

Social Responsibility and Research Ethics in Community-Driven Studies of Industrialized Hog Production

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Environmental health research can document exposures and health effects that result from inequitable relationships between communities of low income or people of color and the institutions that derive benefits (profits, federal and state funding or services, avoidance of wastes) from activities and policies that burden these communities. Researchers, most of whom work in relatively privileged institutions, are placed in situations of conflicting loyalties if they conduct research in collaboration with, or on behalf of, communities burdened by environmental injustices. These conflicts can threaten the self-interest of researchers and may raise social and ethical issues that do not typically arise in research projects that respond to the agendas of institutions. This article describes how we addressed issues of research ethics and social responsibility in environmental health research on industrialized hog production in North Carolina. Researchers and institutional review boards are not well prepared to address ethical issues when interests of entire communities, as well as individual research participants, are involved. Community-driven research partnerships can help address problems in research ethics and can enhance the social responsibility of researchers and their institutions. *Key words:* African Americans, agriculture, confidentiality, environmental justice, livestock, swine, water pollution. *Environ Health Perspect* 110:437–444 (2002). [Online 22 March 2002] <http://ehpnet1.niehs.nih.gov/docs/2002/110p437-444wing/abstract.html>

Most environmental health research has been conducted in relation to problems identified by governments, industries, health professionals, and the scientific community. These institutions have some degree of prestige and power; they have played an active role in developing environmental health science itself, and their members are seldom forced to live with serious environmental contamination. In contrast, communities of low income and people of color seldom have had access to researchers; they have been underrepresented in the research professions (1), they have been used as test subjects for biomedical research (2), and they sometimes have had no choice but to live and work in the presence of contaminants (3). Environmental health research that takes as its starting point the experiences and concerns of communities of low income and people of color raises numerous questions regarding methodology (the formation of study hypotheses, research design, analysis, interpretation, and communication of findings) as well as ethical issues related to the role of professionals and academic and government institutions, responsibilities for communication, respect, collaboration, protection of human subjects, and protection of the communities in which research is conducted.

In this article I describe environmental health studies of industrial swine production facilities conducted by a community-driven research and education partnership. I use these examples to explore ethical issues that arise in community-driven research conducted in the setting of gross inequalities between powerful institutions and communities exposed to environmental injustices.

Industrial agriculture in general, and pork producers in particular, have strong ties to government and academic institutions (4). Researchers can face ethical and legal dilemmas that arise from conflict between groups that create and permit industrial operations and their contaminants, and the communities living with the industries and contaminants. Recognizing the distinction that epidemiologists have drawn between biomedical research focused on individuals and public health research conducted from a population perspective (5), I conclude that community-driven research involves analogous ethical dimensions regarding autonomy and risk of harm to entire communities, not simply to individual research subjects whose welfare is the traditional domain of institutional review boards (IRBs).

Background

In the early 1990s, news stories appeared in rural Halifax County in northeastern North Carolina (6,7) announcing that the historically underdeveloped southeast region of the county was slated for 17 new industrialized hog production facilities that would bring economic development to a predominantly African-American and low-income population.

Public reaction was slow to emerge. Most rural residents of this area are familiar with raising hogs on family farms. However, citizens soon began to learn that industrialized production operations are nothing like family farms. Far from being independent businesses, confined animal feeding operations (CAFOs) are generally owned by or run

under contracts with large corporations that control the animals, feed, veterinary supplies, and management plans (8). If the operation is run under contract, the contractor owns the buildings, equipment, land, and waste but not the animals. Some CAFOs raise hogs from birth to market weight, whereas others are designed for only one stage of an animal's life: birth to weaning, weaning to about 40 pounds, or 40 to about 250 pounds, the weight at which hogs are typically slaughtered. The corporate integrator trucks its hogs between CAFOs that are specialized for growing animals of each size.

Swine CAFOs house thousands of hogs in close confinement in large buildings (Figure 1). Subtherapeutic doses of antibiotics are used to control infection and promote growth. Large ventilation fans exhaust dusts and gases that pose health risks to the animals and workers. Animal waste falls through slats in the floor and is washed into cesspools called lagoons. There the waste undergoes anaerobic decomposition; the remaining liquids are subsequently sprayed on nearby fields (Figure 1).

