

Qualitative Methods In Environmental Health Research

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Abbreviations

ACE – Alternatives for Community and Environment  
CDC – Centers for Disease Control  
CSA – citizen-science alliance  
DPH – Department of Public Health  
EPA – Environmental Protection Agency  
FACE – For A Cleaner Environment  
MTBE – methyl-tertiary-butyl ether  
NIAID – National Institute of Allergies and Infectious Diseases  
NIEHS – National Institute of Environmental Health Sciences  
NIH – National Institutes of Health  
PCE – tetrachloroethylene  
TCE – trichloroethylene  
TURI – Toxic Use Reduction Institute

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### Abstract

Public health researchers increasingly turn to qualitative methods either on their own, or in combination with quantitative methods. Qualitative methods are especially important to community environmental health research, since they provide a way to produce community narratives that give voice to individuals, and that characterize the community in a full and complex fashion. This article first traces the legacy of qualitative research in environmental health, and then uses a case study of the author's experiences studying the Woburn childhood leukemia cluster in order to provide personal and scholarly insights on qualitative approaches. That material then informs a discussion of important components of qualitative methods in environmental health research, including flexible study design, access, trust, empathy and personal shifts in the researcher's worldview, bias, and the nature of the researcher's roles. A concluding discussion addresses issues in funding policy and research practices.

### Introduction: Why We Need Qualitative Methods

Public health researchers increasingly turn to qualitative methods either on their own, or in combination with quantitative methods. Qualitative methods are especially important to community environmental health research, since they give voice to individuals and community-based organizations, as well as characterize the community in a full and complex fashion. By giving such voice, qualitative researchers often support lay discovery of, and action on, hazards and disease. Even when quantitative data is needed to determine the existence of environmental health effects, qualitative data is necessary to understand how people and communities experience and act on these problems, since quantitative data can only render an imperfect or partial picture of health effects and their causes.

Flyvbjerg (2001) offers a compelling argument for the validity of qualitative approaches, in which research focuses on values, gets close to people and phenomena, emphasizes the daily practices that shape social action, employs case studies within a broader social context in which power relations are key, uses narrative as the expository technique, and works to create an interactive and dialogical understanding (63). The dialogic understanding is a “polyphony of voices” that adds to “ongoing social dialogues” rather than generates verified knowledge (139). Using Aristotle’s concept of “phronesis,” or practical wisdom, Flyvbjerg argues that research must combine intuition, experience, and judgment, something that the traditional rationality of positivism cannot provide (2, 21). Because we are studying self-reflecting humans, we must take into account the changes in their interpretation. This requires a “context-dependence,” i.e. an “open-ended, contingent relation between context and actions and interpretations.” (32, 43).

Much disease is caused by substances and conditions in people's surrounding environment, including chemicals and air particles in factories, pesticides in agriculture, toxic wastes in residential neighborhoods, radiation in the atmosphere, indoor allergens, and tobacco smoke. The “environment” is so broad that we could virtually subsume all disease processes under its umbrella of unhealthy living and working conditions. I focus on the narrower health effects caused by chemicals, air pollution, and radiation, which have generated much conflict, policymaking, legislation, public awareness, media attention, and social movement activity.

The first kind of research on environmental health that we usually see is community health studies, direct investigations of environmental hazards and/or environmental health effects. Epidemiologists are the typical collaborators, joined by other scientists. These researchers seek to characterize hazards, measure exposures, and detect health effects. Increasingly, much of this epidemiological research involves community collaboration (Quigley et al. 2000).

In-depth qualitative studies of contaminated communities are undertaken mainly by sociologists, but occasionally by psychologists, public health scholars, and political scientists. Researchers typically come in to study how laypeople have discovered environmental problems and how they have acted on this knowledge. Such ethnographic research is usually done following a health study, because at that point the “contaminated community” (Edelstein 1988) is in the public eye. The distinction between community health studies and community ethnographies is fluid, however. Some community groups collaborate in both forms, as is seen in some recent community-based participatory research. As well, some social scientists enter the research setting as part of a team that is doing the epidemiological research. These hybrid qualitative-quantitative forms are increasingly prevalent, and current interest makes it possible that methods will evolve to a point where there is no distinction between health effects research and community ethnography, where any project seeking to examine environmental health would

combine epidemiological approaches with sociological/anthropological analysis rooted in community collaboration.

This paper focuses on in-depth ethnographic studies of contaminated communities. There are, of course, other forms of qualitative methods used in environmental health research. For researchers less engaged in reflexive ethnographic work, techniques include structured interviewing, focus groups, policy analysis, media analysis, and content analysis of documents. Apart from my focus on contaminated communities, qualitative methods can play important roles in environmental epidemiology and environmental justice research.

Environmental epidemiology examines the health effects of environmental hazards, including chemicals, radiation, high voltage lines, and air particulates. By definition, this must be a quantitative field to measure such exposures and effects. Still, we are seeing increasing qualitative-quantitative linkage where research centers – often academic-community collaboratives – use quantitative environmental epidemiology in tandem with qualitative techniques such as focus groups and interviews, in order to gain a well-rounded view.

Environmental justice research often involves quantification of racial and class disparities in exposure to environmental hazards and in diseases, though some research examines the community discovery of, and action on, environmental problems. For example, Robert Bullard (1990) based his earliest work on the environmental justice movement on his participation in local activism. Bullard's (1993) *Confronting Environmental Racism: Voices from the Grassroots*, a collection of accounts of the environmental justice movement, demonstrates how environmental racism leads to health inequalities by excluding certain segments of the population based on race and class from environmental decision-making. Most of these accounts are voices from the grassroots, as many of the contributors are narrating the struggles of these environmental justice groups from a participant's perspective. Other sociologists have provided analyses of environmental justice organizing efforts, using community voices extensively, though written by the scholars rather than the activists (e.g. Roberts and Toffolon-Weiss 2001).

Virtually all cases of contaminated communities are detected by lay discovery, largely because affected populations tend to notice environmental problems. As well, scientists and government agencies are not usually carrying out routine surveillance that would detect such problems. Even routine surveillance is insufficient; for example, a state cancer registry may be mandated to publish annual reports of cancer excesses by town and city, but will not be required to notify places that have the excess. Even when asked by communities, the agencies do not do enough. For example, a survey of all 50 states' responses to lay cancer cluster reports found that there were an estimated 1,300-1,650 such reports in 1988, a large number for short-staffed agencies. Many health departments discouraged informants, sometimes requesting extensive data before they would go further. Health departments often merely gave a routine response emphasizing the lifestyle causes of cancer, the fact that one of three Americans will develop some form of cancer, and that clusters occur at random (Greenberg and Wartenberg 1991).

