



NATIVE AMERICAN COMMUNITY-BASED CANCER PROJECTS: THEORY VERSUS REALITY

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Introduction

Promotions of health care initiatives, including cancer care, require attention to culture and literacy. This article focuses on three elements of effective health care that are pertinent to Native American communities: (1) the resistance of Native American communities to participate in studies that can be beneficial, (2) the challenges and benefits of community-based and community-driven interventions, and (3) generalizability issues of "successful" interventions.

Although the concepts presented in this report are relevant to many medically underserved communities, the examples are drawn from the Native American cultures. In this report, "Native American" includes American Indians, Alaska Natives, and Native Hawaiians. "Cultural" terminology is briefly summarized in Table 1.

Scientific Questions

Many Native American communities resist participation in cancer research interventions and studies, for several reasons. Often,

these reasons take the form of questions that cannot be answered by communities or scientists without more specific information on how cancer is affecting the Native American communities. For example, is a protective genetic condition or behavioral practice helping to reduce cancer prevalence in many Native American communities? Why did our ancestors rarely experience cancer? Was this due to their healthier lifestyles that included more fiber and less fat in the daily diet and more daily vigorous exercise? Was this due to a shorter life expectancy (although members of certain tribes, such as those in the Northwest, lived to be over 100 years of age)? Or was this lower incidence more a reflection of poor or inconsistent record keeping or documentation than a true insusceptibility?

Why is cancer incidence now increasing among almost all Native American communities? Why is cervical cancer now more prevalent among American Indians and Alaska Natives than among women from other racial groups? Why is cervical cancer more aggressive in Southwestern Indian women compared with other women living in

Table 1. — Selected Cultural Terms

Term	Definition
Sensitive	Respectful of the specific culture's beliefs, practices, etc
Relevant	Specifically targeted to a definite culture
Appropriate	Respectful, relevant to specific culture and literacy issues
Acceptable	Not appropriate but, due to some factor, can be used/implemented within the targeted community
Competent	Culturally sensitive, relevant, appropriate, acceptable concepts

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the Southwest who have more cervical cancer risk factors than the Indian women?¹ Is breast cancer typically diagnosed in Native women over 50 years of age, as is documented for women of other races, or are our women younger at the age of diagnosis?²

We do not know why Indian men and women diagnosed with cancer at a specific stage have poorer survival than do people of other races who are diagnosed at the same cancer stage.³ Is the poorer survival experienced by Indians due to lack of access to screening and state-of-the-art treatment?⁴ Can increased participation by Native American cancer patients in National Cancer Institute clinical trials improve our cancer survivorship?⁵ Is poorer cancer survivorship among Native people due to another biological reaction to cancer treatment (eg, dosage, frequency, duration, or choice of medication) that needs to be altered to best adapt to the biochemical makeup of American Indians?

While information about colon cancer among selected Southwestern clans is limited,^{6,9} almost no data are available regarding patterns of colon cancer in American Indians living outside of the Southwestern region. We know that gallbladder cancer is more common in Native Americans than in other racial groups, but we do not know why.¹⁰ Likewise, why are incidence rates for stomach cancer so variable among Alaska Natives, Northern Plains tribes, coastal tribes, and Southwestern tribes?¹¹ Are our salting or smoking storage practices affecting our

risk of developing stomach cancer? Why do so few of our children survive childhood cancers compared with children from other racial groups?¹² Are the types of childhood cancers different among tribal nations (eg, childhood leukemia in Southwestern tribes vs pediatric brain tumors in Montana tribes)? Why is lymphoma increasing among Native Americans?¹³ These questions will be answered only by participating in trials and studies.

Cultural Sensitivity

When developing and implementing survey instruments, researchers need to recognize that some survey items will never be "culturally sensitive." For example, common survey items to be included among all four of the National Cancer Institute Native American cervical cancer research interventions were reviewed by focus groups, by Native American advisory groups, and by individual Native American communities. Certain survey items (eg, information about the most recent Pap smear and pelvic examination) were not considered "culturally sensitive" because they violated the cultural norms of modesty. However, when the survey interview protocol was modified (eg, a gentle, well-trained interviewer would administer the survey in a quiet, personal manner), those same items were acceptable to the participants, and thus the interviewers could collect accurate information. "Culturally acceptable" means that the project will not be offensive to the participant and will result in fewer withdrawals from the study.