The rapid growth of industrialized hog production in North Carolina occurred between the middle 1980s and the late 1990s (9). As hog production in the state expanded from less than 3 million to approximately 10 million hogs per year, the number of operations shrank dramatically as smaller independent family farmers were replaced by industrial-style operations. At the same time, hog production, which had previously been distributed across the state, became concentrated in eastern North Carolina (9). Expansion of industrial operations occurred under regulatory controls strongly influenced by hog producers and other agribusiness interests in the North Carolina General Assembly. State legislation was enacted to

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prevent local and county governments from zoning agriculture, and research support was provided by state universities closely allied with agribusiness concerns (10).

As citizens of Halifax County began to learn about industrialized hog production, many became deeply concerned about local impacts of such “economic development.” They worried about air pollution and noxious odors. They feared that groundwater could be contaminated in an area with sandy soils and high water tables where most residents depend on private wells for drinking water. They learned of the potential for surface water pollution from spray field runoff and lagoon failures. They were concerned about loss of independent family farmers and the land that they had farmed, and they were concerned about the vitality of their churches, schools, and communities. They felt they had been targeted for this kind of “economic development” because their primarily African-American, low-income communities lacked political power (11).

The Concerned Citizens of Tillery (CCT), a grassroots organization in southeast Halifax County, worked with county officials to develop an intensive livestock

ordinance that would impose stricter environmental controls than state regulations. In that effort, and in the course of providing assistance to other communities in the path of corporate pork production, CCT sought support from environmentalists, social activists, and researchers who could help document economic, social, environmental, and public health issues affecting communities living with swine CAFOs (11). Although university scientists had conducted many studies related to agricultural technologies, veterinary health, and health of agricultural workers, relatively little research had addressed environmental, social, and health concerns of communities affected by industrial hog production.

Environmental Injustice in North Carolina’s Hog Industry

The siting of a landfill for polychlorinated biphenyls (PCBs) not far from Tillery in predominantly African-American Warren County, North Carolina, in 1982 is often cited as an event that introduced the term “environmental racism” to a national audience (12). Ten years later, CCT and other community-based organizations in eastern North Carolina were beginning to see industrial hog

production as an environmental justice and public health issue. During 1982–1997, leading hog-producing areas experienced greater loss of family farms than did other areas of North Carolina (13). This raises concerns for rural communities because family farms keep money in local economies and help maintain local businesses and services. Biologic and chemical contaminants from swine CAFOs, including bacteria, viruses, nitrates, hydrogen sulfide, and endotoxins, threaten community health when they contaminate air, aquifers used for drinking water, and streams and rivers used for subsistence fishing and recreation (14). Ironically, any health effects occurring from these exposures would be difficult to detect by examining medical records because the communities affected most have little access to medical care. Residents also distrust local health departments and other medical care institutions because of a history of segregation, exclusion, and prejudice (15,16).

A Community-Driven Research Partnership

Noxious odors—so severe that residents who can afford it sometimes leave their homes to spend especially bad nights in



Figure 1. Confined animal feeding operations in eastern North Carolina showing fecal waste pits in the foreground, confinement structures (left and right middle), spray fields, and neighboring homes.

motels—prevent neighbors of CAFOs from enjoying their homes and the outdoors. Odorant chemicals can penetrate clothing, curtains, and upholstery, affecting people long after plumes of emissions pass and subjecting them to possible ostracism at school or in public. One study suggested that hog odors can affect the mental health of nearby residents (17); another suggested that neighbors experience respiratory effects similar to those seen among workers in the confinement buildings (18). Mothers in eastern North Carolina report that their asthmatic children experience episodes of wheezing in the presence of strong plumes from nearby hog operations.

I met numerous residents of low-income, African-American communities who told me that industrial hog operations were increasingly being located in their communities. In one area residents had marked locations of churches, schools, and hog operations on a large map to demonstrate the proximity of African-American communities to swine CAFOs. However, when residents spoke to journalists and government officials about discriminatory patterns in the siting of these facilities, they were frustrated by responses that community observations were anecdotal and did not prove any consistent pattern. African-American and white neighbors of swine CAFOs, frustrated by lack of action from local governments, kept diaries to document odors and health problems, took photographs of waste spills and rotting hog carcasses, and wrote to state and federal officials.