Laypeople's role as the typical discoverers of crises creates a special dynamic that makes qualitative research important. Neighborhood residents are trying to figure out what is happening to them, and once they believe they know what is happening, they have a long and complicated route to get something done. They have a multitude of stories of learning about hazards, sharing their problems, organizing politically, challenging scientific and governmental authority, dealing with resistance by fellow townspeople, and becoming scientifically capable. These stories, woven into various narratives, can only be understood through the in-depth study provided by ethnographic research. To convey this, I begin with a look at the history and legacy

of ethnographic studies of contaminated communities. Next I discuss personal and scholarly insights on qualitative research from my study of the Woburn childhood leukemia cluster, as well as from my more recent work on contested environmental illnesses. Last, I look at future directions in federal research funding policy, “advocacy science” and “citizen-science alliances.”

### History and Legacy of Qualitative Research in Environmental Health

The study of qualitative methods in environmental health research takes us to the very origins of the field of environmental sociology. When the 1972 Buffalo Creek flood occurred, Kai Erikson was called by the plaintiff’s lawyers to write a report on the damage done to the residents of the poor Appalachian community that was so thoroughly destroyed by corporate malfeasance. A lake of coal mining sludge, held back by a poorly constructed and inadequately maintained dam, swept down the hollow. It destroyed whole villages with hundreds of homes, uprooted miles of railroad tracks, killed 125 people, wounded many others, and left immense psychological scars on the residents of the coal mining hamlets (Erikson 1976).

Buffalo Creek was not a toxic crisis, but nevertheless served as the first book-length community study of human-caused environmental disaster. Erikson used the eloquent descriptions of the residents to fashion an emotionally powerful, sociologically astute account, tying together the shock of individual trauma and the collective loss of communality. His study was particularly significant in showing the centrality of community effects, and in highlighting the mental health outcomes in addition to physical health. Further, it was exceptional in how it situated the human-made disaster in the cultural, social, and historical context of the community. It was a piece of sociological research in the service of the affected people.

The rich legacy continued with Adeline Levine’s (1982) *Love Canal: Science, Politics, and People*. Levine (1982) recounted the story of a buried waste site in a small suburb of Niagara Falls and the environmental disaster it produced. The story began with routine dumping of hazardous chemicals in the 1940s and ends with the insidious poisoning of children and families, some of whom were forced into a fight with local and national authorities. Levine (1982) was first introduced to the crisis in Love Canal, New York by a television news broadcast. After briefly visiting the community to determine the magnitude of the problem, she became “hooked” and began the arduous search for funding to initiate fieldwork. When no immediate source of funding could be found, Levine responded by utilizing her academic position to organize a graduate field-research seminar, engaging several graduate students in the study of Love Canal. For several years, Levine (1982) and her students conducted interviews with residents and local organizations and attended public meetings and events, maintaining a constant presence in the community.

Other ethnographies of toxic-assaulted communities followed: Michael Edelstein’s (1988) *Contaminated Communities: The Social and Psychological Impacts of Residential Toxic Exposure* examined a water contamination episode in Legler, NJ; Steve Kroll-Smith and Stephen R. Couch’s (1990) *The Real Disaster is Above Ground: A Mine Fire and Social Conflict* studied an underground mine fire in Centralia, PA; Michael Reich’s (1991) *Toxic Politics: Responding to Chemical Disasters* compared the Seveso, Italy dioxin explosion, the Michigan PBB cattle-feed contamination, and the PCB contamination of cooking oil in Japan; Lee Clarke’s (1989) *Acceptable Risk: Making Decisions in a Toxic Environment* detailed the Binghamton, NY state office building fire; Martha Balshem’s (1993) *Cancer in the Community: Class and Medical Authority* looked at the hazard perception of people in a Philadelphia working class neighborhood; and Steven Picou (1990) examined *Social Disruption and Psychological Stress in*

*an Alaskan Fishing Community: The Impact of the Exxon Valdez Oil Spill*. These studies recounted stories not told in the routine scientific literature, offering a rich texture of personal experiences and community effects. They emphasized the democratic rights of individuals and communities to learn about the hazards and disasters befalling them, and to achieve remediation, compensation, and justice. The researchers were largely allied with the concerns of the affected populations, and this was the body of literature that influenced me, some of it predating my Woburn research, and some of it coming later, affecting my subsequent research.

#### Personal and Scholarly Insights from Studying the Woburn Childhood Leukemia Cluster

I highlight my Woburn research, as published in *No Safe Place: Toxic Waste, Leukemia, and Community Action* (Brown and Mikkelsen 1990; revised 1997), because it allows for discussion of access, trust, confidentiality, sharing of data, researcher reflexivity, and benefits to the people and community being studied. I got involved in studying Woburn during a two-year research leave at Massachusetts Mental Health Center, part of the Harvard University Department of Psychiatry. I was involved with both the Laboratory of Social Psychiatry and the Program in Psychiatry and the Law. In the weekly meeting of the latter group, I was intrigued when psychiatrist Edwin Mikkelsen reported on his interviews with the Woburn families who were suing W.R. Grace and Beatrice Foods for contaminating municipal water wells, leading to a large number of leukemia cases, mostly in children. Mikkelsen had been retained by attorney Jan Schlichtmann to demonstrate that the families suffered psychological damage. He recounted a story that went beyond medical interviews and exams, extending to a series of public health investigations prodded by local residents who had discovered this disease cluster. The Woburn residents, without prior activist histories or public health knowledge, had educated and organized themselves in an incredibly effective way. Their efforts made national attention, putting the Woburn case alongside Love Canal as a key example of toxic waste organizing and of community-initiated research. Mikkelsen asked for help in thinking about sociological approaches, and we shortly came up with the idea for a book. My first thoughts went to Adeline Levine's *Love Canal: Power, Politics, and People*, which documented the signal case in the development of the toxic waste movement and, by extension, the whole modern environmental movement. I was amazed at Love Canal residents' efforts to determine environmental health effects and trace them to specific contaminants. My first impulse was to call this "popular epidemiology," though at the time I had no other situations on which to hang this term. As soon as Ed Mikkelsen and I began to talk about the case, I knew that my term was indeed a concept that could explain a new approach to environmental activism.

