Practicing participatory research in American Indian communities[1–3]

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ABSTRACT The purpose of this article is to explore the historical issues that affect research in American Indian communities and examine the implications of these issues as they relate to culturally sensitive, respectful, and appropriate research with this population. Methods include review and analysis of the literature and examination of our collective experience and that of our colleagues. Recommendations are given for conducting culturally sensitive, participatory research. We conclude that research efforts must build on the establishment of partnerships between investigators and American Indian communities to ensure accurate findings and analyses and to implement culturally relevant benefits. *Am J Clin Nutr* 1999;69(suppl):755S–9S.

KEY WORDS Research, American Indians, participatory research, Pathways study

INTRODUCTION

Outsiders, rather than insiders, have historically conducted research in American Indian populations. By focusing on their own goals of benefiting humanity at large, expanding scientific knowledge, and advancing their academic careers, many investigators remained largely unaware of their attitudes toward and effect on the participants. This sometimes resulted in research that was considered exploitative and a perception by the participants of the researchers as ignorant of the wishes and beliefs of American Indians. Research, therefore, often benefited investigators and their academic communities more than the American Indian groups they purportedly served. As tribes have asserted their sovereignty and self-determination in recent years (1) by establishing laws, policies, and procedures for outsiders working on their reservations (2), researchers have begun to respond with increased awareness of and sensitivity to the wishes of native peoples. However, many researchers have yet to develop cultural sensitivity toward the American Indians with whom they work. Investigators practicing participatory research in American Indian communities not only must establish and maintain trust with the residents, interacting knowledgeably and on an equal basis, but more importantly, must shift away from conventional research approaches by designing research projects in partnership with these communities and in response to their needs. This article *1*) explores the historical issues that affect research in American Indian communities; *2*) examines the implications of these issues as they relate to culturally sensitive, respectful, and appropriate research with this population; and *3*) promotes participatory research as a viable paradigm for the future.

HISTORICAL CONTEXTS

Even though their communities may benefit from the results, American Indians may view requests to participate in research studies with suspicion. Along with such success stories as the clinical trials of isoniazid to treat tuberculosis in the 1950s (3) and of *Haemophilus influenzae* type B vaccines in the 1980s (4), research has also brought native peoples harm and stigmatization. For example, a state health department conducted an epidemiologic study of an outbreak of syphilis on an Indian reservation. After local newspapers published the findings, the neighboring non-Indian population ostracized not only the American Indian adults from that reservation, but the children as well. A later scientific article neglected to mask the community's identity sufficiently (5), resulting again in a sense of betrayal among the participants. In another instance, identifying a native community in a study of alcoholism led to an adverse credit rating by lenders (6). In some cases, researchers disregarded requests for privacy from tribal authorities. Publications in 1993–1994 about hantavirus pulmonary syndrome listed the Diné (Navajo) sites involved, although the Navajo Nation had specifically requested that investigators not do so (7, 8). Repeated violations of trust by researchers have justifiably soured American Indian interest in participating in research projects.

Ethnocentrism manifests itself not only in researchers ranking the demands of Euro-American science far above the wishes and needs of American Indian communities; it also pervades many interactions that nonnative researchers have with American Indian advisors. Although many contemporary native people

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coexist in both the US-dominant and native cultures, few nonnatives possess an analogous awareness of American Indian cultures and belief systems. When problems arise, researchers too easily assume that American Indian participants are unreasonably uncooperative instead of considering the cultural clashes that may be occurring.

With rare exceptions, researchers have little understanding of the ethnohistorical context of the relationship between native and nonnative people, or of the continuing effect of American history on the peoples they seek to study. Before colonization, American Indian tribes, each with their own discrete language, culture, stories, and beliefs, flourished on the North American continent. Today, after 500 y of genocide, pandemics, wars, government policies, and assimilation into white populations, fewer than 600 nations remain (9). Day-to-day interactions between American Indians and non-Indians are sometimes suffused with thoughts of the history of their relations. Colonized peoples do not easily forget the experiences that decimated their nations. Many tribes must still fight for the water and fishing rights guaranteed them in treaties in exchange for land cessions. American Indians remember constantly that they once controlled all lands on this continent.

