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Breast Cancer–Screening Behavior among Rural California American Indian Women

FELICIA SCHANCHE HODGE

INTRODUCTION

Cancer is a significant problem in American Indian populations nationwide. Recent studies indicate that cancer incidences, mortality, and survival rates vary according to geographic location and tribe.¹ The Indian Health Service (IHS) reports the cancer incidence rate as 7.8 percent for all IHS areas with a range of 14.5 percent for the IHS Aberdeen area, 13.2 percent in the IHS Billings area, and a low of 5.8 percent in the IHS Portland area.² The risk for certain cancers, such as cervical cancer, is almost three times greater for American Indian women than for the white population. Although breast cancer rates appear somewhat low, other cancers such as cervical, prostate, colon, and rectal cancers are high.³ Furthermore, American Indians found to have suspicious symptoms are less likely to receive follow-up care, thus increasing their cancer mortality risk.⁴

Less frequent use of prevention measures, such as cancer screenings, are reported among American Indians.⁵ Cultural and socioeconomic barriers to cancer screening call for special research attention. Although American Indians experience many of the same barriers to early cancer detection as other populations, such as lack of knowledge regarding the need for cancer screening and treatment methods, the cost of medical care, and lack of transportation and patient advocacy, these problems are compounded by the fact that cancer is a relatively “new” illness among American Indians. Fifty years ago, Indian mortality was often the result of acute illnesses such as tuberculosis, measles, and smallpox. Thus, many Indians did not live long enough to develop cancer. This trend, however, is changing. A rise in cancer incidence among American Indians is expected because their life expectancy

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has steadily increased during the past twenty years.⁶ Today, Indians are dying from chronic health illnesses, such as cancers, which can be readily diagnosed and treated with appropriate and timely screening.

Noncompliance with recommended health care procedures or prevention measures has generated interest among researchers. Screening programs, such as those for breast cancer, are recommended for specific segments of the population. These screening programs are often available without charge to American Indian populations through the IHS or tribal clinics. The inability of individuals to take advantage of these screenings requires further investigation in order to respond to these cancer-screening barriers.

Nationally, American Indian women have the lowest self-reported rate of mammograms (45%) of all ethnic groups reported in 2002.⁷ The "Women's Health USA 2002" report indicates that mammography screening rates for US white women (68%) are higher than for California Indian women (56%).⁸ Mortality from breast cancer could be reduced by more than 30 percent in American Indian women if current recommendations for screening were followed.

This study examines the breast cancer–screening patterns of American Indian women using clinical breast exams (visual and manual examination by a physician) and mammography.

BACKGROUND

The Wellness Circles Project, a five-year research study funded by the National Institute of Nursing Research from 1997 to 2003, was developed and implemented among California rural populations. The overall aim was to evaluate a culturally appropriate community-based health care model for American Indian families. The study examined the health and wellness aspects of adult American Indians and tested a wellness intervention to improve the lifestyles of the communities. The Behavioral Risk Factor Surveillance System (BRFSS), a national survey instrument, was employed as the assessment tool used to collect data on health status, health knowledge levels, high-risk behaviors, and demographics. The BRFSS is an ongoing random-digit-dialed telephone survey used to determine the prevalence of behaviors and practices (such as cancer screenings) among adults eighteen and older. The questionnaire is standardized and used across participating states in the United States. Many questions used in the survey have been obtained from national surveys, such as the National Health Interview Surveys and the Nutrition Examination Surveys. Our project selected a majority (23 out of 30) of the screening questions from the 1998 BRFSS; however, in-person administration of the survey was employed among the study's subjects.

According to the US Bureau of the Census, 333,000 American Indians live in California, the largest concentration of American Indians in the United States.⁹ The census reports 107 federally recognized tribes and 95 federal Indian reservations (as well as 40 unrecognized tribes in the state). Despite this large population, American Indians living in California are among the most medically underserved populations in the entire nation.¹⁰ The Indian population that resides on or near the reservations/rancherias often obtains

its medical care at one of the twenty-three rural Indian health clinics, as well as from local non-Indian health centers and hospitals.

METHODS

Approximately 110,000 American Indians live in areas served by rural Indian health clinics in California.¹¹ Thus, rural Indian clinics were selected as a focal point to identify and access the population in this study. The principal investigator of the research project approached thirteen Indian health clinic sites on or near rural reservations/rancherias, and a presentation was given to the respective tribal council and/or health committees. Resolutions of support and letters of agreement to participate in the study were obtained from all thirteen sites. The criteria for inclusion in the study were: American Indian, eighteen years of age and older, Indian clinic user, and resident of the targeted rural site in California.

The sampling frame was constructed from lists of adult American Indian patients provided by the clinic administrator at the targeted rural sites selected. Each clinic was asked to provide a list of adult American Indian clients during the past five years. A random sample list was constructed, and the name, address, and telephone number of the selected individuals were identified so that the research team could contact the household to make home or clinic visits in order to administer the survey to the heads of households and to adult household members who were present at that time.