I did not have formal training in community-driven or community-oriented ethnography, though my graduate education had included a little about participatory action research. I was mainly familiar with ethnographic excursions into illness experience, such as living with chronic illness. My graduate school advisor at Brandeis, Irv Zola, was a natural fieldworker, comfortable with entering many different social worlds. One of his best pieces of work, also his most personal, was *Missing Pieces: A Chronicle of Living with a Disability* (Zola 1985), in which he stayed in Het Dorp, a Dutch community created for people with physical disabilities. Having lived his whole life disabled from polio and a major auto accident, Zola had adapted well, despite the body brace and canes he needed to get around. He did not write about or act on his disability until later in life, when he became active in the disability rights movement and a key initiator of sociological research on disability. I knew from Zola's experience about respect for the

community one was researching. I also knew the vagaries of being a sympathetic insider who had to deal with the temptation of partisanship that could conceivably reduce scientific rigor.

When offered the opportunity to investigate Woburn, I drew upon the skills and sensibilities I learned from Irv Zola. Taking the lead in the joint research project, I worked rapidly to get the story down as quickly as possible. I clearly gave thought to the sensitivities needed to do this, but only later did I become fully aware of what I was doing in practice – studying community-driven research by victims of toxic waste contamination. From the mid 1960s onward there had been a prior history of community participation, often in community mental health centers and neighborhood health centers, but there was no rich environmental health research tradition. So I had little guidance for my study. I understood that Woburn followed on Love Canal, and I saw that other similar popular epidemiology situations were developing, complemented by social science studies of those efforts. But I did not realize that the Woburn residents' research was part of a nascent approach that would shortly become nationally significant.

At Woburn, the community health study was unique as a collaboration between residents and professionals, and hence the prototype for popular epidemiology. I came in after this began, as an outside observer analyzing that collaboration. For community ethnography to be authentic and useful, it must also be a collaborative effort. At the primary research level where we study health effects, we clearly need trust between residents and professionals. The collaboration must address the issues of concern to residents, and must involve them in all aspects of problem definition and study design. A growing body of work, funded by NIEHS, NIAID, EPA, and CDC, has supported such action. My task here is to address the second level – community ethnography – when qualitative methods are used to analyze how contaminated communities deal with environmental crises. At the first level of health studies, communities seek to define the problem, remediate the contamination, prevent future occurrences, document health effects, and obtain medical, psychosocial, and monetary support. They may not begin with a concern for the fuller portrayal of the community narrative, though it is likely that they will develop such a concern once they realize that their community's struggle will get repeated elsewhere. The authenticity of the second level of community ethnography depends on how well the later researchers can portray the community's response to toxic waste contamination.

#### Brief summary of the Woburn case

I begin with a brief summary of the Woburn case; complete details can be found in *No Safe Place* (Brown and Mikkelsen 1990), especially the 1997 revision. Woburn residents had for decades complained about dishwasher discoloration, foul odor, and bad taste. Private and public laboratory assays had indicated the presence of organic compounds. The first lay detection efforts were begun earlier by Anne Anderson, whose son, Jimmy, had been diagnosed with acute lymphocytic leukemia in 1972. Anderson knocked on doors and put together information during 1973-4 about other cases. She hypothesized that the alarming leukemia incidence was caused by a water-borne agent. In 1975 she asked state officials to test the water but was told that testing could not be done at an individual's initiative. In 1979 builders found 184 unmarked barrels in a vacant lot; they called the police, who in turn summoned the state EPA. Water samples from a number of municipal wells showed wells G and H to have high concentrations of organic compounds known to be animal carcinogens, especially trichloroethylene (TCE) and tetrachloroethylene (PCE). Well G had forty times the EPA's maximum tolerable TCE concentration. As a result the state closed both wells.

A few weeks later, an engineer who worked for the state EPA drove past the nearby Industriplex construction site and thought he saw violations of the Wetlands Act. A resultant federal EPA study found dangerous levels of lead, arsenic, and chromium, yet EPA told neither the town officials nor the public. The public only learned this months later, from the local newspaper. Reverend Bruce Young, initially distrustful of Anderson's theory, came to similar conclusions once the newspaper broke the story. Along with a few leukemia victims, he placed an ad in the Woburn paper seeking people who knew of childhood leukemia cases. Working with John Truman, Jimmy Anderson's doctor, Young and Anderson prepared a questionnaire and plotted the cases on a map. Six of the 12 cases were closely grouped in East Woburn. Over the years they identified more cases, claiming 28 cases over a longer period, 1965-1980; 16 of those people died. In January 1980 Young, Anderson, and 20 others formed For a Cleaner Environment (FACE) to galvanize community support, deal with government, work with professionals, and engage in health studies.

Jimmy Anderson died in January 1981, and five days later the CDC/DPH study was released, stating that there were 12 cases of childhood leukemia in East Woburn, when 5.3 were expected. Yet the DPH argued that the case-control method (12 cases, 24 controls) failed to find characteristics that differentiated victims from nonvictims, and that lacking environmental data prior to 1979, no linkage could be made to the water supply.

The conjuncture of Jimmy Anderson's death and the DPH's failure to implicate the wells led the residents to criticize official scientific studies. They received help when Harvard School of Public Health biostatisticians Marvin Zelen and Steven Lagakos became interested. Working with FACE members, they designed a health study, focusing on child leukemia, birth defects and reproductive disorders. The survey collected data on adverse pregnancy outcomes and childhood disorders from 5,010 interviews, covering 57% of Woburn residences with telephones. The researchers trained 235 volunteers to conduct the survey, taking precautions to avoid bias.

During this period, the state EPA's hydrogeological investigations found that the bedrock in the affected area was shaped like a bowl, with wells G and H in the deepest part. The contamination source was not the Industri-Plex site as had been believed, but rather facilities of W. R. Grace and Beatrice Foods. This led eight families of leukemia victims to file a \$400 million suit in May 1982 against those corporations (*Anne Anderson et al. v. Cryovac et al.* 1982). A smaller company, Unifirst, was also sued but quickly settled before trial.

The trial was separate from the health study, but was a contiguous struggle over facts and science. The families accumulated further evidence of health effects in collaboration with consultant physicians and scientists. In February 1984 the FACE/Harvard data were made public. Childhood leukemia was significantly associated with exposure to water from wells G and H. Children with leukemia received an average of 21.2% of their yearly water supply from the wells, compared to 9.5% for children without leukemia. Controlling for risk factors in pregnancy, the investigators found that access to contaminated water was associated with perinatal deaths and some birth defects (deaths since 1970; eye/ear anomalies, and CNS/chromosomal/oral cleft anomalies). With regard to childhood disorders, water exposure was associated with kidney, urinary and respiratory diseases. However, the trial never focused on defining a causal link between the contaminated groundwater and the leukemia; the community-catalyzed research was never admitted as evidence. In July 1986, a federal district court jury did find Grace had negligently dumped chemicals; Beatrice Foods was absolved. An \$8 million out-of-court settlement with Grace was reached in 1986. The families filed an appeal

against Beatrice, based on suppression of evidence, but the Appeals Court rejected the appeal in 1990, and the Supreme Court declined to hear the case.