CULTURAL CONTEXTS

Many American Indians feel that researchers do not recognize the rich diversity of tribal heritages that remain vital today, or the uniqueness of the tribe with which they work. Instead of regarding native people as Anishinabe, Lakota, or Hopi, many non-Indians lump peoples from vastly different cultures under the umbrella term *Indian*. The wide variety of tribal origin stories exemplifies the wealth of cultural diversity among native peoples. Members of American Indian nations commonly believe that, despite the contentions of Western scientists, they originated from this continent, not from Asia by way of a land bridge that once connected eastern Siberia and Alaska. Some origin stories describe life issuing from a Sky Father and an Earth Mother, some portray a fortunate-fall creation story with movement from a sky world to a water world, whereas others depict an earth-diver who plunges into a flood to bring up mud from the bottom to form this world. Other origin stories, such as those of the Diné and Pueblos, relate how ancestors emerged through sacred openings from worlds below current homelands on this continent. Different aspects of American Indian cultures, such as religion and language, strengthen these beliefs about origin.

Despite the vast variety in American Indian religions, some concepts are shared in many cultures. For example, most cultures maintain that the Creator formed all animate and inanimate things, including humans, out of a few elements and that those elements were derived from the earth. American Indians therefore regard the earth as mother. Laguna Pueblo author Paula Gunn Allen (10) writes that "we are the land, and the land is mother to us all…. The land is not really a place, separate from ourselves, where we act out the drama of our isolate destinies…. Rather, for American Indians…, the earth *is* being, as all creatures are also being: aware, palpable, intelligent, alive." Consequently, most American Indians consider humans as brothers and sisters to all other life forms because of their common composition. American Indians therefore hold respect for the entire biota because of this relation, whereas the Western-dominant culture views humans as superior beings presiding over other life forms. The Creator is believed to have also brought certain powerful forces into being, some of which humans do not understand and cannot see. Along with forms of animate and inanimate life, American Indians respect these spiritual forces. Tribal religions generally assert that life comprises a balance between good and evil and between harmony and discord. Regardless of these similarities, difference rather than sameness characterizes American Indian beliefs and religions, and researchers should familiarize themselves with the specific cosmologies of the peoples they intend to study.

Unfortunately, few researchers comprehend the intensity with which many American Indians adhere to their religious beliefs. For most scientists, religion plays no role in their research. In contrast, religion permeates and governs the thoughts, actions, and daily lives of American Indians. Among the Diné, for example, researchers may collect blood for analyses yet remain ignorant of Diné religious beliefs and thus the effect of their actions. The Diné consider blood the sacred fluid that carries the spirit of the Creator throughout a person's body. Further, blood obtained from a newborn baby's umbilical cord, which is biologically rich as well as rich with scientific information, has the added sacredness of issuing from the link between new life and the mother of that life. Blood carries the essence of a person's identity that comes from her or his mother and mother's mother, extending back to *Áltsé asdzáá* (First Woman) and *Áltsé hastiin* (First Man) in the *Diné bahané*, the sacred story of creation. This belief about blood is sacred and held by many Diné, just as analogous beliefs are held by members of other American Indian tribes. Consequently, many native people hesitate to approve research, no matter how well intended or what the benefits might be, that proposes to collect blood specimens for analysis. This may also apply to organ transplantation. Researchers who complain that American Indians do not cooperate with or refuse to follow research protocols dealing with blood or other bodily fluids consistently neglect to consider native beliefs and customs surrounding certain aspects of those research efforts. It is important to recognize that a diversity of beliefs exists within tribes, and hesitation may indicate a need for more information to be provided by the researcher.

Understanding of both the religion and language of American Indians are necessary to understand their origins, religions, and beliefs; interpret their physical and spiritual evolution; and understand their lifestyles. With few exceptions, such as the Anishinabe and Ojibwa birch scrolls of the Midéwewin sacred medicine lodge, American Indians transmit their stories, history, rituals, and ceremonies from generation to generation orally rather than in writing. Consequently, thought and word hold great importance in American Indian societies as a means of cultural survival. The Laguna Pueblo origin story illustrates the power of thought and word: Ts'its'tsi'nako (Thought Woman) and her sisters think elements of this world into existence and name them. In short, as LaVonne Ruoff (11) writes, "American Indians hold thought and word in great reverence because of their symbolic power to alter the universe for good and evil. Breath, speech, and verbal art are so closely linked to each other that in many oral cultures they are often signified by the same word." Congruent with the ontological role of language in American Indian philosophies, information regarded sacred by Indian cultures cannot be transmitted to outsiders. As they work with American Indians, researchers should be aware that information regarded as secular in dominant society could compromise sacred knowledge in American Indian cultures. Researchers

should also recognize that English, the language of science and research in the United States, fails as a communication tool to explain native cosmologies. Not only can many day-to-day expressions not be translated from native languages to English, but American Indian concepts, derived from and articulated in some of the world's most linguistically complex languages, cannot be sufficiently communicated in English. Translators employed at Indian Health Service facilities to assist with communication between health care providers and patients, frequently challenged by new terminology such as AIDS, may create new words in the local native language to facilitate the communication process. Including native speakers as members of the research team becomes critical in fostering clear communication and overcoming barriers associated with language.