Community Resistance to Participation in Cancer Programs

Selected issues must be addressed in order to increase the likelihood of developing and implementing culturally competent interventions in Native American communities. Many of the same issues are relevant to other cultures, but the interventions to address those issues must be competent for the specific and intended population. Typically, medically underserved communities are poor communities in need of health care services. Program directors, educators, or researchers sometimes assume that if a program is offered, community members will quickly take advantage of the new facilities or services, but this rarely occurs. Table 2 summarizes several reasons for resistance to participating in studies and projects.

There are valid reasons for resistance. For example, in the early 1990s, two HIV/AIDS cases in an Alaska Native village were reported to a government official. The official's report included characteristics of the two patients and the fact that both had attended a conference in Seattle. Unknowingly, that description alerted members of the community about the identity of the infected individuals. This report inadvertently violated the confidentiality of the patients, who were ostracized by members of the village. Once the publication was released, the village was harassed by researchers and members of the media who wanted to learn more about the HIV epidemic. The Tribal Governing Council of the village

changed the name of the village to make it more difficult for “outsiders” to find it.

Another example from the last decade involves the Hanta virus outbreak throughout the Southwest. The virus was reported by news media and by scientists at the Centers for Disease Control and Prevention (CDC) as “the Navajo virus,” which led to a massive influx of reporters and CDC scientists to the Navajo Nation. They harassed bereaved family members for information about the death of their loved one. The scientists and members of the media unknowingly

showed a lack of respect for cultural values and mores. Among the Navajo customs is a strict three-day mourning period, and it is inappropriate to ever use the name of the deceased individual again. In attempting to complete their epidemiology paperwork, the scientists continued to ask about the deceased person by name, and news stations harangued local community members for specific information about the deceased individual. The Navajo community had to arrange for expensive ceremonies to protect against the damage done by these scientists and media reporters. From the perspective of

the Navajo community, the media showed no regard for local belief systems, the Navajo people or their way of life. The Hanta virus affected members of many communities in addition to those living on the Navajo Nation, yet few people were aware that any group other than Navajos were afflicted.

Advantages of Participation

Despite the Hanta virus violation and others, numerous benefits would accrue to Native American communities from participation in studies. An example of the benefits is the eradication within the last few decades of infectious diseases (eg, tuberculosis, hepatitis, and meningitis) that were rampant in Native American children. Through participation in studies, effective prevention and treatment strategies were developed and implemented. Most infectious diseases either have been eliminated or occur rarely compared with the infectious disease rates of the 1950s and 1960s. This progress is primarily due to Indian Health Service projects and studies implemented since 1955.

Distrust followed by anger is the initial reaction of Native American community members when confronted with someone who wants to study the local population. However, these same communities are also angry when no information is available about how or why disease may act differently in Native Americans. For example, we do not know why cervical cancer is more

Table 2. — Participation in Grant-Supported Studies: Reasons for Resistance by Native American Communities

Native people do not want to be “guinea pigs.”
Lack of access to resources (eg, transportation, telephones, Internet) inhibits the ability of community members to participate.
Study results are not shared with the Native community.
Researchers get promotions, and Native communities get poorer.
Native Americans distrust the people conducting the studies.
Native Americans distrust the “Western medical model” and prefer to focus on traditional American Indian healing practices.
Native Americans believe that participation in particular disease studies causes that disease to appear in one’s family or community.
Researchers are disrespectful of cultural practices.
Researchers feel that Native American community-based organizations are too dysfunctional, codependent, and/or unstable to be reliable partners in research.
Native Americans fear that studies are designed to harm (or kill) them.
Study results are too technical to be understood by the Native Community.
Promised study “benefits” rarely reach the Native Community.
Process for the “protection of human subjects,” which requires approval from the tribal IRB, IHS Service Area IRB, and national IHS IRB, may take years.
Explanation of the study by the provider or researcher is not clear or understandable.
IRB = Institutional Review Board IHS = Indian Health Service

aggressive in American Indian and Alaska Native women compared with white, black, or Hispanic women. An in situ stage may develop into invasive cancer in less than two years in a Native American woman compared with four to five years in a white woman. However, given the lack of available data, are these observations accurate? Are they limited in relevancy to only the small group of Indian women for which we do have data? Are they accurate for most Southwestern women, or are they also applicable to Northern Plains women?