Throughout, Woburn activists had to keep defending their data. They were looking for confirmation from a DPH reanalysis of reproductive health effects. In 1995 a draft report was issued for public comment that claimed no environmental basis for reproductive disorders. Upon examining the research design, FACE activists and their scientific colleagues found that the DPH had analyzed only a brief time period, which was too late to capture many of the earlier effects. However, the DPH found a dose-response relationship between childhood leukemia and maternal consumption of water from the contaminated wells G and H. Since the leukemia cluster was the primary problem, this DPH admission was quite a vindication for the families.

Through this long process, Woburn had achieved national recognition as a toxic waste case that sparked many other communities to action, as the country's most complex community environmental health survey, and as a public drama – Jonathan Harr's (1995) *A Civil Action* was a bestseller, and the resultant film starring John Travolta was a box office hit.

### Important Components of Qualitative Research Methods in Environmental Health Research

#### Flexible study design

The qualitative researcher must decide how to frame the study, and thus how to tell the story. The Woburn story had many components, and there was no automatic way to decide which components to focus on? Qualitative researchers are always faced with such questions, and in truth, we don't always know until we're well into the project where we are placing our emphasis. Often we change directions and take new tacks in the midst of the work, due to our own realizations about the material, and in part from the ongoing interaction with people.

Part of framing the study is also deciding how much historical and cultural context should be included. Kai Erikson's Buffalo Creek research was saturated with social history of the Appalachian region, going back to the last century, in order to show the isolation, but also the resiliency, of the people. Steve Kroll-Smith and Steve Couch's (1990) research on an underground mine fire, and Steve Picou's (1990) work on the Exxon Valdez oil spill are other notable examples of intense local background. Louise Kaplan's (1997) work on lay efforts to uncover the Hanford Historical Documents, that showed accidental and deliberate radiation releases at the Hanford, WA nuclear weapons facility, required a historical overview of the local salience of a pro-nuclear culture in a community that primarily wanted to avoid conflict. Not all researchers go into such depth. I provided a very small amount of such background (primarily the town's history of tanning and chemical production), preferring to focus on the contamination crisis itself.

Furthermore, how much attention should be placed on conflicts within the community on how to organize and carry out research? Again, the unique constellation of community, industry, and government actors help shape the focus. Steve Kroll-Smith and Steve Couch's *The Real Disaster is Above Ground* (1990) details the events in the Pennsylvania community of Centralia following the discovery of a rapidly spreading coal fire underneath the town. They later expanded this concern to a generalized idea of "corrosive communities," since there were other such areas with internal conflict among residents. Levine's Love Canal research mentioned such conflicts but did not make them central. My choice in Woburn was to mention, but not dwell on them, largely because it didn't seem a major part of the situation, nor did it affect the outcomes.

There are other basic questions to consider. How closely-grained will the research process be? Steve Kroll-Smith and Steve Couch decided that one of them would actually move into the community in order to ensure good access relations and to be present at all possible meetings. After two years of collecting field data from various public events conducting interviews, Stephen Kroll-Smith moved into the very heart of the affected area, where for eight months, he became part of the contaminated community and was able “observe and experience daily life in a hazardous area” (Kroll-Smith and Couch 1990). Participation in the daily life of the community also made Kroll-Smith subject to the internal ideological divisions within the community. Various town factions sought validation of their positions regarding the fire. This close working relationship with the community forced Kroll-Smith and Couch to face a “complex moral and methodological quandary” (175). Caught between competing interests, the line between social science research and advocacy was blurred. In this instance, the tandem efforts of the authors provided enough objectivity to produce a critical interpretation of the events in Centralia. Kai Erikson lived and breathed the aftermath of the Buffalo Creek flood during prolonged stays in the area. I had come to the Woburn situation too late to be present at the many meetings that fashioned that struggle, but I tried to attend any ongoing meetings to observe the continuing organizing.

In part, framing also requires thinking about rich data sources. All scholars working in this area use open-ended interviewing as their primary data source, in addition to observation and documentary materials. Documentary material for Woburn included activist newsletters and leaflets, newspaper articles, legal documents, government reports and documents, and medical and scientific reports (neurology, cardiology, hydrology, immunology). Interviews are the main tool to bring alive the lived experience of people and communities. For my Woburn work, I focused on the families who were parties to the lawsuit, and who were by extension the main activists, but I also interviewed other activists who were not health-affected and thus not part of the lawsuit. I interviewed relevant state and federal officials who had been involved in the case, as well as health professionals who had conducted health studies with and for the residents.

Deciding on the nature of the study also includes the decision on what theoretical frameworks to employ, and what themes, concepts, and issues to analyze. A theoretical framework may come from one, but typically several sources. It is important to have this pretty well in mind before beginning, since it shapes the way the research project is framed and conducted. I was drawing on several frameworks – Edelstein’s (1988) notion of threats to the assumed safety of the home (“inversion of the home”), Krimsky and Plough’s (1988) work on lay-professional disputes in environmental hazards, scholarship on citizen participation by Nelkin (1984), and a variety of inputs concerning the critique of value-neutral science and the political economy of environmental hazards – and working on weaving them together into my new popular epidemiology approach.

Themes, concepts and issues for analysis are decided in several ways, and need not be all in hand before starting. One, they may be known from prior research by other scholars in similar work. This is especially useful since you want to contribute to a standard body of knowledge, and hence sharing concepts is key. Without some starting point, it will be impossible to develop good questionnaires and coding schemes. Two, themes, concepts, and issues may be detected in pilot interviews and in initial examination of observations and interviews. Three, themes, concepts, and issues may be observed during the expanded analysis of the observations and interviews. This can be determined by word counts, concept counts, and by skilled multiple

readings of transcribed material. All three approaches are typically used together, since you never know ahead of time the full range of material you are dealing with.