In late 1996, a partnership formed by CCT with the Halifax County Health Department and the University of North Carolina (UNC) School of Public Health received funding from the National Institute of Environmental Health Sciences' (NIEHS) Environmental Justice: Partnerships for Communication program (11). Along with environmental justice education and outreach to communities and medical providers, we were funded to conduct research that, using official records, could quantify systematically the extent to which hog CAFOs and their potential impacts on health and quality of life disproportionately affected communities of low income and people of color (primarily African Americans) in the state. Our aims were to evaluate data for local communities, to consider possible alternative explanations for observed patterns, and to consider data on household water source (well or municipal), because groundwater contamination is an important public health concern.

Although data analyses were conducted at the university, the study questions originated in the exposed communities. Community members participated in evaluating data quality through their knowledge of local CAFOs. In consultation with our community

partners, we made decisions about how to define the study population and data sources, how to choose and define variables for the analysis, and how to interpret results. We augmented our statistical analyses with maps and charts. And we found that hog CAFOs were far more common in poor communities and communities of people of color, that this concentration was more extreme for integrator-owned or contracted CAFOs than for independent operations, and that the pattern was explained only partly by differences in population density. Furthermore, we found that hog operations were concentrated in areas where most people depend on household wells for drinking water (19).

Reactions to the Environmental Justice Study

We were invited to present our findings at an environmental justice session sponsored by the NIEHS during the annual meeting of the Society of Toxicology in March 1999. The North Carolina General Assembly recently had passed a moratorium on construction of new hog CAFOs (except those using “new technologies”), the governor’s office was developing a plan to address environmental problems from the lagoon and spray field system, and industrial hog producers were in the news because of waste spills and impacts of nutrient loading on fish, shellfish, and a recently discovered toxic dinoflagellate, *Pfiesteria piscicida*. The CCT had worked in partnership with numerous grassroots groups and traditional environmental organizations to educate the public about effects of industrial hog production and to provide organizational support to local affected communities. To support these efforts and contribute to the ongoing policy debate, we decided to release information about our findings to the press in conjunction with my presentation at the national meeting. The release was coordinated with the UNC News Service, which routinely prepares stories about topical research when it is publicly presented or published. Several major state newspapers ran stories on our findings.

I immediately received calls from representatives of industry groups who wanted to explain to me how the pork business is run. In their view, it was just good business to select the cheapest land for hog CAFOs—and that just happened to be areas that were rural, poor, and disproportionately African American. I soon learned that one of the industry representatives who called me was a member of the UNC Board of Governors. In early April I received an invitation to appear before the House Agriculture Committee of the North Carolina General Assembly. I was pleased by their interest and excited about the opportunity to address a

group of policy makers interested in our findings. However, when I told CCT Executive Director Gary Grant about the invitation, he explained that the committee included a number of hog producers, was friendly to agribusiness concerns, and was probably not very pleased with our research. I asked Gary to appear with me before the committee.

The UNC-Chapel Hill Associate Vice Chancellor for Government Relations set up a meeting to discuss my impending appearance at the General Assembly with the Associate Dean of the School of Public Health. The administrators stated that they did not want to tell me how to present our research, but they were clearly concerned that I make a good impression at the legislature, which, after all, votes on UNC appropriations. Meanwhile, in Tillery, at the weekly meeting of the Open Minded Seniors, one of CCT’s most active member organizations, Gary Grant announced that I had been called to the General Assembly to present our findings on environmental justice, and that I was not likely to be warmly received. Many members of the group were interested in attending the session to support Gary and me as we presented our research. About 30 CCT members traveled to Raleigh to attend the meeting of the House Agriculture Committee on 27 April 1999.

The Associate Vice Chancellor accompanied me to the hearing. The Open Minded Seniors had filled most of the public seating when we entered the hearing room; a couple of dozen lobbyists, staffers, environmentalists, activists, and other spectators stood at the back of the room. After staff members finished setting up the slide projector and providing water for the committee members, the CCT members were the only African Americans remaining in the room. Some committee members had a few technical questions about my presentation, such as why we didn’t use more recent income data, and made other remarks about the business logic of locating hog CAFOs in poor areas. Committee members also wanted to know whether state funds had been used for our research. Next, Gary Grant spoke about the policy implications of our work and the urgent need for the North Carolina General Assembly to help citizens of eastern North Carolina living with air and water pollution from hog CAFOs. At one point the Open Minded Seniors began to applaud, which prompted the committee chair to use his gavel to quiet the room with the statement that applause was not permitted. Despite this admonition, the Open Minded Seniors had made their support for us clear to all present.