The overall lower cancer incidence and mortality experienced

by our ancestors and attributed to tribes located in Arizona and New Mexico and in selected geographic areas raises further questions.^{10,14-32} Is there some protective genetic condition or behavioral practice that helps to reduce cancer incidence in many Native Americans? Cancer risk factors (eg, eating high-fat, low-fiber convenience foods, leading sedentary lives, drinking alcohol, and smoking cigarettes) that are common practicing behaviors in the majority populations were not behaviors of our ancestors. This is why many of our interventions stress that we must “be healthy again” and retain active lifestyles that were common to

American Indians prior to the relocations and restrictions to reservation lifestyles. In addition, why do other regions of the country report elevated cancer incidence and mortality rates for American Indians and Alaska Natives?^{11,20,23,28,33-39}

These are only some of the questions that remain unanswered. Similar questions exist for other cultures. For example, why are breast cancer incidence rates increasing among immigrants? Why do black men respond to cancer therapeutic treatments less effectively than do white men? Why are brain tumors increasing in white populations? These questions will be answered only with culturally respectful research conducted in our communities with our leaders in decision-making roles. Selected possible benefits for Native American communities participating in a study are summarized in Table 3. The majority of these benefits are also relevant to other cultures.

Table 3. — Benefits to Native Communities Resulting From Study Involvement

Opportunities for the local community to:

- Take a leadership role and create a program that is “community-driven” rather than institution-driven
- Increase the local community’s access to state-of-the-art health services (eg, screening tests, diagnoses, treatment)
- Modify the health delivery system to be culturally respectful of the local community
- Increase knowledge of most important health problems or conditions in the local community (help set tribal health priorities)
- Increase skill, education, training of local members of the local community (eg, develop interview skills, learn how to write applications for funding for the tribe or community, increase health knowledge)
- Learn how a program needs to be modified to be culturally respectful
- Publish successful programs so that other local communities can use that program as a “model” (rather than developing their own “similar” program from scratch)
- Learn more about culturally “comfortable” outreach and recruitment into health promotion programs
- Train with researchers to enable Native members of the community to take leadership in subsequent research applications
- Collaborate with others to increase likelihood of receiving funding for needed programs in the local community
- Increase awareness of research participants with regard to health risks and prevention and treatment of health conditions

Challenges and Benefits of Community-Based and Community-Driven Interventions

Community-driven interventions are initiated by the community itself and include community members in active decision-making roles. These cancer initiatives generate both challenges and benefits for the community. Community-based interventions are implemented in community settings, but local community leadership is frequently not involved in decision making.

The community-driven intervention allows the local members of the community to develop the leadership and administrative skills needed to manage these program independent of outside experts. In addition, these programs often continue long after grant-funding ceases. Community leadership in cancer initiatives also ensures that the project will be adapted in order to be considered culturally acceptable to a local community. For example, "focus groups" are often implemented to interact with target populations and collect information about programs, products, and educational materials in an atmosphere where the participants are not influenced by health professionals, managers, or opinion leaders.⁴⁰ Focus groups have fairly strict protocols (eg, no more than three questions to be addressed in a two-hour session). However, we have found that if we slightly modify the focus group protocols, we obtain more interaction and feedback from the community. We begin our focus group meetings with a blessing and smudging (burning sage to help "cleanse" the air and spirits of all present). Each person then introduces herself and explains what interest she has in cancer or why she agreed to take part in the focus group. This procedure is similar to the "Talking Circles" tradition, which promotes respect for spiritual foundations prior to discussions.⁴¹ Food is always served, which is socially expected. The introductions are followed by a brief explanation of how cancer is affecting Native American communities. For approximately 45 minutes before the actual beginning of the focus group meeting, the

members can ask questions and discuss issues. We learn much more from the participants with this approach because the level of trust increases and the participants are more likely to discuss personal issues that typically are not introduced outside of specific situations.

Implementing community-based interventions includes several challenges. Compared with clinical trials, these interventions require more time to organize, and funding can be more difficult to obtain. The greatest challenges are to remain focused on the potential positive benefits to the community and to ensure that the health project remains separate from tribal politics.

