Ethical Considerations in Research Methodologies for Exposure Assessment of Toxic and Radioactive Contaminants in Native Communities

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I. Introduction

A special section on “Ethical Considerations in Research Methodologies for Exposure Assessment of Toxic and Radioactive Contaminants in Native Communities” has been developed to highlight how “technical” or “scientific” research is improved when the community is fully involved as a partner or collaborator in exposure assessment studies. The subsistence lifestyle of Native Americans and other culturally-diverse populations present challenges to the study of epidemiology and risk assessment that include exposure assessment analyses.

Various studies and environmental regulations in the past have made assumptions about the exposure routes of environmental contaminants to culturally-diverse populations that were based on the lifestyle patterns of predominately Caucasian communities (Bullard and Wright 1993). These studies have reflected large gaps in the understanding of the subsistence and dietary habits of culturally-diverse populations; leading to an underestimation of exposures in their immediate environments. This has been a major concern of the environmental justice movement in the United States and presents both ethical and technical challenges to the scientific community in resolving these concerns.

In this section, a small number of case studies of exposure assessment are reviewed for the modifications and innovations they utilized to account for cultural differences. These studies also add to the evidence of environmental injustices to culturally-diverse (Native populations) who carry a higher burden of exposure and/or disease due to the presence of environmental contaminants from industry or government in their homelands. These research studies specifically focus on special lifestyle and diet considerations in conducting exposure assessment analyses.

Two categories of studies are included. These are (1) studies of Native communities affected primarily by contaminants in fish and (2) studies of Native communities who were at risk for downwind radioactive fallout. The first set of studies exclusively focus on a series of exposure assessment studies conducted on PCB contamination in fish in the Mohawk Nation of Akwesasne from 1995 – 1999 and one study of the Mohawk community of Kahnawake. The second set of studies focus on improving exposure assessment scenarios in Native communities exposed to radioactive fallout; the first study is of the Umatilla Reservation in Oregon and the Yakama Indian Nation in Washington state; the second study is of Native communities in Nevada and Utah downwind from the Nevada Test Site. Abstracts of these studies and several related studies are appended.

a. A Summary of Mohawk Fish Contamination Studies

Akwesasne is located along the St. Lawrence River in New York, Ontario and Quebec. It is a community of 10,000 persons, which has become a Superfund site due to extensive PCB contamination into the St. Lawrence River from General Motors-Central Foundry site, as well as PCB contamination from Reynolds Metals and Alcoa aluminum companies into the river and its tributaries. Five studies of PCB contamination to Akwesasne from local industries were conducted from 1996-1999. Collectively, these studies reflect innovative strategies to exposure assessment.

Such strategies included:
(1) Community Collaboration and Research Partnership Arrangements: All five studies included Native researchers as an integral part of the research team and as co-authors of the studies. The partnership included the Akwesasne Task Force on the Environment (ATFE) and the New York State Health Department for most of the studies. One study had several other collaborators.
(2) Utilizing a Native Field Staff: Native community researchers implemented the studies' interviews; assisted in the questionnaire development and the identification and recruitment of participants. Hwang et al. (1998) state that “The success of our sampling (soil sampling) was due to the Mohawk’s willingness to cooperate with the sampling efforts. This was most likely attributable to the field staff being of Mohawk heritage and the genuine concern of the Mohawk people for their environment.”

The Akwesasne Studies:
A study in 1995 of “Fish PCB Concentrations and Consumption Patterns among Mohawk Women at Akwesasne” assessed exposure to PCB’s for nursing Mohawk women with a comparison of nursing Caucasian women from local fish consumption. It was determined that the fish were contaminated with PCB’s and a higher rate of fish consumption was prevalent among Mohawk women compared with controls.

In 1996, a study was conducted with Mohawk men at Akwesasne to determine if there were associations between dietary, residential and occupational exposures to PCBs and DDE (Dichlorodiphenyl Dichloroethylene) in Mohawk men, specifically husbands, partners, fathers and other male relatives to the women in the other Akwesasne studies. The study confirmed elevated body burdens from the contaminants incurred from dietary and occupational exposures. A 1998 study by the research team sought to determine the relation between the consumption of contaminated fish and concentrations of the PCBs and the PCB cogeners in the milk of nursing mothers at Akwesasne. 97 Mohawk women were compared with 154 Caucasians. Mohawk mothers who gave birth between 1986-1989 had a significantly higher percentage of PCBs in their milk than the control group and also had a significantly higher total of nine PCB cogeners.