At the end of the hearing, I spoke cordially with the committee chair and a number of spectators, including one industry lobbyist.

Then I was approached by another industry lobbyist who introduced himself by handing me his business card. He refused my offer to shake his hand, demanded a copy of our full report, and said that if I did not send him one immediately I would be facing a lawsuit. I was startled by his hostility but shrugged it off as an overreaction.

The Rural Health Survey

In addition to the environmental justice study, we were also involved in more traditional health effects research. In the fall of 1998, with support from the North Carolina State Health Department, we initiated a survey of rural residents in eastern North Carolina. Reports of odor problems and respiratory effects had been coming in from hog CAFO neighbors across eastern North Carolina, and the State Health Department was interested in obtaining more information. To our knowledge, only one small study, from Iowa, had been published on respiratory health effects among swine CAFO neighbors (18). In consultation with our community partners and staff from the State Health Department, we designed a survey to compare health and quality of life of residents of three communities, one in the neighborhood of a hog CAFO, one in the neighborhood of a dairy operation that used a liquid waste management system, and a third with no intensive livestock production.

Design and Conduct of the Health Survey

Designing the study presented a number of challenges. Our environmental justice analyses were, by then, confirming the observations of community members that hog CAFOs are disproportionately located in low-income and African-American communities. We would need to ask for the participation of people whose past experiences led them to distrust health departments, medical providers, universities, or researchers. The relationships with community-based organizations that we had established in our environmental justice project would be essential for collecting reliable data and establishing a high response rate in defined populations in the three areas. At the same time, we knew that to avoid potential biases that could be introduced by community participation in areas divided between those with negative feelings about the hog industry and those whose livelihood depends on the industry, we would need to insulate the data collection process from peer pressure or leading questioning. Quantification of individuals' exposures to hog CAFO emissions, a key component in establishing dose-response relationships, would be extremely expensive; furthermore, even if we could afford to make

environmental measurements, it was not clear which of the many hazardous agents present in odorous plumes are most relevant to health effects. Clinical confirmation of symptoms would also be desirable; however, severe responses to air pollution episodes are too uncommon to evaluate statistically in small populations, and poor access to medical care could lead to underestimation of problems. We debated carefully whether it would be ethical to conduct a study if we could not measure exposures and outcomes sufficiently well to detect a health effect if one existed, recognizing that our design would be constrained by funding that could be provided by the State Health Department. Our decision to proceed was influenced by evidence from previous studies and by community members and state officials who felt an urgent need for respiratory health data from North Carolina.

We developed a structured symptom questionnaire based on previous studies and input from eastern North Carolina residents who helped us use culturally appropriate language. We used the same questions in each of the three communities, and included no questions about odor, hogs, or livestock because one community had no livestock. We chose three communities with similar demographic characteristics according to census data. In each community, we conducted a household census, noting each occupied dwelling on a map and assigning a code to the residence (20).

We collaborated with a community-based organization in each area. Community members helped us locate roads and houses, and they served as community consultants during the data collection. Trained interviewers from UNC visited households in each area, accompanied by a community consultant who made the initial introduction of the researcher. Interviews were conducted without the presence of the community consultant unless the participant requested that the consultant remain. The interviewer read aloud, and provided the study participant with a copy of, an "Agreement to Participate" that explained that the study was about environmental exposures and health of rural residents. Participants were assured that their responses would be kept confidential and that their name would not be written on the questionnaire, although a link would be maintained between their address and responses. UNC's IRB gave us permission to obtain oral consent because we used no interventions or sensitive questions, and because a signed consent form would have been the only record of a person's name.

In the two livestock communities, interviewing teams visited households nearest the CAFOs first and then visited households in

order, moving away from the CAFO, until they reached our target sample size of 50, with one adult in each household interviewed. Data collection took place in January and February 1999. We completed 155 interviews, with a refusal rate of 14%. Respondents were 92% African American and 65% female, and 27% were 65 years old or older (20).