The above elements of flexible study design are congruent with Marcus' (1995) notion of "multi-sited ethnography." Individual research sites, while capable of rich description and analysis, are insufficient to convey larger trends in an increasingly complex and interdependent world. Hence the ethnographer must trace a cultural formation across diverse sites, while simultaneously developing the interaction of the macrosocial context with those specific sites. For Marcus, any ethnography of a single cultural formation is by extension a study of the larger system in which that single formation is embedded. What knowledge the researcher gains of the micro-level affects their understanding of the macro-level, and vice versa. Further, this "mobile ethnography" enables the researcher to have a more emergent and complex view of the local site than would be possible by merely studying that single site (Marcus 1995). As Burawoy (2000) remarks, in a postmodern world where there are many local connections to the world system, it is necessary to engage in "welding ethnohistory to ethnography, combining dwelling with movement." For the multi-sited ethnographer to do their job, Burawoy argues, he or she must have "delved into external forces," "explored connections between sites," and uncovered and distilled imaginations from daily life." Rapp (1999, 12) speaks of this multi-sited ethnography as an "endeavor to break the connection of space, place, and culture," because there are no clear boundaries to the research sites, the people who populate them, and the places from which those people came.

Indeed, this multi-sited approach describes my current research on disputes over environmental factors in asthma, breast cancer, and Gulf War illnesses. In this project I began with main four research sites: Silent Spring Institute in Newton, MA on breast cancer, the Boston Environmental Hazard Center in Boston on Gulf War illnesses, Alternatives for Community and Environment in Boston on asthma, and the Toxic Use Reduction Institute in Lowell, MA on toxics reduction. From those, I expanded to a variety of other environmental breast cancer activist groups, another environmental justice group working on asthma, and an environmental activist group that developed out of the toxics reduction approach. Observations and interviews at these sites were supplemented by interviews with scientists and government officials, formal media analysis, document analysis, review of scientific literature, and historical/political-economic analysis of the issues under study. Throughout, I am tracing interconnected locales that make up environmental and health social movements without being tied together in a formal organizational form, and whose boundaries are continually in flux. I further theorize this in terms of "boundary movements" that traverse a wide range of actors and institutions, with continual boundary crossings (Brown et al. 2002).

### Access and Trust

Access is more important in qualitative methods than in quantitative methods, since qualitative methods involve intensive interviewing and create the space for more personal and emotional contact. The very nature of the kinds of questions and answers makes for a more charged situation, hence access is a negotiated interaction. Access often results from connections – Kai Erikson was brought in by lawyers to assess the impact of the Buffalo Creek Flood, and his idea to write a book was a later decision. I had Ed Mikkelsen's connection to the Woburn families; they trusted him as a confidant who had helped them examine their emotional reactions to illness, suffering, and death. Ed Mikkelsen and I went together to the interviews that I conducted, to help cement the connection; later I continued interviews and observations alone. I

further had access through attorney Jan Schlichtmann, who the families trusted as the person who was bringing their story to public light and helping them focus blame on W.R. Grace and Beatrice. Jan called each family personally to encourage them to cooperate with me. In this sense, access and trust are thoroughly intertwined.

What happens when people do not have “automatic” access as I did? They have to build access from scratch. Adeline Levine did not have a prior connection. Rather, she made herself appear as a trustworthy scholar who could help tell the Love Canal story to the world. Access was a question of how she presented herself. Often a single key organizer opens the way to major community access, as Lee Clarke found with his study of the toxic contamination from the Binghamton, NY state office building fire. Community groups can tell who is sincere or not, having already been through many tests of sincerity involving public health and environmental officials. Sincerity, however is not enough; researchers have to be educated enough about the background of the situation. That is both a sign of the researcher’s interest and their capabilities, as well as an indication that the residents will not have to spend needless effort in bringing the researcher up to a basic level of knowledge about the situation.

Of course, even connections do not guarantee that residents will share their experiences. The researcher still has to generate personal trust and confidence, as well as a belief that the research will be helpful to people and the community. What I mean by sufficient trust is a level of trust in which you are convinced that the people you are researching have faith in your rationale for doing the study, and feel you are trying to tell their story in a supportive fashion. This sufficient trust means that they will therefore include you in notification of meetings, go out of their way to connect you to other people, and give you broad access to themselves and to materials relating to them.

#### Empathy and personal shifts in the researcher’s worldview

My empathy for the Woburn families’ plight was visible to them, and I think that hastened their trust in me. I worked hard to come across as genuinely interested and concerned, not like the voyeurism of the many journalists who had sought catchy quotes, and some of whom had even asked parents to stage reenactments with their children getting in and out of the car en route to the hospital for treatment. I felt very sad in talking to people who had lost a child, and the weight of this clearly colored how I approached the book – I wanted to convey to readers the sense of these families’ loss, and how that was amplified by the corporations’ mean-spirited approach to the situation and by the problems in state and federal agencies’ research processes. I am convinced that – and this so spectacularly obvious – that deep empathy is necessary in order to adequately study contaminated communities. All the other scholars I have seen engage in such work have had that spirit.

I know how I was changed by the process of doing this research. Martha Balshem (1993) is another scholar who experienced a major shift. She was hired as a medical anthropologist by a Philadelphia cancer prevention project, but soon found that cancer center’s risk-factor approach to individual responsibility clashed with the white, working-class neighborhood’s belief system. The project identified excess cancer in this area, a fact widely known by the residents and the media. The medicalized approach of the health educators focused on individual habits, especially smoking, drinking, and diet. Tannerstown residents countered this worldview with their belief that the local chemical plant and other sources of contamination are responsible. The professionals approached the working-class as a monolithic mass of people with many unhealthy behaviors and nonscientific attitudes. What professionals call working-class “fatalism” appears

more sensible as a response to economic insecurity in the face of Philadelphia's declining industrial workforce. The health educators' medicalized notion of working class fatalism as a "disease" leads those educators to focus on how people fail to comply with cancer prevention experts' prescriptions. Yet, from a community standpoint, official medical approaches to prevention, by emphasizing lifestyle changes, amount to what Balslem (p. 57) notes is "to adapt to life in the 'cancer zone'." Balslem shifted away from thinking individual-level explanations were important, to believing that there were broader, structural explanations for elevated cancer rates. Hence she could no longer tolerate her job, and left it.

### Bias

Whether access comes from connections, or is built from scratch, the emotional and political context of such endeavors puts the researcher into close contact, often involving friendships, with the people s/he is studying. For example, Adeline Levine became friendly with Lois Gibbs, the Love Canal leader. Critics of such reflexive research argue that this closeness of access colors the nature of the research and introduces bias. I would argue that there is some bias – if that is really the appropriate term – in that we study these situations because we sympathize with the affected citizens. Indeed, all research has some implicit values, despite claims to the contrary. By virtue of conducting a research project with Edwin Mikkelsen, the plaintiffs' psychiatric expert, I had to recognize the potential for siding with the residents. But our underlying sympathy does not mean that we accept uncritically all the beliefs and perspectives of the citizens. Our goal is to understand the social scientific nature of community discovery and action, both to make our society healthier and to increase our knowledge of how people, organizations, and communities perceive and act on important matters. Many researchers have had to deal with the fact that there was no confirmation of community claims of environmental health effects. These scholars may have hoped for such positive findings, as did the communities, but the scholars had to adjust their conclusions as a result.

There is a second bias to consider. Are environmental sociologists and other environmental researchers already biased to community groups? The origin of the whole field of environmental sociology, for example, is tinged with a pro-community ethos. This is especially true for the social scientists doing community studies of contaminated communities. They are typically very supportive of community concerns, and take seriously the community's need to control their destiny. Social scientists often perceive community contamination episodes as insults brought about by corporate malfeasance and amplified by government inattention or failure to act. They believe that residents groups and other environmentally-affected populations (that may be spread about, rather than necessarily being residents of a specific geographic area) lack the resources to adequately learn about and act on environmental crises. Hence, these social scientists feel a responsibility to balance the resource inequity by allying with affected people.

The matter of such bias can be examined by the researcher throughout the research process. Becker (1967) argues that research uninfluenced by personal and political sympathies is an impossible goal for social scientists. He proposes instead the question of whose side are we on? By confronting that directly, we are able to examine possible sources of bias. Only by not allowing sympathy to guide our work and by recognizing and reporting the limitations of our studies will we move in the direction of eliminating bias from our work (Becker 1967). Yet many researchers contend that it is not possible to completely remove such bias, even though they would argue that we gain much by the open presentation of potential for bias. Scott et al. (1990) argue that more often than not, researchers become involved with the participants of a

scientific debate. They believe that an “epistemologically symmetrical analysis of controversy is almost always more useful to the side with less scientific credibility or cognitive authority.” A symmetrical analysis, they continue, is an illusion, and researchers who fail to acknowledge this are involved in perpetuating the illusion of symmetry.

More generally, the initial choice of topics, research sites, and specific organizations on which to focus is itself full of value commitments. Qualitative researchers, typically well versed in a critique of positivism, usually believe that all research is based on some sort of commitment, implicit or explicit. Some fieldworkers face the challenge of bias and wind up actually intervening in the process they are studying. Such scholars argue that this is justified because not to intervene is a value choice, just as is the choice to intervene, since research cannot be value-neutral despite claims to be so (Scott et al. 1990; Martin 1996). Opposing such an interventionist stance, Collins (1996) holds that rather than choosing one side in a debate, it is the role of researchers to demonstrate the asymmetrical nature of scientific controversies. Thus a symmetrical approach is a scientific approach – which can lead to political involvement, but through the products of research not the process of activism.

### Roles, reflexivity and member validation

Positivism seeks to use natural science as a model for social science, attempting to apply universal laws and to employ neutral language. Most typically, positivist approaches try to quantify as much as possible, to have measures that appear to be universally valid. In opposition to positivism, many researchers seek to take a “naturalist” approach that claims to study the world in its “natural” state, undisturbed by researcher. In such an approach, the researcher would try to describe more phenomenologically the community or group they are studying, without being involved in it. But in truth, this is similar to positivism in that the researcher assumes that there is a “natural” world that all observers would view similarly. It is thus similar to positivism in seeking to identify a positive fact or phenomenon. The seemingly opposite poles of positivism and naturalism in epistemology and research methodology share something in common: they both maintain a sharp distinction between social scientists and the group or community being studied.

Increasingly, qualitative researchers move to repair that distinction, by realizing that the people we study also shape the data. Our conversations and observations with people in our research sites lead them to make analyses of their situations, which then provide an iteration of their initial perceptions and experiences. By entering the field, we have changed it; quite literally, people know what we are interested in and they may change their thoughts, conversations, and actions to reflect our interests.

This leads us to be concerned about the role we are taking in our research site; do we seek as neutral as possible a stance, hoping that it will avoid such co-construction of data, or do we move toward that level of co-construction of data while simultaneously making all efforts to identify and grapple with that co-construction? What is the appropriate role to take? It is unfortunately not always possible to decide ahead of time what role you will take, since roles change along with other features of the project. As I mentioned earlier, my collaboration with Ed Mikkelsen put me into the role of an interested party who was attached to the case. But I also sought to have my independent role as a scholar who knew about other environmental struggles, and an activist who had been involved in many political efforts. Both these roles made me into someone who understood the Woburn situation beyond the bounds of just the legal case. I don’t think that it is wise, or even possible, to take a markedly detached and disinterested stance. Such a stance

would mean a loss of residents' trust, and would yield less comprehensive data about personal and collective illness experience. Even if one wanted to, the community might not let you in if they perceived you to be detached, since it is a lot of effort for them to cooperate with you. And if they did let you in, despite feeling you were detached, they would not likely open up that much, and therefore might only provide you with a very small part of their story.

Martyn Hammersley and Paul Atkinson (1995) view reflexivity as a way to avoid the problems associated with how both positivism and naturalism try to remove the effects of the researcher on the data. As Hammersley and Atkinson point out, "we are part of the social world we study." Reflexivity tells us that we actually change the social field by studying and interacting with it. Reflexivity also forces us to realize that another sociologist, even sharing similar sympathies to the situation, would likely experience and analyze the case differently, and hence we must analyze why we do it a particular way.

For example, my published work on the Woburn case presented a public face of the Woburn situation that will in some sense appear as representative of the residents and their organized efforts. Therefore, I felt it incumbent on me to 'get it right.' In order to 'get it right,' I used "member validation" techniques. This involves sharing parts of the research process and its products with the members, the people you are studying. Member validation can correct factual errors, but more importantly it can point to additional areas for current and future research. As participants hear and/or read what you have said about them, they can reassess their initial interview responses or come up with new material, thus enriching the whole dataset. This process changes the field and alters subsequent narrative content. Member validation and data sharing communicate narratives that may otherwise have been kept private. Social scientists draw from a different perspective that participants inside the phenomena do not have, precisely because they are embedded and their purpose is direct action rather than social research and publication. The process of member validation may provide new concepts or language from which community members may draw when constructing subsequent narratives.

At the same time, member validation fulfills an ethical responsibility to involve community members in an important aspect of the research project. It is a courtesy to the people you are studying, so that they feel they are part of the loop. I shared the completed book manuscript with three leaders of the citizens' group (FACE), one epidemiologist involved in the case, and the lawyer, Jan Schlichtmann. I was glad that these people were able to detect some factual inaccuracies that I wouldn't have wanted to see in print, but more so that they felt I had successfully told the Woburn story in a useful and interesting fashion.

