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Author

Joe, Jennie R.

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Roundtable Discussions: Recommendations from Subcommittees

JENNIE R. JOE

The final item on the agenda at the First National Research Conference on Cancer and Native Americans was a series of four group discussions on selected issues of cancer research in Native Americans: "Research Gaps and Needs," "Education and Prevention," "Tribal Participation," and "Support Care and Services for Cancer Patients." Each group selected a chair and recorder for the sessions, and the following highlights reflect some of the items that were discussed and/or recommendations that were reported back to the rest of the conference participants.

Group A: Research Gaps and Needs *James Justice, chair*

The committee discussed a number of problems related to research, but the most critical problem identified was the lack of cancer researchers who are Native Americans. Although some progress has been made over the last decade, the continual underrepresentation of Native Americans with college and post-graduate education remains one of the key barriers to attracting more Native Americans into research.

Jennie R. Joe is director of the Native American Research and Training Center at the University of Arizona, Tucson, Arizona.

Because there are no role models in research, most Native Americans seeking a college education are more likely to select other professions that are visible in Indian communities, i. e., educators, nurses, lawyers. In most rural, isolated Indian communities, research as a career may never be considered, because there are no research institutions and/or role models in the community. In fact, research often is viewed negatively, because it is associated with exploitation and development of negative stereotypes. Thus, different kinds and levels of research and researchers are generally unknown.

Dr. John Horm explained efforts he has made and continues to make to employ Native American college students in his cancer surveillance data collection as a means to interest young students in cancer research.

Other related research topics or recommendations also emerged out of this group. Because the cancer data on Native Americans is very fragmented and not available in many areas, Dr. James Hampton proposed establishing a national tumor registry for Native Americans. Suggestions were made that this database could either include all Native Americans or be geared to regions with significant Native American populations.

Another research gap that requires attention, according to a number of participants, is the effects of environment (manmade contaminated environment) on the prevalence and incidence of cancer among Native Americans. Examples such as exposure to uranium and other radioactive materials were mentioned.

The other recommendation from the committee was the need for more research meetings and symposiums that address specific diseases such as cancer and their impact on Native Americans.

Group B: Education and Prevention

Julie Sprott, chair

This committee explored a number of issues related to cancer prevention education and ways to initiate early cancer detection programs. During the discussion, a recommendation was made that cancer prevention education should focus on the most preventable cancer and its cause, i. e., lung cancer and smoking.

Some concerns were expressed about smoking and the fact that many tribes have smoke shops and sell cigarettes. This is one of the few enterprises that has been a money-maker for tribes, and it would be difficult for the tribes to close these smoke shops. There

was also some discussion about the need to emphasize to health care providers that they serve as important role models and should “practice what they preach.”

One successful lung cancer prevention model that was shared with the group was the use of children to influence their parents to change their smoking behavior. Other educational interventions included the following:

1. The impact of smoking on life expectancy: This education model includes examples of subtracting the number of minutes each cigarette is smoked from the normal life expectancy.
2. Hands-on exercises, including cartoons and other media. For example, a thirty-minute video, “Death in the West,” features the Marlboro men, who, after twenty to thirty years of smoking, have lost the normal function of their lungs and have become dependent on oxygen tanks. These men talk about the devastation smoking has inflicted on their lives. One group participant noted that “this video delivers a powerful message, and most people who see this film feel that it should be shown in every school.” Health educators need to purchase and show attractive and relevant films or videos that carry the message of saying “no” to smoking and to drugs.
3. Another recommendation was to advocate that tribes legislate “no smoking” policies in their communities, especially in the schools or on tribal grounds. [This recommendation really needs to be made and advocated by local tribal members or tribal leadership, because most Native Americans do not like to interfere with the personal choices and freedom of others, unless the decision is put to a vote or some consensus is arrived at.]

In regard to the early detection of breast and cervical cancer, the committee agreed that most Indian women would prefer to be examined by a woman health provider during prenatal or ob-gyn visits. In this context, one of the group members commented as follows: “If such services were possible, there would be more women coming for screening and/or keeping appointments for Pap smears and/or to learn self-breast examination.”

Because of cultural notions about the body held by many Native American women, it was also suggested that holistic health clinics

for women, with services provided by women health care providers, should be encouraged in order to improve prevention efforts and early cancer detection among Indian women. Health records of Indian women coming for other outpatient services should also be evaluated in order to ascertain if there is a need for a mammogram or Pap smear. This recommendation is especially important for women who are past the child-bearing age. Wherever possible, some of the clinics serving Native Americans should also be encouraged to emphasize wellness by refocusing some of the acute care activities towards keeping people well.

The lack of mammography resources remains a critical problem in most Indian communities, according to members of the committee. In most Indian Health Service facilities, Indian women have to be referred out for mammograms, and consequently follow-up is poor. Further, the cost for a mammogram is high in most rural areas, and therefore almost no one in the community gets baseline x-rays. In some instances, if an Indian woman requests a mammogram, she is told to go to a private agency and to pay for the service out of her own pocket. This further discourages Indian women from seeking preventive care for breast cancer.