The stratified probability sample of households, obtained from the thirteen sites, had a sampling rate of 2 percent, assuming an average household size of four. Seven percent of households refused or were not able to participate. Replacement samples were drawn to replace households unwilling or unable to participate. The sites served as strata while the households were the clusters. The BRFSS was used in a structured approach.¹² Households were identified by the sampling protocol and were contacted by mail, telephone, and site visits in attempts to conduct the survey. A trained American Indian interviewer administered the survey in person with the head of household members. This took place in the homes or at the clinic meeting room, depending upon which site was more comfortable to the participant. Following that initial interview, all adult (age 18 years and over) American Indian family members living in the participating household were interviewed. At each household, the head of the household was identified and surveyed. Each household member that fit the study protocol eligibility was identified and administered the survey. Project researchers and staff were trained for security protocols and confidentiality assurance. Participants were provided a written summary of the study, and the protocol was verbally read to each participant. Each participant, following protection of human subjects protocol, signed written consents. Incentives were provided in the form of t-shirts and cups. The University of California at Berkeley, University of Minnesota, and the IHS Institutional Review Boards reviewed and approved the study protocols. Associated tribal letters of support and approvals were obtained from each participating tribe.

DATA ANALYSIS

Data from the needs-assessment survey were entered into a computerized database and verified. The database was analyzed using statistical frequencies and chi-square tests to measure significance. Cancer-screening variables were analyzed by utilizing frequencies and cross tabs. The statistical program SPSS data analysis package provided the software for the analysis. A subsample consisting of American Indian women over the age of eighteen years was selected from the needs-assessment survey for a subset analysis. Variables examined included demographics, clinical breast exam, and mammography.

FINDINGS

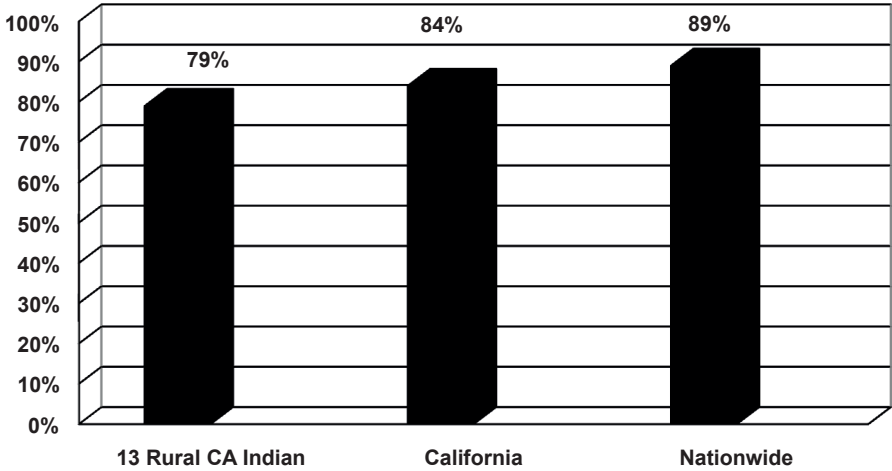
A total of 459 adult American Indians at the thirteen sites were interviewed in the original survey, and of these a cohort of 323 women became the subsample for data analysis and reporting for this manuscript. The average age of all female participants was thirty-seven years; average annual income was \$24,468. Eighty-seven percent reported being enrolled (or officially recorded as a member) in a tribe, and only 8.5 percent had an Indian blood quantum (percentage of Indian blood) of at least 25 percent; 41.3 percent had 50 to 75 percent; and 23.3 percent had 75 to 100 percent. Thirty-five percent were married or living with a partner (17.4%); 22.8 percent were single; 12.2 percent were divorced; 7.9 percent were widowed; and 4.7 percent were separated.

BREAST CANCER SCREENING

The two breast cancer–screening procedures analyzed in this study were clinical breast exams (visual and manual examination by a physician) and mammography (a low-dose X-ray test). Clinical breast exams are generally conducted on women aged eighteen or older during the annual physical. California Indian women reported less breast cancer–screening behaviors than women in the general population. Our study found that only 79 percent of California Indian women aged eighteen years and older reported ever having had a clinical breast exam. This was significantly less ($p = .001$) than the screening behavior reported by the Centers for Disease Control for the US population of women (89%) and the state of California women (84%) (see table 1).¹²