In 1999, a larger study was conducted of “Local Fish Consumption and Serum PCB Concentrations among Mohawk men at Akwesasne”. The data from this study suggests that local fish consumption has contributed to body burdens in this population and that advisories have been effective in modifying local fish consumption patterns. Another 1999 study “Assessing Environmental Exposure to PCBs among Mohawks at Akwesasne through the Use of Geostatistical Methods” illustrated how mapped residential information and environmental sampling data can be united to assist in exposure assessment for epidemiological studies using GIS technology and statistical methods.

It is important to note that fish advisories over the past years have reduced the body burdens of PCBs for Akwesasne community members. The involvement of Native researchers in these studies likely contributed to the effectiveness of these advisories the minimizing of exposures to the local Mohawk population. Collectively, the Akwesasne studies may be informative to environmental health researchers in determining both culturally-appropriate and technically effective research approaches to culturally-diverse community members with PCB contamination. The progression of specific research methods and study objectives in the seven year period may also be informative to communities and researchers dealing with similar contamination risks. The involvement of the Native community as a partner and part of the research team was a significant contribution to the success of these studies.

Akwesasne Studies:

The Consumption of Freshwater Fish in Kahnawake: Risks and Benefits

Kahnawake is another Mohawk community on the south shore of the St. Lawrence River. This study is profiled as it is another example of a research partnership initiative between an academic institution and a tribal government organization – McGill University and Kahnawake Environmental Office (KEO). The study came at the request of community members. Its objective was to study the health risks of contaminant exposure associated with freshwater fish consumption among Kahnawake fishermen. The McGill University researchers submitted a research agreement to the KEO and it was signed by each representative. Study participants were identified through an informational meeting about the study, through word-of-mouth and newspaper advertisements.

The interview questionnaire was used to obtain socio-demographic information, fishing practices (past and current) and fish consumption practices, including portion sizes and preparation methods. It was developed from a literature review, from questionnaires in similar studies and community input. It was pilot-tested in the community before its finalization. Interviews were conducted by two community members who had been trained by a nutritionist. The nutritionist checked the completed interviews for accuracy and completeness. 131 samples of six species of fish were collected and tested for contaminants.

The significant results of this study were that mercury and PCBs in predator fish (walleye, bass and pike) are of specific concern. PCB levels however were an order of magnitude lower than those in Akwesasne. The PCBs were also one order of magnitude lower than Canada’s government guidelines. This suggests that the fish collected from Kanawake were not contaminated by PCBs or other organochlorines and should pose minimal health risk to high-end fish consumers in the community. Levels of Hg were close to or exceeded government guidelines in predatory fish. The fish consumption rate among fishermen was found to be higher than the general population (23g/day) but similar to other Native fishing communities.

As the consumption rate has declined among fishermen over the years, it was concluded that the risk associated with infrequent consumption of locally-caught fish was minimal. The researchers however developed a consumption level of fish that would remain within acceptable guidelines. The KEO then decided to promote fishing and consumption of locally-caught fish within these guidelines.

This study exemplifies several major ethical considerations in conducting exposure assessment in a Native community. These are (1) a tribal and academic research agreement before the research is begun (2) informational meetings to the community before the study (3) the input of community members to the questionnaire with the pilot testing of the questionnaires and (4) the training of Native community members in the implementation of the questionnaire.
b. Exposure Assessment Studies with Communities Exposed to Radioactive Contaminants

Both these studies highlight the important ethical issues of conducting good science. This is demonstrated by the need for tribal community input and collaboration in the research process in order to gather and assess accurate data from the field. One study also addresses the reframing of the research objectives and outcomes to fit within the cultural framework of a Native society.

Study One: “A Native American Exposure Scenario”, Harris, Stewart and Harper, Barbara

Two Native researchers of the Confederated Tribes of the Umatilla Indian Reservation (CTUIR), Oregon, and the Yakama Indian Nation, Washington present an exposure scenario that reflects the Native diet as well as the exposures that would be received during the acquisition of those foods and other cultural and religious activities as currently practiced. These tribes are downwind from the Dept. of Energy Hanford Nuclear Reservation which has released considerable contamination of radiation for over forty years to downwind populations.

This exposure scenario was developed as an alternative to EPA Risk Assessment Guidance for Superfund (RAGS) which provide guidance for estimating exposure received from suburban and agricultural activity patterns and lifestyles. The authors point out that these guidelines are not suitable for tribal communities whose members, in part, live a traditional lifestyle. “This lifestyle is actually a living religion that includes values about environmental responsibility and community health as taught by elders and tribal religious leaders.”