In mid-April 1999, before submitting our report to the State Health Department, we invited members of the three community-based organizations to a meeting to discuss our initial findings. We obtained input from community members and responded to questions and concerns about excesses of respiratory and digestive symptoms that had been reported by hog CAFO neighbors compared with residents of the other communities. Community members decided at this meeting that they did not want the names of their communities to be included in our report. We therefore removed from our report any data on numbers of households, population size, race, and income characteristics of the census block groups in the study. These characteristics had been used to match communities in the study, but the figures could have been used by others to deduce the identities of the communities. We also removed from the report any exact information about the size of the hog and cattle CAFOs, which had been derived from Department of Water Quality permit data, and replaced the numbers with approximate figures.

At the end of April, we submitted a draft report to the State Health Department. Our analyses showed that the frequency of miscellaneous symptoms such as muscle aches and vision and hearing problems was similar in the three communities. In contrast, residents near the hog CAFO reported increased numbers of headaches, runny noses, sore throats, excessive coughing, diarrhea, and burning eyes. They also reported many more occasions when they could not open windows or go outside even in nice weather. The report was reviewed by State Health Department staff, the chief statistician for the State Center for Health Statistics, the chair of the UNC Department of Epidemiology, and others. Our final report incorporated their comments.

The Pork Industry Response

The State Health Department issued a press statement releasing our report to the public on 7 May 1999. Later that day, attorneys for the North Carolina Pork Council wrote to my coauthor, Susanne Wolf, and me requesting that we

make available for copying by this office any and all documentation in your possession (or that you are aware of in the possession of other State agencies or State personnel) that contain, represent, record, document, discuss, or otherwise

reflect or memorialize the results of the Study or any conclusions or recommendations that you or any local, state or federal agency might draw from the Study or any other matter discussed in the Report, including, without limitation, the studies of the three communities referred to in the Release; any notes or other records from any site visits or interviews made during the course or as a part of the Study; any sampling, testing or other analysis that was performed as a part of the Study; any calculations, research, or other work papers that reflect any analysis that you or others made from or using the data collected as a part of the Study; any contracts or other similar documents that define the Study or any having to do with payment for the study; the identities of all persons who worked on or contributed to the Study (including persons interviewed); and any other documentation that were generated as a part of or in the course of the Study.

This request was made under the North Carolina Public Records Statute, which defines a public record as all

documents, papers, letters, maps, books, photographs, films, sound recordings, magnetic or other tapes, electronic data-processing records, artifacts, or other documentary material, regardless of physical form or characteristics, made or received pursuant to law or ordinance in connection with the transaction of public business by any agency of North Carolina government or its subdivisions.

The North Carolina Public Records Statute does not protect documents collected in the course of research involving human subjects and requires public officials, defined to include university faculty, staff, and graduate assistants who work for pay, to turn over records in a timely manner. The letter also stated that attorneys for the Pork Council would evaluate whether any of our statements were defamatory. Finally, the letter stated:

it is imperative that we be given access to those documents no later than Wednesday, May 12. If we are not granted access to those documents in a timely manner, we have been directed to prepare an action for filing in the appropriate division of the General Court of Justice, pursuant to N.C. Gen. Stat. §132-9, for an order compelling disclosure or copying of those records and to seek such other remedies as are available for those statutes.

The Pork Council request raised a number of concerns. First, I was obligated to protect the confidentiality of participants. My name and contact information appeared on the Agreement to Participate that had been given to each participant. Although we did not record participants' names, we did have maps of the locations of their homes linked to their responses by a randomly assigned study number. Even without the maps, information about participants, including age, race, sex, occupation, industry, number in household, water source, and responses to questions about health status, was certainly

sufficient to deduce which individuals from a particular area were in the study in these sparsely populated rural communities.

Breach of confidentiality was a concern not only from a legal and ethical standpoint. The community trust upon which our research depended would be seriously compromised as well, potentially destroying valued professional and personal relationships and threatening the continuation of research into exposures and health of neighbors of swine CAFOs. Given my professional and institutional position, I could not expect a second chance. Furthermore, if I violated my agreement with participants I could be branded, across the state and in other regions where there is a growing network of communities affected by corporate swine production, as untrustworthy.