Michael Bloor (1988) makes a valuable point in his discussion of the outcomes of such sharing: "While my accounts were recognizable to members, they were not isomorphic with their common-sense knowledge of their work practices." And of course, they should not be isomorphic. Woburn residents did not have the concept of popular epidemiology; they were simply doing what they and other contaminated communities had to do: investigating the environmental health crisis in which they were enmeshed. We are feeding back not just facts, but also analytic concepts, thus helping residents shape the social scientist research literature on their community and similar places. They might later come to accept such an analytic concept, but it is not their initial framework.

Kai Erikson studied an underground petroleum leak in East Swallow, CO, where he filed a report with the county District Court. He asked twenty-one residents to read copies of that report while sitting with a tape recorder, and to dictate comments when they were struck by anything in the report. Erikson describes several purposes for such an effort. He wanted to know how the

overall report reflected each individual person's feelings of the situation. He wanted "to bring the people I was writing about into the composing of their own story." And he also wanted them to help provide material that could be useful in cross-examination by the defendant's lawyers in court. What is so intriguing about the outcome of this research is the way Erikson published it – in *A New Species of Trouble* (Erikson 1994) he produced the entire report, with almost half the space devoted to footnotes on each page where he provided the individuals' responses from sitting with their tape recorders. Erikson thus provided one of the most interesting methodological approaches to member validation, and one that deeply brings the people into their individual and collective narrative. Lather and Smithies (1997, 215-236) did a similar thing in their *Troubling the Angels: Women Living With HIV/AIDS*, in which they self-published a draft version of the book to send to all women they had observed and interviewed. They met with the women in the support groups that were the focus for the study, engaging in detailed discussions that led them to change the book title, rearrange chapters, and shorten "intertext" chapters that dealt with historical and literary material. Lather and Smithies provide process notes and large segments of dialog resulting from their member validation work. As with Erikson, the idea is to give a rich voice to the people being studied, and to do it through interaction rather than in a merely formal method.

Some sociologists even argue that member validation is appropriate when we may not be supportive of the group we are studying. When Rochford (1992) brought his analysis back to the national Hare Krishna organization, they challenged his methodology and argued his analysis was biased due to his close involvement with the more liberal Los Angeles Hare Krishna organization. The national organization made Rochford's life difficult, discrediting his research in national forums and denying him future access. Nevertheless, Rochford argues there is a legitimate conflict between members' practical consciousness and the representation of their consciousness in the text. This conflict weakens the privileged position typically held by researchers. Member validation then, gives groups political power to "gain recognition for their views and interpretations of their cultures, subcultures, and communities."

#### Current and Future Issues in Funding Policy and Research Practices

Next I want to briefly talk about funding for qualitative research, especially from federal sources, and then to conclude by addressing some issues of citizen-science alliances that come up in community-based research practices.

#### Government funding of qualitative research

There is growing acceptance of qualitative methods among federal agencies, but in some cases it is still very subsidiary to traditional quantitative approaches. For example, in 1999, the NIH Office of Behavioral and Social Sciences Research sponsored a workshop to assist qualitative grant applicants. The document produced by this workshop, "Qualitative Methods in Health Research: Opportunities and Considerations In Application and Review," offers qualitative researchers suggestions to improve their chances of receiving funding from NIH (Office of Behavioral and Social Sciences Research, NIH, 1999) . However, this NIH approach is less suitable for the research we are talking about here, and probably more useful as a supplement to quantitative methods or studies of general illness experiences. It is too formalized to benefit most researchers interested in exploring environmental health research through qualitative methods. For instance, the report suggests that the use of qualitative methods be

justified by comparing the potential benefits of their use to those of quantitative methods. Furthermore, the report suggests that researchers provide a detailed sampling plan that should anticipate several logistical difficulties that may be faced in the field. Though a researcher should always have a sampling design, the dynamic nature of community research (as suggested in several of the examples of community research provided above) can make such a formal procedure difficult at best.

### Creative approaches to research

Despite such limiting criteria for government funding, there are an increasing number of academic-community partnerships and related collaboration grants, that by their very nature call for qualitative methods either alone or in partnership with quantitative methods. NIEHS and NIAID have been awarding grants through training and communications programs, largely to support environmental justice efforts. In these cases, the traditional research methodology that would be expected in an R01 grant is not applied, since the primary goal of these grants is not to conduct research, although community collaboration in research is common in projects funded under such mechanisms. One example is NIEHS' R25 grant program "Environmental Justice: Partnerships for Communication (ES-03-002)." It is possible that growing experience with this type of funding will demonstrate to more people that non-traditional, largely qualitative approaches, can be used very widely.

Lay participation in science forces the professional scientist to step outside of their traditional training to consider the importance of first-hand knowledge possessed by the community. Furthermore, for laypeople, traditional methods may not be suitable to capture concerns related to environmental hazards. Researchers interested in academic-community partnerships may need to develop innovative techniques to incorporate lay knowledge in their research. Qualitative research methods can do just this. For example, researchers studying potential environmental causes of breast cancer in collaboration with community groups have used innovative methods such as creating life histories of possible exposures and conducting "shopping trips" to determine chemical exposures from common household and commercial products. The "shopping trip" model was actually used by Silent Spring Institute to develop quantitative measures, but it represents the type of innovative techniques that community-based research often employs.

Sociologists and environmental scholars have to be prepared to quickly respond to crises in the making; adequate funding could make rapid responses possible. As an example, Adeline Levine recruited a group of graduate students to do research on the ongoing situation. Christina Zarcadoolas, my colleague at Brown University, did a similar thing – she took her qualitative research class in Environmental Studies to conduct 90 interviews in Pascoag, RI, site of a massive contamination episode where the fuel additive methyl-tertiary-butyl ether (MTBE) polluted local water to the extent that it was unusable. In early September 2001, the 5000 residents of Pascoag were informed by the Pascoag Utility District that their public water supply was contaminated by MTBE. What followed was a four-month period during which concerned, frustrated and inconvenienced residents were advised not to drink, cook with or bathe young children with this water. Residents began to report symptoms ranging from skin rashes, to headaches and breathing difficulties.

Chris Zarcadoolas and her 26 students in the Environmental Studies qualitative methods course focused more than half the semester learning how to learn from Pascoag residents. They designed and implemented an interview protocol to investigate how residents perceived and

responded to the water contamination problem, official responses and community impacts. The primary goal of the project was to capture the voices and experiences of Pascoag residents, with particular emphasis on residents' information sources, concerns, behavior modifications, interactions with government officials, and perceptions of the community. Study participants were recruited through posted flyers in local gathering places, ads in the *Bargain Buyer*, and a snowball method using residents to supply names of other residents. Students conducted a total of 90 interviews, 72 in person interviews and 18 by telephone (Zarcadoolas 2002).

