in the evaluation phase. The participating women were asked to evaluate the workshop in terms of logistics, information provided, and strengths and weaknesses of the presenters or speakers. The results of the evaluation were favorable and are reported in a separate publication.

### DISCUSSION

Few health education materials exist for American Indian populations, and there is a dearth of breast cancer materials designed specifically to promote early detection screening and treatment for breast cancer among American Indians. For this reason, cultural adaptation and cultural sensitivity were major goals in the development of the Pathways to Health project educational materials. These materials—a video, a resource directory, and a patient breast cancer treatment guide—were designed specifically for American Indian women. Additional educational materials included a video and a booklet for providers at American Indian health care clinics on improving communication with American Indian women at risk or with breast cancer and a booklet designed as a breast cancer treatment manual and a resource guide. These provider materials were disseminated separately to the Indian health care clinics in California.

Findings from the focus group interviews identified significant educational constructs important in designing and implementing instructional workshops in the American Indian community. These educational constructs include the importance of the American Indian family, orientation to the present and to short-term goals, modesty and the value of privacy, and cultural illness beliefs.

Developing and presenting educational materials and implementing educational workshops designed to heighten awareness of breast cancer and to increase breast cancer screening compliance require an understanding of the target populations' illness beliefs, environmental milieu, and barriers to screening. Providing culturally appropriate educational materials heightens the acceptance of the materials and encourages the adoption of these materials.

The breast cancer educational program developed and implemented by CAIRE designed the Pathways to Health program based on the findings from the focus groups. The Pathways to Health project differs from other breast cancer programs by using this information as a framework for material development, therefore increasing the likelihood of meeting the needs of and acceptance among American Indian women. The material also provides general knowledge about breast cancer. Educational material focused on the

importance of family and cultural illness beliefs to encourage participation and compliance in screening, treatment, and follow-up. The project also provided women with tools to work within the current health care delivery system as well as skills to improve communication with health care providers. The results from our pre and post-test demonstrate that we reached our immediate goals.<sup>10</sup> Further long-term follow-up is necessary to see whether the information the program presented has significantly changed future behavior.

## NOTES

1. Department of Health and Human Services, PHS, Indian Health Service, *IHS Trends* (Washington, DC: Government Printing Office, 1992), 34.
2. S. Valway, M. Kileen, R. Paisano, E. Ortise, *Cancer Mortality among Native Americans in the United States: Regional Differences in Indian Health, 1984–88 and Trends Over Time* (Rockville, MD: Indian Health Service, 1992).
3. Felicia Schanche Hodge, *American Indian Health, The California Endowment* (Los Angeles, California, 1997).
4. L. Burhansstipanov and C.M. Dresser, *Documentation of the Cancer Research Needs of American Indians and Alaska Natives*, NIH Publication No. 94-3603 (Bethesda, MD: National Cancer Institute, 1994).
5. “California Area Profile FY 94/95,” Indian Health Service, PHS, Office of Planning, Evaluation and Information Resources Management.
6. B. A. Miller, L. N. Kolonel, L. Bernstein, J. L. Young, Jr., G. M. Swanson, D. West, C. R. Key, J. M. Liff, C. S. Glover, G. A. Alexander, et al., eds., *Racial/Ethnic Patterns of Cancer in the United States 1988–1992*, NIH Pub. No. 96-4101 (Bethesda, MD: National Cancer Institute, 1996).
7. A. M. Michalek, M. C. Mahoney, “Cancer in Native Populations—Lessons to Be Learned,” *Journal of Cancer Education* 5 (1990): 243–249.
8. Angela Harras, ed., *Cancer Rates and Risk*, 4th ed., National Institutes of Health, National Cancer Institute, Cancer Statistics Branch, Division of Cancer Prevention and Control (1996), 36.
9. Department of Health and Human Services, PHS, NIH, NCI, *Report of the Special Action Committee, 1992: Program Initiatives Related to Minorities, the Underserved and Persons Aged 65 and Over* (Washington, DC: Government Printing Office, 1992).
10. Felicia Hodge, “Evaluation of a Breast Cancer Educational Project for American Indian Women in California” (in progress, 1999).