In addition to impasses between American Indians and researchers arising from cultural misunderstandings, conventional research approaches frequently leave community members feeling invaded (12). In most cases, American Indian communities participate voluntarily in research efforts, yet individuals commonly feel reduced to mere objects by the researchers, who are the principal planners and decision-makers of the project. Traditional approaches can produce this effect on anyone involved as subjects rather than as collaborators in the research process. However, American Indian participants sometimes intuit a condescension from researchers who maintain a higher social, educational, and economic status in dominant society. Other times, native peoples have a feeling of inferiority because they have different, and often more prevalent, diseases than the researchers' cultural groups. Furthermore, many American Indians consider their participation in such projects of low importance in their lives compared with activities directly related to day-to-day existence. Community response to feelings of exploitation from conventional research efforts may result in either indirect resistance or direct sabotage. Such responses constitute forms of self-defense in response to a perceived imposition. Alternatively, American Indian communities may simply refuse to participate in research projects, especially those initiated by parties with no track record of assisting the community.

TOWARD PARTICIPATORY RESEARCH

Despite the lapses and misunderstandings of the past, researchers can work with native people. American Indians recognize the importance of appropriate and meaningful research among their people and appreciate research when they participate in a project's development and execution and when they can live healthier, fuller lives as a result. Currently, approaches to research are changing in parallel with the growing self-determination of American Indians. Perhaps the most important change is the shift toward participatory research, defined by Green et al (13) as "systematic enquiry, with the collaboration of those affected by the issue being studied, for the purposes of education and taking action or effecting change." Much of this initiative owes its origins to Lewin's (14) "action" research in the 1940s, which contributed to the public health approach of the 1950s and 1960s. Another pioneer in the field, Hall (15–17), described the participatory process in the field of education as early as 1977. The participatory model is further described in position papers disseminated by the World Health Organization Europe Health Promotion Office (18) and furthered by the Ottawa Charter (19), the Epp Report in Canada (20), and the Healthy Cities project (21, 22).

The participatory approach has evolved in many regions of the world and in various forms. For example, the work of Freire (23) and Fals-Bordo (24, 25) in Latin America revived interest in community development and empowerment through active involvement in self-study, learning, and action in public health education and promotion. Their work focused on helping powerless and impoverished peoples mobilize indigenous economic resources through community development. Educators such as Kassam and Mustafa (26) developed participatory research approaches explicitly in the context of community development and land use in developing countries. At its essence, participatory research seeks to improve the quality of life of the people studied by involving them in the research process and by using their knowledge in the search for relevant solutions to relevant problems (27).

Recently, participatory research has been described as research conducted with the full and equal involvement, at all levels and in all stages, of scientists and representatives from the intervention population (28). Both share equally in research planning, implementation, evaluation, and dissemination of results, as well as in any resulting benefits. In minority population research in particular, investigators need the perspective of community residents to determine how the cultural norms of the community relate to the appropriateness of the research question, the methods of study, and the results (29–31). Likewise, minority communities regard participation as necessary to ensure the accountability of the researchers, the relevance of the research, and positive outcomes for the participants and their communities. Participatory research recognizes the benefits of partnership between those with the scientific and technical knowledge and those with the equally valuable personal and cultural knowledge of the problems the research project studies. Participatory research begins with the assumption that minority communities can and must benefit from research. It seeks an ecologic give-and-take approach to community resources. Rather than the one-sided transfer of information from participants to researchers characteristic of conventional research, participatory research requires reciprocity. If researchers take something valuable, such as participants' ideas, time, or bodily fluids, then they must return something of equal value, such as skills, employment, training, mentoring, or increased access to funding. Just as researchers bring essential scientific knowledge and skills, community representatives offer equally essential cultural and community knowledge and skills. Although balancing different sets of values, experiences, and interests is the goal, give-and-take between both parties is the reality.