One member of the committee suggested that it may be possible to have a private booth or room in the IHS hospital waiting room where women can go to see a film on cancer, learn the steps in breast self-examination, and palpate a model of a female breast with a lump so that the women know what to look for. (Again, the approach in some Indian communities may have to be different, because many Indian women are very reluctant to do breast self-examination for cultural and other reasons.)

Various suggestions were also summarized by members of the committee regarding health promotion ideas. The use of community events such as health fairs for screening and education is considered very effective in many Indian communities. "Piggy-backing" community social events such as powwows with health screening activities is also seen as an effective way to do outreach.

The other issue discussed centered around the need to reinforce positive behaviors of patients. "Praise people for making small changes in their lives, such as losing one pound or even staying at the same weight," suggested one member. "Negative feedback discourages patients, but encouragement and positive feedback keep patients coming back and trying," was another suggestion. Using peer and group support was also mentioned, especially for activities such as weight loss programs.

Another topic discussed was nutrition education and approaches that might work better than the standard approach of eliminating foods, i. e., to introduce the notion of balance and moderation in diet. Healthy eating should be expanded to include recommendations for having healthy foods in vending machines.

Group C: Tribal Participation in Cancer Programs

Lois Steele, chair

In many Indian communities, cancer is either feared or hidden. Because cancer is often associated with death, there is a feeling among Indian peoples that cancer cannot be treated. There are many misconceptions about cancer, and unfortunately there are also assumptions that cancer cannot be prevented. In order to change the attitudes of the Indian communities, much public education is needed. In addition to training a cadre of Indian health care workers to help educate and encourage awareness, innovative and culturally relevant public education materials are required. Indian communities also need to be aware there are cancer survivors and that cancer is treatable and preventable.

In many Indian communities, a pivotal health care worker is the community health representative (CHR). CHRs are, in most instances, members of the Indian communities they serve and are often recruited because of their ability to work with community members. Because CHRs are an important link between the health care delivery system and Indian communities, the committee recommends that CHRs be given opportunities for career mobility by building on their expertise. Some CHRs in every Indian community should be encouraged to become women's health specialists. Requirements for acceptance into such a program are two years of experience and at least one year of formal training. As women's health specialists, trained CHRs will be able to focus on community programs for cancer prevention and take responsibility for doing follow-up on women who need additional testing and/or treatment.

Because the role of CHRs is often misunderstood by new health care providers coming to work in Indian communities, orientation must be furnished for the new staff, as well as periodic meetings with CHRs and tribal leaders to discuss specific health issues. CHR directors also need to schedule frequent meetings with tribal leaders to update them about major health activities and about

critical issues such as cancer.

Because tribal leaders in most Indian communities are busy, health care providers need to be more aggressive in order to make time on the agenda to report on special health concerns, especially diseases like cancer, which may be overshadowed by other problems such as substance abuse. In order to get and maintain tribal support for health programs, tribal leaders need to be kept informed. Future conferences on cancer and Native Americans should include workshops for tribal health workers, especially trainings that will increase their skills in cancer education, prevention, detection, and follow-up care.

Group D: Support Care and Services for Cancer Patients

Jennie R. Joe, chair

Little is known about the experiences and problems encountered by Indian patients who are diagnosed with cancer. Most rural communities have few or no resources. Most patients requiring surgery or chemotherapy are referred to facilities that are off the reservation, and frequently follow-up is lost. In other instances, an Indian woman with an abnormal Pap report may be sent a notice to return to the clinic but may fail to do so, because she may not view this as a serious problem and/or may not want to know if she does have cancer.

Indian cancer patients may have the support of their families, but rarely do they know about support groups or resources offered by the American Cancer Society. If these resources exist, they are frequently not available on the reservation, and the patient would have to travel a considerable distance to obtain these services. Health care providers on most Indian reservations may also not be aware of resources to which they can refer cancer patients. For example, the American Cancer Society can provide literature on different types of cancer and the required treatment regime.

Because of isolation, many Indian patients with cancer are also not able to obtain second opinions and/or have alternatives explained so that they can make an informed decision. Cancer patients should be able to understand treatment options, step-by-step procedures in the surgical or therapy intervention, the common side-effects, length of recovery, prognosis, and resources that are available to aid them in treatment and post-treatment plans.

Because of the general lack of resources to support Indian

patients with cancer, the following recommendations have been made:

1. Encourage the American Cancer Society to include Indian communities in advertising their services and resources, especially to groups such as health care providers, including CHRs.
2. Develop a system of follow-up for Indian patients referred out for cancer treatment and, where applicable, encourage patients to return periodically to Indian Health Service facilities for follow-up. CHRs or PHNs might be able to maintain such a registry and follow-up.
3. Include cancer survivors in community education programs on cancer.
4. Where it is feasible, establish support groups for cancer patients and their families.
5. Conduct more studies to ascertain the kinds of problems or successes encountered by Indian patients with cancer. This should include their attitudes and perceptions of cancer.
6. Encourage and support studies of cultural attitudes and knowledge about cancer among different tribes.