Harris and Harper developed the scenario by:
(1) using expert elicitation and unstructured surveys to gather input from 35 tribal members and supplemented this with information in the open literature. (The authors state that the formal surveys do not work well in tribal communities due to cultural differences in modes of communication and mistrust of conventional survey methods.)
(2) gathering interview data on tribal activities, seasonal patterns, diets, other lifestyle elements that are important for preserving the traditional cultural-religious way of life. Information about particular species, locations and activities is typically considered proprietary information by tribal governments and is forbidden from being published.
(3) information about activities and diets was converted into estimated means for intake rates and for exposure frequency and data.

Interview results have these findings. The “Subsistence Residence Scenario” centers around the Columbia River with substantial additional hunting and root gathering components. For example, one hour everyday is spent in activities with groundwater, surface water or seeps/springs (and their sediments), including bathing, collecting and washing foods and medicinal plants and
drawing water. Table 1 provides a representation of the exposure scenario with a mixture of activities and diets related to hunting, fishing, pasturing of livestock, gathering of plants and materials, religious practices and preservation of natural and cultural resources.

The authors also have developed alternative considerations for evaluating community quality of life. EPA has developed these guidelines for a decade for comparative risk assessments. Interviews among tribal members helped to identify and modify these descriptors to reflect tribal values. These are condensed into Table II. The authors estimate that the Native average subsistence lifestyle would be equivalent to the 90th percentile of the average suburban lifestyle. “Initial sensitivity analyses show that the difference between the means of the two types of lifestyles ranges from two to hundred fold.” The authors note that this subsistence exposure scenario could still underestimate actual exposures as children and other subpopulations with greater exposures/sensitivities are not estimated. Certain other exposures could be underestimated such as nonfood preparations and uses of animal parts and plants.

The authors conclude that typical risk assessment results are presented for human exposure, ecotoxicity and sometimes socioeconomic or social quality of life. They offer an alternative organization (from individual people or organisms, through biotic and human communities, to cultures and landscapes). This would be more ethically and scientifically valid for sensitive and diverse populations than providing mere numerical analyses for a narrow set of principles.


Study Two: “The Assessment of Radiation Exposures to Native Communities from Nuclear Weapons Testing in Nevada”, Frohmberg, E; Goble, R; Sanchez, V; Quigley, DP

This article is illustrative of the ethical and technical inadequacies of scientific analyses that are conducted with the exclusion of Native community input and consultation. The Nuclear Risk Management for Native Communities (NRMNC) Project is a collaborative participatory research project representing Clark University, Citizen Alert Native American Program (CANAP—a Native environmental organization), the Ely-Shoshone Tribe, and the Childhood Cancer Research Institute (a small national environmental health organization). Native community activists and the Western Shoshone National Council had long-held concerns about the effects of nuclear test blasts on their Native communities downwind from the Nevada Test Site. They observed that their people had unusual cancer excesses. They sought assistance from researchers to investigate these concerns.

In a subsequent article (Quigley et al. 2000) research arrangements are described whereby Clark University arranged a subcontract to CANAP, providing funding and training for Native community researchers to conduct semi-structured interviews, primarily with elders in several downwind reservation areas. The academic staff reviewed government studies (DOE, EPA) on radiation fallout risks to downwind communities. A community advisory committee representing 18 Native community members from nine tribes also provided input and reviewed the research efforts.

It become evident from the interview information and the review of the DOE dose reconstruction analyses that Native people were not consulted in DOE’s development of exposure routes and analyses. Their Native lifestyle was included under a “shepherd lifestyle” exposure scenario. The community interview data indicated that significant exposure routes for Native lifestyles were omitted from the Doe’s analyses. In this study, the authors, including a Native researcher, conducted an estimate of exposures for one omitted exposure pathway for small game consumption. They highlighted these conclusions:

• Native Americans living in their ancestral lands received substantial exposures from nuclear weapons testing.
• DOE’s dose reconstruction did not adequately describe (1) missing pathways of radio-iodine exposure from small game consumption; (2) model assumptions about cattle feeding that provide dairy products do not apply. (3) other food pathways were not included.
• The lack of participation by Native community members in the collection, interpretation and planning for the use of key lifestyles and concerns led to the failing of DOE to adequately address their exposures.
• Radioactive iodine exposures were calculated from existing data and shown to be severe.
• A successful dose reconstruction that is useful and accurate can only be achieved with the active participation of the affected communities.

The collection of local knowledge of Native community members in the technical aspects of dose reconstruction was essential to the technical accuracy of the study. To not seek out and facilitate the collection of this information would be an unethical practice as it leads to inaccurate findings and bad science. To adequately collect this knowledge often requires that this knowledge be collected by Native community researchers.

(Frohmberg, E; Goble, R; Sanchez, V; Quigley, DP; “The Assessment of Radiation Exposures to Native Communities from Nuclear Weapons Testing in Nevada”, Society for Risk Analysis, March 2000)

Related Studies: