

Including Residents in Epidemiologic Studies of Adverse Health Effects in Communities with Hazardous Exposures

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Abstract

For individuals who live within the shadows of hazardous waste sites, there is a constant worry about what impact releases from these sites are having on their health and environment. Public health agencies at the local, state, and federal levels are routinely asked to investigate these concerns and determine what, if any, exposures are occurring or may have occurred in the past, and what the health risk to nearby residents may be. To ensure the credibility of research findings, full participation of affected communities is needed. Including communities in research activities can, however, be a difficult process.

This paper discusses the concerns, needs, and expectations of U.S. communities in which environmental exposures are occurring, or in which exposures have occurred in the past. Three case studies are presented in which activities were undertaken to involve a community in the research process where environmental contaminants were of concern. The strengths and limitations of these activities are discussed, and recommendations for community involvement in future research are made.

Introduction

Community concern regarding environmental issues is often in the forefront of public attention in areas that have, or have had, extensive industrial activity. This is especially true when hazardous chemicals from the facilities are found to be migrating off site, or when water supplies located near the facilities are found to be contaminated. Residents in the area become justifiably concerned about health effects that may result from exposure to these contaminants, and their concerns are heightened when they learn that others in the area are suffering from similar health effects.

Public health agencies at the local, state, and federal levels in the United States are routinely asked to investigate these concerns and determine what, if any, exposures are occurring, or may have occurred in the past, and what the health risk to nearby residents may be.

The investigation of health concerns related to potential environmental exposures can range from examining existing data to conducting an epidemiological study examining associations between disease and exposure. No matter what type of investigation is undertaken, the participation of affected communities, from origin to completion, is

needed in order to increase the credibility of the research findings. This paper will discuss the concerns, needs, and expectations of communities in the United States in which environmental exposures are occurring, or in which exposures have occurred in the past. In addition, three case studies will be presented, describing activities undertaken to involve a community in epidemiological research when environmental contaminants were of concern. The strengths and limitations of these activities will be discussed, and recommendations for community involvement in future research will be made.

Concerns, Needs, and Expectations of the Community

For individuals who live within the shadows of hazardous waste sites, there is a constant worry about what impact releases from the industries are having on their health and environment. People living in these areas may be exposed to hazardous chemicals from accidental releases, fugitive emissions, hazardous waste incinerators, or wastewater outfalls. They may be concerned that not enough chemical monitoring is being conducted by regulatory agencies to ensure permit compliance by the nearby industries. Residents also have fears about the safety of their drinking water and of the air, and about the impact the hazardous chemicals might have on their children's health.

In the United States, community residents usually contact local environmental agencies, public health agencies, activist groups,

or elected officials to have their concerns addressed. If appropriate measures are not taken in a timely and meaningful manner, residents often contact state or national environmental or public health agencies, or activist groups. If their concerns still are not addressed, they may enlist the media to draw attention to and get action on their concerns.

Once attention has been captured and public health or environmental agency officials arrive to address the issue, community residents have a number of expectations of those agencies. They expect that the government agencies will understand the public's point of view and that their concern will be the agency's top priority. Community residents also expect that their concerns will be scientifically investigated, researched, studied, documented, and addressed. They expect that the reason for their illness will be found and further exposures will be prevented. They expect proper and effective enforcement, and they expect that there will be a permanent documentation database of records and information. They expect that their concerns will be validated and that personal medical evaluation, education, and treatment will be provided to them at no cost. All of this is expected in a timely manner.

Community residents may assume that time, money, and resources are unlimited for the government agencies investigating their concerns. They also may assume that all government agencies that need to be involved to address the problem will automatically be involved and that there will be full communication and cooperation within each agency. Community residents also assume that an epidemiological study will identify the source of the contamination as the cause of their illness.

Case Studies

Including community members in epidemiological studies can be a difficult process for several reasons: 1) it is often difficult to determine who makes up the community, 2) community residents are often frustrated and mistrustful of government officials and therefore also suspicious of the activities they conduct, and 3) there is the challenge of explaining that epidemiological studies cannot show cause and effect. The following case studies describe activities undertaken to include community residents in epidemiological studies in three areas of the United States where a nearby hazardous waste site prompted concerns about adverse health effects from potential exposure.

Calcasieu, Louisiana

The Calcasieu Estuary area of Louisiana is a heavily industrialized corridor containing many chemical-manufacturing plants that produce chlorinated hydrocarbon solvents, vinyl chloride monomer, and other petroleum-based chemicals. Residents in the nearby communities were concerned about dioxin exposure from industry emissions. Area residents researched the adverse health effects of the substances to which they suspected they were being exposed and contacted local, state, and federal environmental and public health agencies to get their concerns addressed. They felt frustrated and suspicious of the activities being conducted by these government agencies because their concerns had not been addressed despite years of complaints.

Local groups competed for leadership within the community along with a number of local environmental activist groups that represented specific areas of the community.

Initial investigations in 1998 by the Agency for Toxic Substances and Disease Registry (ATSDR), a federal public health agency mandated to help prevent exposure and adverse health effects associated with hazardous substances from waste sites, indicated that some community members had higher-than-expected blood dioxin levels (Orloff et al., 2001). ATSDR decided to conduct a study to determine the nature and extent of dioxin exposure in Calcasieu Parish. There were many factions within the community, however; some residents were adamant that local industries were killing people in the area, while others worked for these industries and trusted that they were not. Local groups competed for leadership within the community along with a number of local environmental activist groups that represented specific areas of the community. Some of the groups communicated with each other and some did not. Some of the local groups

aligned themselves with national environmental groups, resulting in a loud voice demanding that the focus of the investigations be in their area. Residents of other areas felt alienated by these groups.

ATSDR personnel understood that a commitment to the study design would be needed from the diverse groups within the community in order for the study to be accepted. In order to achieve this goal, ATSDR staff attended community meetings with the various groups in the area and actively sought participants to serve on a Community Work Group to assist in the design of the study. Seventeen people volunteered to serve on the workgroup, who lived in different areas in the parish and represented different environmental groups. The responsibilities of workgroup members included attending meetings to discuss the study design, providing advice regarding issues in the area, and researching questions pertinent to the study. The workgroup was involved in all aspects of the study design, including selection of the comparison community and questionnaire development. During the workgroup meetings, ATSDR staff educated members on scientific and technical issues, tradeoffs in the study design, and policy issues such as external peer review of study protocols.

The workgroup decided on a cross-sectional study to examine blood dioxin levels of individuals exposed to industrial contaminants. These results would be compared with dioxin levels of people living in a nearby parish who were not exposed to industrial contaminants. In total, it took six years to complete this study—four years to form the community workgroup and develop a study protocol and two years to collect and analyze the data. Overall, no differences were found in the blood dioxin levels of participants between the target area and the comparison area, although in some subgroups the dioxin levels were higher among the comparison area participants (ATSDR, 2003). These results were unexpected since it was assumed that individuals living near the industrial corridor were more likely to be exposed and would have higher blood dioxin levels. The reaction of the community to the study results was one of surprise—and some disappointment—but not anger. Community members felt an ownership of the process and a belief that the study results, whatever they were, were valid.

Memphis Depot, Memphis, Tennessee

Citizens living near the Defense Depot in Memphis, Tennessee, were concerned that contaminants from the depot had migrated

off site and that exposure to these contaminants caused many diseases in their community. From 1942 to 1997, the site was a fenced and guarded military supply, storage, and maintenance facility. Commodities distributed from the depot included food, clothing, medical supplies, electronic equipment, petroleum products, and industrial chemicals. Chemical warfare-related materials also were stored during the earlier years of operation. In 1992, the site was listed on the U.S. Environmental Protection Agency's (U.S. EPA's) National Priorities List for cleanup.

Over the years, community residents became distrustful of local, state, and federal government officials who were working in the area. The residents felt that the government agencies did not provide them with all the information on activities being conducted in this area. A local activist group approached ATSDR about assisting community residents to address the issues of environmental contamination and cleanup, health effects, and medical care. To accomplish this mission, the Greater Memphis Environmental Justice Working Group was formed, with co-chairs from the local activist group and ATSDR. Since the issues of concern to local residents were varied, several subgroups were formed. Each subgroup consisted both of area residents and of local, state, and federal government officials, depending on the issue.

To address concerns about the occurrence of disease in the area, the Health Concerns Subgroup was formed, consisting of community residents, representatives from the Tennessee Department of Health, ATSDR, and the National Center for Health Statistics. Initial meetings of this subgroup took place in Memphis at facilities chosen by the community representatives. The purpose of these meetings was to determine specific health concerns of residents and to develop a mechanism to address these concerns if possible. Of particular concern to area residents was the perceived high occurrence of cancer in their area. Community members felt that too many people in their area had cancer and that the illnesses were a result of living near the depot. They also felt that the way to document this link was to conduct a door-to-door survey.

The Health Concerns Subgroup met regularly—in person, via conference calls, and through e-mail—to discuss methods available for addressing their concerns. The methods discussed included conducting a door-to-door survey as well as use of existing data sources from the state health department. The

Community residents were responsible for defining the geographic area to be included in the analysis, as well determining the types of cancers to be examined.

strengths and limitations of these methods were discussed. The group agreed that a health statistics review of cancer incidence data in the area would be conducted and that community members on the workgroup would be involved in every step in the process of conducting this review. Specifically, community residents were responsible for defining the geographic area to be included in the analysis, as well determining the types of cancers to be examined. Information provided to the Tennessee Cancer Registry was discussed, as well as the strengths and limitations of the data, and the analytical methods available for analyzing cancer incidence data.

Community members on the workgroup decided that six census tracts surrounding the depot would be considered as the geographic area for the analysis and that all cancer types would be examined for this area. The limitations of conducting an analysis of such a small geographic area with so many outcomes were discussed. A written report summarizing the workgroup activities was prepared and was reviewed by all workgroup members before any data were analyzed to make sure that all community concerns were being addressed. Community members on the workgroup also attended a meeting in Atlanta, Georgia, to meet with the statistician who would be conducting the analysis. This visit provided area residents the opportunity to discuss questions regarding the statistical analysis that would be conducted and clarify any methods that were not clear. Once the data had been analyzed, the report was modified and again reviewed by all workgroup members. Additional meetings were held to discuss the results presented in this report, and modifications to the document were made on the basis of workgroup recommendations.

A section was also included in the report answering questions that the workgroup thought would be asked by other community residents. Once complete, the report was released for public comment and copies were sent to local libraries and other repositories for public review. Public comments were addressed and the report was modified on the basis of these comments. A final copy of the report was printed and distributed to all interested individuals.

Overall, the results from the cancer incidence analysis presented in the report showed that cancer rates were not elevated in this community (ATSDR, 2000). In addition, a review of environmental sampling data did not show that contaminants from the depot were migrating off site to nearby residences. Although the community's beliefs were not substantiated, the results were accepted. Being kept informed of the activities being conducted by different government agencies, as well as having input into the geographical area and types of cancer to be examined for the cancer analysis, helped community members accept the results.

El Paso, Texas

The Texas Department of Health (TDH) conducted a cluster investigation of multiple sclerosis (MS) in El Paso, Texas. The investigation was the result of citizen concerns about a possible excess of MS among children who had grown up in the 1950s and 1960s in two El Paso neighborhoods and environmental concerns related to a large metals smelter, particularly with respect to past operations at the facility. Historically, high levels of metals have been documented to have resulted from the facility's air emissions (ATSDR, 1996).

A retrospective study was used to examine the prevalence of MS in two elementary-school cohorts. Enrollment at one of the elementary schools from 1948 through 1970 was used as a surrogate for residence in the neighborhoods during that time period. Using school records, TDH attempted to track the former students and obtain current addresses. A one-page questionnaire requesting demographic information and disease history was mailed to cohort members. If a study participant indicated that he or she had ever been diagnosed with MS or considered for an MS diagnosis, medical records related to the MS diagnosis were requested. The medical records were reviewed by a consulting neurologist and the diagnosis confirmed.

Community involvement in the study took several forms. First, there was the informal, ongoing involvement of several of the ele-

mentary-cohort members who had expressed a strong desire to participate. These individuals participated as consultants to TDH, providing additional contacts, suggesting alternate methods of communications with other cohort members, and reviewing study documents. Second, there were more formal routes for community participation, including public meetings held during the course of the study and a public-comment period for the final report. In addition, the local medical and public health communities were instrumental in the design and execution of the study. They were apprised of all study activities, and participated in the public meetings and in the final release of the study results.

Twenty-two cases of MS were self-reported in one of the cohorts during this investigation (ATSDR, 2002). The crude MS prevalence estimate for this cohort was 360 per 100,000 (95 percent CI = 197 to 603 per 100,000), two to six times higher than previously published MS estimates. No cases of MS were reported for the second cohort.

Although several groups in the community expressed an interest in this study, including current residents in the area, there was a very low participation rate for both cohorts (44 percent and 20 percent, respectively). The reasons for the low participation rate are unknown but may be due to issues of access to medical care in the United States, the availability of health care in Mexico, or the lack of trust in government or perceived benefit for the community. Many members of the elementary school cohorts were either part of the childhood lead studies conducted in the early 1970s in El Paso or had family or friends who had participated. Several people raised the issue of the blood lead studies and noted their concerns about being used as study subjects again. Issues also were raised regarding environmental conditions during the period of 1948 through 1970 and the perceived lack of government response to those complaints.

Limited community awareness of the seriousness of the disease may also have affected study results. Multiple sclerosis is not a familiar diagnosis for most of the general public. Compared with studies of birth defects or cancer, the MS investigation generated far less publicity and attracted far less community attention. Even a public meeting in El Paso generated a lower level of concern than is usually associated with a serious disease connected with environmental concern.

As the MS cluster study neared completion, residents of other El Paso neighborhoods expressed their concern about additional MS clus-

ters in the area, as well as concerns about other diseases and about metal contamination. To address concerns regarding MS in the area, TDH is currently conducting a prevalence study of MS in El Paso. TDH also is finalizing an MS prevalence study in a 19-county area surrounding Lubbock, Texas. The results from these prevalence studies will provide an appropriate comparison estimate with which to re-evaluate the El Paso MS cluster data. In addition, these studies will provide current MS age- and sex-specific prevalence estimates for Texas based on a standardized case definition and case ascertainment protocol.

Discussion

Conducting epidemiological studies of adverse health effects in communities with potential environmental exposures is difficult because characterization of exposure is often limited or not available, the population currently living in the area is usually not the same population that lived there when exposure was occurring, and data may not be available for examination of rates of particular diseases in the area. In addition, it can be difficult to explain epidemiological methods—as well as the strengths and limitations of those methods—in addressing community concerns. These difficulties are best overcome, and any obstacles addressed, before epidemiological activities are initiated so that the results from these activities are more likely to be accepted. By not involving the community from the beginning, researchers lose credibility, and results may be ignored. Communities may then lobby to have the study redone, and government officials may find themselves conducting the same activities in the same area.

Community members are often a great source of institutional memory of an area and can provide information about activities that have occurred in their area in the past. Although including community members in research activities can be a time-consuming process, their involvement in epidemiological studies helps ensure that community concerns are being addressed and usually results in acceptance of study findings.

Researchers need to realize that community groups in different areas of the United States often interact with each other and discuss activities being conducted by government agencies in their areas. Community residents use the Internet and other sources to seek out information to verify what is being told to them, contact other experts in the field, or find publications or other literature on topics of interest. They may not have faith in a researcher or a researcher's organization if the

researcher or the organization has failed somewhere else. The authors have compiled a list of activities (see below) that should assist researchers when conducting research activities in communities. Each community is different, however, and activities that may work in one community may not work in another.

Communicate

- Become familiar with the community—know the groups in the area (homeowners, community groups, workers, industries, civic leaders, activist groups), as well as individuals who are not part of those groups.
- Identify one person as a point of contact for questions regarding project activities.
- Determine the questions and needs of community members.
- Know that the loudest voice does not always represent the community.
- Be present in the community in which you are working.
- Change meeting locations, days, and times to accommodate different community groups and schedules.
- After rapport is established, use conference calls—but still have face-to-face meetings.
- Send updates, reminders, and minutes of meetings to all members to make sure you are all on the same page; identify items and individuals responsible for follow-up actions.

Educate

- Be willing to educate and to be educated.
- Be clear about what you can and cannot do.
- Discuss potential research alternatives: study designs, available data, strengths and limitations, tradeoffs of each alternative, cost versus result.
- Bring “experts” to meetings for discussion of a particular issue.
- Provide information resources.
- Explain your responsibilities to your agency: clearance process, institutional review board, deadlines, and so forth.

Facilitate

- Develop a forum that is respectful of ideas.
- Give everyone a chance to participate and have his or her voice heard.
- Solicit participation from all groups.
- Include representatives from as many community groups as possible—including “squeaky wheels,” silent-but-interested, and community leaders.
- Take time to make sure everyone understands what is happening; don't proceed with a study/investigation without buy-in or at least understanding from the community.
- Encourage interaction among team members.

Ask Questions

- Present ideas and solicit responses.
- Make sure that community residents are comfortable with, and understand, the research process.
- Ask "Does that make sense?", "What do you think?", "Does that answer your question?"

Listen

- Listen to what people are feeling—not just to what they're saying.
- Be willing to compromise.
- Understand the community's perceptions.

Share

- To the extent possible, share documents (questionnaires, informed-consent statements, letters, fact sheets, etc.).
- Have study materials reviewed by group, if applicable, for readability and clarity.

Laugh

- Never underestimate the power of laughter to help a group work together. 🐷

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Water activity vs. *Listeria* *monocytogenes*.

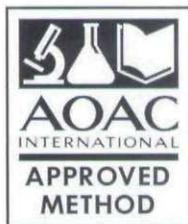
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- FSIS Directive 10,240.4 for *Listeria monocytogenes* (Lm) control on RTE (Ready-to-Eat) products.

- Water Activity is accepted as a post-lethality treatment in Alternative 1 or 2.

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