In a recent article Green et al (32) described several ways in which participatory research contributes to research for health: by *1*) combining research, education, and action; *2*) bringing resources into line with the perceived and actual needs of communities; *3*) bringing research into line with the circumstances of communities; and *4*) bringing communities into line with the realities of resources, data, and the scientific base of knowledge. Only in the participatory process do external researchers and community members alike become responsible partners in the research, learning, and action processes. The education is a reciprocal process, with the researcher able to offer research skills and the community members able to provide context for the health issue being studied. The commitment to action means that the researchers cannot simply walk away after completing the research or collecting and analyzing the data. They must follow the process through to the accomplishment of some action

for the community, such as changes in policy, programs, services, regulations, or the allocation of resources. This approach not only strengthens intercultural bonding between researchers and communities but ensures that neither party will feel shortchanged at the end of the process.

The participatory model has proved critical to the success of researchers working in native communities. Projects in which investigators display sensitivity to the needs, desires, and beliefs of the population with whom they work; recognize the participants' rights to determine the kind of research and the questions that may be asked; and request community representatives to participate in the implementation of the interventions reap success (33–35). For example, a research study conducted in the Diné used the participatory model to examine the Diné perspective regarding the discussion of negative information and to consider the limitations of dominant Western bioethical perspectives (36). This study yielded valuable information for all parties involved in this area of health-care delivery.

The Pathways study represents another case study of the participatory approach to a complex multitribal intervention. Although not explicitly designed from the outset using a participatory model, Pathways evolved into an example of the application of such a model. The study's steering committee, initially comprising the principal investigators and funding agency staff, expanded to include 2 American Indian representatives with full voting privileges. Further, they created a major committee, the Seven Nations Committee, as a forum for the American Indians involved in the study to discuss and make recommendations related to the cultural aspects of study materials and methods. Community members (teachers, parents, and school administrators) in 6 Indian nations (Oglala and Sicangu Lakota tribes, Navajo Nation, Gila River Indian Community, Tohono O'Odham Nation, and White Mountain Apache Tribe) developed the Pathways intervention in conjunction with university researchers, therefore creating a culturally relevant and sustainable health program (37). Investigators obtained approval from each of the respective tribes for the overall study goals and design, and all publications resulting from and related to Pathways require tribal approval. Combined, these activities provide a range of opportunities for dialogue between the researchers and the American Indian communities. The cost of this participatory effort is primarily in time. With use of the participatory approach to research, several program elements took longer to develop, receive tribal approval, and implement than expected. The benefits, however, have far exceeded the cost and have allowed this complex multisite study to progress with the support of the respective tribes involved.

RECOMMENDATIONS

Many Indian tribes and nations have established procedural guidelines for investigators who seek to conduct research among them. In addition, researchers should follow certain guidelines for culturally sensitive, participatory research. Based on our experience, as both American Indian and non-Indian investigators, and that of our colleagues we recommend the following guidelines.

Before approaching Indian communities

- Determine how the potential results of the study will truly benefit American Indian communities.
- Learn and understand the religion, beliefs, and culture of the people to ensure that the proposed study is compatible with that culture.
- Conceive the study as a partnership project between American Indian communities and investigators.
- Participate in cultural sensitivity workshops or training to refine intercultural communication skills and foster respect for cultural diversity.

During negotiations with American Indian communities

- Involve members from American Indian communities in the development and execution of research efforts.
- Respect different philosophies regarding time and decision-making. Many American Indians do not regard time as a linear path of progress; some perceive it as a temporal continuum composed of myth, memory, and what non-Indians consider reality in which events cyclically recur. Some cultures reach decisions by consensus rather than majority. Tribal elders may need to be consulted.

During and after research

- Schedule feedback sessions with community members to ensure correct collection and interpretation of data and project evaluation.
- Invite American Indian professionals in the field of study or discipline to participate in peer review.
- Establish with community representatives a value exchange program for their investment of time, ideas, and knowledge (eg, skills, employment, training, access to funding, and mentoring).

CONCLUSIONS

Research efforts increasingly build on the recognition that educators and researchers must work in cooperation with American Indian communities to ensure accurate findings and analyses and to implement culturally relevant benefits. American Indians willingly cooperate in research efforts in which investigators show understanding and respect toward their customs and beliefs and in which community representatives work in full partnership on a project to solve a problem.

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