The pork industry responded not only to the university but also to our federal funders. Shortly after receiving the letter from the Pork Council attorney, I received a message from the official at NIEHS in charge of the environmental justice grant program: "I've had a request to put together a summary of your project. Do you have any relevant health effects data available? I have been asked to do this ASAP so any help you can provide will be greatly appreciated." He further explained that "this request has to do with a congressional inquiry" and that "we may have to provide records under the Freedom of Information Act." I interpreted this as an effort of the industry to challenge federal support for our research, and responded by sharing with NIEHS the letter from the Pork Council attorney and suggesting that material from our annual report be used to respond to the request. There were no further requests from NIEHS.

Although the primary purpose of the Pork Council's request appeared to be harassment and intimidation, the request related to an important and legitimate part of scientific inquiry: the ability to replicate findings and evaluate evidence independently. In fact, I had recently conducted an independent reevaluation of environmental health effects using data from a study that had been designed and conducted with funding from industry (21–23). Just as some community members in that case were concerned about conclusions from an industry-funded study, now an industry group was concerned about findings from a study that was conducted with community participation. To evaluate the quality, internal consistency, and analytical methods in our rural health survey, the industry would need to be able to conduct an independent reanalysis. The need to protect confidentiality would have to be considered in relation to a scientific culture in which reanalysis is essential

and in relation to power inequalities between industry and the exposed communities.

The university attorney, who had been copied on the Pork Council attorney's letter, explained to me that North Carolina law required us to turn over all documents related to the study as quickly as possible. Because this would have violated our agreement with study participants, I consulted with the chair of our IRB and other university officials. One administrator told me that if I refused to turn over documents as directed by the university attorney, the university "would call the SBI [State Bureau of Investigation] and have me arrested for stealing state property." We discussed withholding documents on the grounds that their release would have a chilling effect on future research, and on grounds that we would be violating the confidentiality promised in the Agreement to Participate. The administrators were not hopeful that these arguments would be accepted, and in any case deferred to the university attorney on making a final decision.

In June, the university attorney agreed to release records to the Pork Council, including computerized files of individual responses, interviewer training instructions, draft copies of our report, other statistical tabulations, and study related correspondence, including electronic mail messages of all project staff. To protect confidentiality of the participants and the communities, the university attorney agreed that we should withhold any information that could lead to disclosure of where the study was done, including maps, driving instructions, and any references in our communications or study materials to locations or names of persons that would identify locations in the study. We reasoned that no individuals could be identified, even with information in the survey, unless the locations of the survey were known. Staff members and I spent considerable time in assembling and redacting documents. In the presence of the rural health survey project director and other staff, an attorney for the Pork Council reviewed the documents and copied many of them. They continued until August to request information that we had withheld and then ceased to express interest.

In July 1999, I was invited by the State Health Department to present findings of our study at a conference on the public health impacts of intensive livestock operations. The conference was held at North Carolina State University in Raleigh, which has the Animal and Poultry Waste Management Center, a veterinary school, and other programs related to industrial agriculture. A number of pork producers attended the conference and posed hostile questions after my presentation. Later, I was approached by an assistant professor

from another UNC-system institution, who told me, “I have been conducting research on neighbors of hog operations, but I’m afraid that if I have to deal with legal problems like yours, I’ll never get tenure. So I’ve decided to drop my research for now.”

The Sustainable Hog Farming Summit

In the fall of 2000, I accepted an invitation to speak about our environmental justice and public health research at a conference being organized by a coalition of independent farmers, environmentalists, and grassroots organizations billed as the “Sustainable Hog Farming Summit.” The conference was scheduled for January 2001 in New Bern, North Carolina. On 8 December, I was copied, along with the Dean of the School of Public Health and the UNC Chancellor, on e-mail correspondence from the UNC Associate Vice Chancellor for Government Relations. Staff in the UNC system president’s office had written to the Associate Vice Chancellor:

We have received several questions and complaints from legislators and others—received through different offices in the University—about the Sustainable Hog Farming Summit announced for Thursday, January 11, 2001 at New Bern.... Five faculty members at three different UNC institutions show on the Summit agenda as program participants (moderators or panelists). I’ve been asked whether those faculty members are representing themselves or the universities where they are employed, are attending on university time or their own, and whether they are paying their own expenses or is someone else (presumably meaning the university or the conference sponsors).

During 15 years on the UNC faculty I had presented research at scores of meetings but had never before been asked to account for myself in this way. The associate vice chancellor described a senior member of the North Carolina Senate who “had concerns about Carolina’s [UNC’s] ‘involvement’ with the program.” She also described a conversation with two Pork Council lobbyists “whom I consider to be friends” and reported that “they are fully cognizant of the fact that we cannot and will not censure our faculty.” I responded to the administrators by explaining that I was appearing as a university employee to present my research, and that I would be funded by our environmental justice research and education grant.

Social and Ethical Responsibilities of Researchers

Environmental health research can influence conflicts between communities of low income or people of color and the institutions that derive benefits (profits, federal and

state funding or services, avoidance of wastes) from the activities and policies that burden these communities. Researchers, most of whom work in relatively privileged institutions, are placed in situations of conflicting loyalties if they conduct research in collaboration with, or on behalf of, communities burdened by environmental injustices. These conflicts can threaten the self-interest of researchers and may raise social and ethical issues that do not typically arise in research projects that respond to the agendas of institutions.

Principles of Research Design

Before addressing some of these conflicts as they apply to our case, it is important to be clear that researchers performing community-driven environmental health research should not encounter conflicts over the logic used to design research. Our scientific culture values expert opinion and standardized, replicable techniques over lay opinion and observation. Because observations of community members do not “count” in the scientific literature used by policy makers and courts, researchers can maximize their service to communities by devising standardized procedures, including data collection and measurement techniques, that comport with professional standards, even as we may need to change those standards to improve science. First among our considerations should be to conduct studies that have the sensitivity to detect an effect if one exists. The ability to detect no effect when one does not exist is also important, although in the case of community-driven environmental health, researchers must carefully distinguish “no effect” for a specific biologic end point from “no effect” in an ecologic context that encompasses social, psychologic, and economic impacts.

The challenge for researchers is to work with community members to frame questions, and design procedures to produce answers, that respect community concerns by investigating them with the best technical approaches possible, including newly devised methods to enhance community input and analyze data. Results of these investigations will be useful to communities burdened by environmental problems because such research can address topics that could not be investigated without the technical resources of institutions, and because the findings can be used in situations where community observations are not valued. Rather than facing a conflict between standard procedures and alternatives that are acceptable to the community but viewed as “unscientific” by scientists, both researchers and community members benefit from negotiating the use of rigorous methods.

Responding to Government, Industry, and the Media

In responding to concerns and inquiries from the state legislature, university administration, and federal granting agency, I might have distanced myself from the communities living with hog CAFOs and their allies. Instead, I kept them informed. This strategy had two effects. First, I maintained the trust of the communities who had been instrumental in identifying research questions, conducting fieldwork, and educating the public about our findings. This trust would continue to be essential if we were to address additional research questions. Second, the communities responded by appearing at the legislative hearing, giving advice on acceptable means of responding to the public records request, helping to identify external legal support, and providing strong encouragement and support. If I had backed away from the community under institutional pressure, not only would I have compromised relationships essential to conducting high-quality research, our research partnership would have lost support of an outside constituency at the very time when it was most needed.

Some academics are reluctant to interact with the media. They feel that their findings are misrepresented and misunderstood and that interviews take considerable time and have little potential to influence scientific publications or grant funding, the criteria that matter most for career advancement. However, community-driven researchers have responsibilities regarding publication of scientific findings, making those findings public in appropriate ways, and participating in processes involving the media and policy makers (24,25). Environmental health findings can help exposed community members protect themselves, can motivate participation in democratic processes, and can influence public opinion and policy makers. Researchers have an obligation to be involved in targeted efforts to inform affected communities about research results as well as to participate in activities that have a wider audience (24). These activities must be conducted in partnership with affected communities.

Researchers have a responsibility to report findings of studies even when they can be expected to produce negative reactions from industry, government, or universities. Publications are a key goal of researchers seeking to compete for positions and grant funding in an entrepreneurial environment. However, when research sheds light on institutional discrimination, environmental contamination, or health effects that could create legal problems for institutions that provide jobs and funding to researchers, researchers

may be motivated to withhold or delay publication, or to provide benign interpretations even when there is evidence of harm. Such actions fail to meet responsibilities to research participants, exposed communities in the study area and elsewhere, policy makers, and researchers working on the same or related problems.