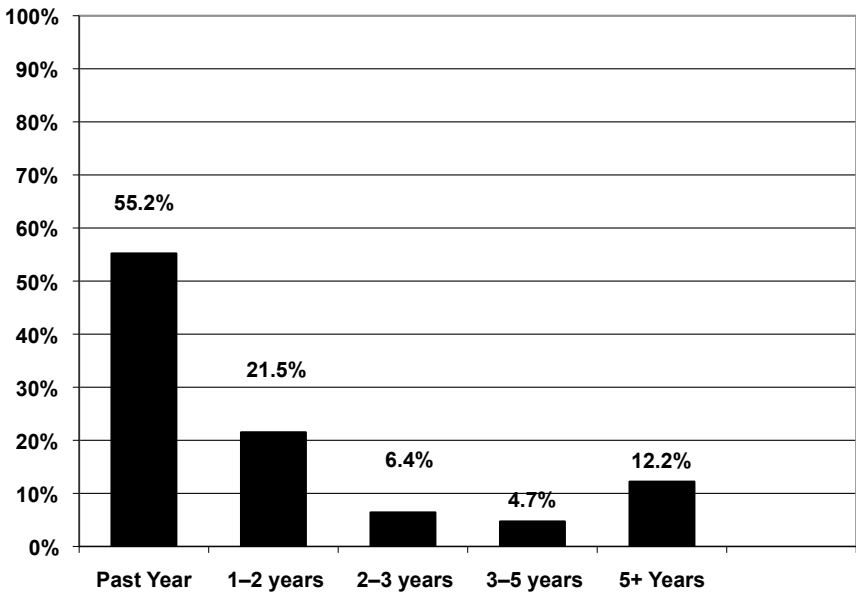
Screening protocols call for annual mammograms for women aged forty and older. We asked American Indian women (over the age of 40) if they had ever had a mammogram. Only 29.1 percent ($n = 94$) of the eligible sample had followed the recommended screening for annual mammograms. One hundred and eighty women (56%) reported having at least one mammogram in their whole lifetime. Of these women, 55.2 percent reported having the test within the past year; 21.5 percent had one in the last one to two years; 6.4 percent in the last two to three years; 4.7 percent in the last three to five years; and 12.2 percent had a mammogram screening more than five years ago (see table 2). These findings indicate low screening behaviors and poor survival risk.

Table 1
Percent Clinical Breast Exam by Study Group and by California and Nationwide Sites for Women Aged 18 Years and Older



Source: Rural CA Indian data was derived from a research project supported by the National Institute of Nursing Research R01 NR04528; California and nationwide data on clinical breast exam rates was derived from the Centers for Disease Control and Prevention (<http://CDC.gov>).

Table 2
Reported Last Mammogram by Percent California American Indian Women Who Ever Had a Mammogram Aged 40+ (n = 180)



Source: Data derived from a research project supported by the National Institute of Nursing Research R01 NR04528.

Studies have found that mortality from breast cancer could be reduced if current recommendations for annual breast cancer screenings were followed.¹³ Unfortunately, cancer-screening behaviors have been shown in this study to be poor—12.2 percent of California Indian women reported delaying their mammography for five years or more. This places these women at risk for breast cancer mortality and poor survival, as early diagnosis is a must for good survival outcomes.

SUMMARY

A community-based Wellness Circles Program was designed and implemented at thirteen sites in California. Data obtained from the BRFSS that was administered to a subset of women demonstrate that American Indian women continue to underutilize breast cancer-screening procedures. American Indian breast cancer-screening rates were compared to national and state general populations. On all measures, screening procedures among the study population were found to be below that reported by the state of California and national BRFSS data reports and the Healthy People 2010 objectives.¹⁴

Despite the availability of many cancer-screening tests, a significant number of American Indian women do not follow recommended screenings. Barriers to participation are complex and often involve cultural values and beliefs.¹⁵ Even when, for example, mammography appointments have been scheduled, many Indian women fail to keep them, and the noncompliance rate among American Indian women is particularly high.¹⁶

The concept of “deferred care” may provide an explanatory reason for noncompliant behavior in breast cancer screenings. California American Indian women reported delaying their mammography for five years or more, which can be described as deferred care. Discussion of “putting up with and enduring” is suggested as a possible reason for late screening or noncompliance with recommended screening. This behavior may be a significant cause for reported failure to obtain cancer screening and deserves further attention.

Cancer screening is an important behavior that health educators and health care providers seek to reinforce. Many groups, including American Indians, fail to participate sufficiently in prevention screening activities. To improve this situation, the design and implementation of cultural and multi-generational educational materials are recommended. In short, culturally appropriate cancer education is needed to improve screening participation among this special population.¹⁷ The need for improved screening rates and the need to address barriers to screening among rural Indian groups are essential if cancer is to be prevented and controlled in these groups. The failure of many ethnic groups to adhere to recommended screening is of concern to health educators and providers. In American Indian populations, culturally appropriate social support interventions may be particularly effective in promoting cancer screening and thus in reducing cancer mortality.¹⁸ The sense of “putting up with and enduring”—generated from role expectations and placing oneself as less of a priority—creates barriers that further

repress cancer screening. We must address this sense of deferred care directly and seek to alter its logic in future cancer-screening programs. To move from the cultural concept of deferred care to the contemporary concept of “self-responsibility” is a necessary step.

The literature on health-seeking behaviors describes the route or pathways to obtaining care through advocates, self-help, or education. This literature, however, does not recognize the concept of deferred care. Doing without and delaying or deferring preventative screening in the belief that family or community members are more important, and that their needs take precedence over one’s own personal health needs, can lead to serious health conditions. Family roles and responsibilities, barriers, or priorities, as determined by cultural and economic conditions, can lead Indian women and men to forgo their health screenings—resulting in the burden of illness.

NOTES

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