Additional challenges that are more subtle also need to be addressed. Some researchers are accustomed to working with cancer centers and academic organizations that have immediate access to state-of-the-art communication systems. They may become frustrated with the many unanticipated communication breakdowns experienced in these communities. When working with project staff in rural communities, reservations, or small villages, assumptions about communications (eg, priority mail, Internet access, fax machines, electronic messaging) need to be adjusted and appropriate alternatives need to be developed, if feasible. For example, the cost of installing analog telephone lines, as well as purchasing fax and computer equipment, needs to be included in the project budget. Investigators need to be apprised of such communication barrier issues, and they should provide sufficient time for all

project staff to receive intervention resources prior to implementation.

Generalizability Issues of Successful Interventions

Attempts to duplicate successful cancer prevention and control interventions in other settings often produce unsatisfactory results. An intervention can be effective in one subpopulation in one geographic setting and ineffective in a similar subpopulation in another geographic setting. While various reasons can be cited for the inconsistent results, the most consequential is that each local community has characteristics that are unique to its own setting, and those characteristics need to be addressed when replicating an intervention.

Cultural Modification of Replicable Models

When working with medically underserved populations, most researchers and service providers find that modifying a "replicable successful intervention" in order to be culturally competent requires input by some local community leadership. Although this process is met with skepticism by behavioral medicine scientists, it represents the difference between working in a laboratory and working with people in community settings. While some modification may be necessary, it is important to retain as much of the original protocol as possible to allow comparisons of some study results. For example, in the "Pathways" project designed by the National Heart, Lung, and Blood Institute to reduce

obesity in American Indian children, one segment of the protocol included traditional storytelling. The model story involved the trickster behaviors of a coyote and required children to decide between gluttony or sharing food. The story, which originated in the Southwest, would have little impact on Indian children living on the East Coast or in the Northwest. Both of these areas had stories with a similar theme, but they included characters that are common in their region — such as a fox on the East Coast and a raven in the Northwest — instead of a coyote. To be culturally relevant, the story needed to be relevant to their geographic region of the country. Rather than using the identical story in all geographic settings, which would not have had the desired outcome, the protocol retained the same concepts but was culturally relevant.

Collaborative Partnerships

Occasionally, interventions are not replicable due to conditions inherent in one region that cannot be duplicated effectively in another. For example, an intervention to enhance breast cancer screening that was effective in a Southwestern tribe of New Mexico could not be replicated in communities outside of New Mexico. The model tribe had a productive working partnership with the Indian Health Service, the New Mexico Tumor Registry, the New Mexico Comprehensive Cancer Center, and the Cancer Prevention and Control Program of the New Mexico State Department. This partnership has developed excellent col-

laborative efforts to recruit and screen women in culturally comfortable settings. Attempts to replicate this program in states other than New Mexico failed due to the lack of an Indian Health Service, the lack of a comprehensive cancer center or tumor registry in partnership, and no support for screening from the State cancer prevention and control program. While the New Mexico Indian project failed in other states, it has been replicated successfully in other communities within New Mexico. This state now has higher breast and cervical cancer screening rates among Native Americans than any other state.⁴²

An intervention can be effective in one underserved population and ineffective in another underserved population. For example, Sister-to-Sister, which relies on close collaboration with local churches, has been well received among many black communities. However, efforts to replicate this program with Native American churches have been negatively regarded by the Native American population as attempts to link cancer with a spiritual ceremony.

Effects of Population Density and/or Isolation

A Su Salud (To Your Health), a successful intervention within Hispanic and Latino populations,⁴³ relies on local community leaders to initiate one-on-one cancer education and positive social reinforcement with their neighbors. Cancer survivors canvas neighborhoods to educate others of the benefits of early detection. Indian populations,

however, tend to live in scattered areas throughout urban areas or in isolated areas in rural communities or reservations. Obviously, door-to-door contact is more challenging when only one Indian lives within five blocks than when a neighborhood is largely composed of a specific cultural group. The *A Su Salud* model has had more positive effect in New Mexico and Arizona — where Indian communities are easier to identify — than in other regions and reservations around the country. *A Su Salud* was also successful in Ft Berthold, ND, and may be an appropriate intervention for other tribes.

Conclusions

Researchers and service providers for cancer prevention and control interventions and replication models must proceed with patience and respect for medically underserved populations. While more time may be required to implement community-driven interventions in the Native American populations, these interventions tend to continue in the community long after funding ceases. Community-driven interventions are innovative, creative, and dynamic, and they provide local people with new skills that can be applied to other projects.

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