Respecting Interests of Individuals and Communities

Our experiences with the public records act request have similarities with cases of other researchers whose records have been subpoenaed in law suits involving large corporations (26–30). Tobacco, oil, and pharmaceutical industries have sought and obtained research records that university investigators had assumed would be protected by confidentiality requirements. Furthermore, it cannot be presumed that university administrators will take a strong advocacy role in protecting research records or faculty members (26,27). Our compromise, revealing responses but not locations of the respondents, was based on the assumption that both pieces of information would be required for deductive disclosure of the identity of participants through age, sex, race, occupation, and household characteristics. This compromise was accepted by the university attorney despite the concern that the university might have to go to court to protect the identity of communities. However, given the complexities of deductive disclosure from a statistical as well as an ethical standpoint, it is inappropriate for a researcher and an attorney, especially under threat of litigation, to make the final decision about release of data. Researchers and institutions faced with similar decisions should consult a panel, possibly an IRB or a committee of an IRB, that includes a statistician, community members, and others experienced in protection of human subjects.

A more fundamental problem is that IRBs are concerned only with protecting individual research participants. In our research, we were also concerned with protecting the communities where the research was conducted. The presence of industrial hog operations has split communities between those who depend on the industry for income and those whose quality of life and health have been adversely affected (31). In some areas, community members have been fearful of participating in research because of the influence of the hog industry in local affairs. One resident told us, “If you want to do a survey in this community, you’d better finish on the first day, because you won’t be able to come back.” We were also advised not to call the sheriff’s department if we had trouble on the road. Several community members who have publicly opposed the industry told me that they have

been followed and threatened, and that they carry weapons for their own protection.

In 1998, attorneys for a hog grower wrote to Elsie Herring, a North Carolina woman who had requested help from local and state public health officials regarding spraying of hog waste that drifted onto her and her mother’s homes and cars (32). The attorneys threatened to sue Herring and impose a restraining order if she persisted in her requests for assistance. “If you violate any such restraining order,” the letter stated, “we will ask the court to put you in prison for contempt.” At the Sustainable Hog Farming Summit, Herring reported that the grower blocked passage of her car on the road to her mother’s house, and that he entered her mother’s home without invitation, shouted at her mother, and shook her as she sat in her chair. Herring’s mother was in her 90s.

On 11 September 1995, Dana Webber reported in the *Wilmington Star* (33) that two residents of Duplin County, North Carolina, who had publicly opposed industrial hog production became concerned for their jobs after their supervisors were contacted by representatives of Murphy Farms, then the largest hog producer in the world. Although both left their jobs, “not solely because of Murphy’s intimidation tactics,” one of the workers said, “It’s a mind game. This pork industry has got people scared thinking that they’re so big and strong and that we can’t do without them.” According to Webber, “Duplin County officials contend that people in the county have complained to them about the kind of intimidation tactics [the workers] describe.”

In this adversarial climate, the very choice of research topics almost invariably involves taking sides, whether it is research on environmental health or waste management technology. Human subjects are not the only ones at risk in public health research; community organizations that cooperate with researchers, community consultants who facilitate contacts between researchers and human subjects, family members, and others may reasonably fear intimidation and threat. Furthermore, communities that host facilities widely known for repellent odors may fear stigmatization if their identities are known. Researchers working on environmental health issues in the area of environmental injustice need to consider not only their obligation to individual human subjects but also their social responsibilities to entire communities (5,34).

Conclusions

Most researchers are accustomed to full-time employment with health insurance, pension benefits, and wages that afford housing in

neighborhoods with access to clean water, sewerage, adequate schools, and medical facilities and that are free from major sources of environmental contamination. For us, antagonism from an industry that is threatened by environmental health research, or the question of support from our own institutions, can be very disturbing. However, these problems pale in comparison with the situations of people who live every day in a contaminated environment, unable to enjoy their homes and neighborhoods, unable to sell their property (if they are owners), fearful for their own health and the health of their family members. Although I have focused on the perspectives of an epidemiologist working on community-driven research, it is important to emphasize that researchers may choose to walk away from pollution and conflict; most community members who live with discrimination, pollution, and conflict have no choice but to accept or to fight injustice.

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