But this example is not only about the interest and dedication of researchers who are willing to disrupt their regular routine. Rather, it is also about federal funding policy. Indeed, it would be wise to have a program funded by relevant federal agencies that could provide rapid disbursement of small grants for researchers to respond to such situations. This could build upon the example of the Natural Hazards Center Quick Response Program at the University of Colorado, which uses funds contributed by the National Science Foundation to enable social scientists to travel to the site of a disaster soon after it occurs to gain valuable information concerning immediate impact and response. As well, funding should be available specifically for non-immediate, longer-range research studies of community response.

#### Advocacy science, citizen-science alliances, and meeting community needs

“Advocacy scientists’ (Krimsky 2000) are those individuals who extend their personal responsibility and commitment to their professional work. In his narrative of the emergence of the environmental endocrine disruptor hypothesis, Krimsky (2000) witnessed several scientists become visible activists for the hypothesis despite gaps in their knowledge and the subsequent risks for their image and professional careers. In Krimsky’s words, advocacy scientists “view their role as bifurcated between advancing the scientific knowledge base and communicating to the public, the media, and policymakers.”

“Citizen science alliance” (CSA) – my term for a lay-professional collaboration in which citizens and scientists work together on issues identified by laypeople – is one way in which advocacy science is practiced. Collaboration between community groups and scientists serves to educate both parties. While researchers clearly benefit from the input of community members, the collaboration also educates the community about strengths and limitations of the scientific process. Citizen groups often have expectations about science that may not be achievable within the scope of the proposed research. Collaboration between citizens and scientists also serves to ease apprehensions either party may feel towards each other; community members may feel exploited by outside researchers while the researcher can feel intimidated by activist groups. Overall, the CSA benefits both parties by introducing laypeople’s concerns into the research project and by allowing the researcher an insider’s glimpse into the community.

By doing community ethnographies of contaminated communities, researchers are helping to uncover data that might not otherwise surface. This is a notable contribution, but to what extent does the community directly benefit? In addition to reflexivity and member validation, another way to ensure community control is to freely share data. Researchers who study contaminated communities have often presented their work at activist conferences. This is one way to make the information public so that community groups can use it as they see fit. It provides an ethically-based approach by researchers to the communities they are studying and collaborating with. This is clearly an important area, given the history of problems with many forms of research on communities.

Sometimes research presentations can serve more general interests, rather than the interests of a specific piece of research and a particular group. I was very pleased to be asked to give a talk at the 2001 annual conference of the Toxics Action Center, a very effective organization in New England that provides organizing help to hundreds of local environmental groups. My talk on “The Larger Impact of Toxic Struggles: How Will the Toxics Movement Be Written About in Your Children’s Textbooks?” discussed how significant local toxic struggles had been for the whole society, and how much they had influenced environmental sociology and other discipline in deciding on what to study and how to study it. On this occasion, I was confronted with the choice of whether to attend a professional conference on hazards—where I would learn much from my social scientist colleagues—or to carry on with my talk to the Toxics Action Center. My decision to go to Toxics Action Center and not to the hazards conference seemed natural. I would lose something in terms of growth in academic scholarship skills from 3 days of intense working together with colleagues doing similar work, but I would gain in hearing how my analysis of toxic activism meshed with the perceptions of those doing it. And, I was convinced, I owed this to the activists from whom I had learned for many years, and who had furnished me with much of the raw material and encouragement on which my career was built. Such is the work of an advocacy sociologist.

In my current research on disputes over environmental factors in asthma, breast cancer, and Gulf War illnesses, I have four foci where I strive to practice advocacy science: Silent Spring Institute in Newton, MA on breast cancer, the Boston Environmental Hazard Center in Boston on Gulf War illnesses, Alternatives for Community and Environment in Boston on asthma, and the Toxic Use Reduction Institute in Lowell, MA on toxics reduction. Of these, only ACE is a grassroots community organization. Some people might argue that the issues of community research ethics do not pertain to the other three, all professional research or advocacy enterprises. But these three groups are in many ways similar to grassroots groups: Silent Spring Institute is a research establishment dedicated to studying environmental causation of breast cancer, but it was established by the Massachusetts Breast Cancer Coalition, an activist group; the Precautionary Principle Project/Alliance for a Healthy Tomorrow is an organization that incorporates activism with science advocacy; and the Boston Environmental Hazards Center was jointly created and run by the Boston University School of Public Health’s Department of Environmental Health, a unit with a long history of strong advocacy relationships and collaborations with grassroots organization.

At each of these, I had access through knowing key people in the organizations who trusted my research capacities and sensibilities, by virtue of my past work in related environmental health areas. During the research process further trust developed to the point that these organizations asked me to be involved in various ways. Alternatives for Community and Environment (ACE) suggested I give feedback on my observations to their staff. The Boston Environmental Hazards Center asked me to be on the science board for a research project they were proposing. The Precautionary Principle Project, which was informally connected through overlapping members to the Toxic Use Reduction Institute, asked me to be a workshop facilitator at their 2002 international conference on the precautionary principle; when the Precautionary Principle Project later transformed itself into a broader group, the Alliance for a Healthy Tomorrow, the Alliance asked me to collaborate on several things: developing and performing a pesticide awareness survey, working on a project to examine environmental factors in autism, and participating in meetings to develop communications projects with scientists. Silent Spring Institute requested the assistance of myself and one of my research assistants in collaborating on

a research project that included a presentation at the American Public Health Association annual conference and preparation of a companion journal article (McCormick et al, in press). That project sought to demonstrate a long historical legacy of community involvement in health research, which would help justify the continuation and strengthening of community participation in current research on environmental factors in breast cancer. These examples indicate a high degree of confidence, which indicates that I, as the researcher, am providing the organizations with collaborative relationships worthy of their trust.

### Conclusion

My experiences in Woburn and with advocacy organizations affirm that qualitative methods are an important instrument enabling community narratives to be constructed and shared. Furthermore, they also provide social scientists with an opportunity to contribute to community activism and advocacy. Research efforts by Erikson, Levine and others over the past two decades have laid a foundation for continued use of, and funding for qualitative methods as either a solo methodology, or in tandem with quantitative epidemiological studies.

Not all environmental sociologists that draw on qualitative methods will act in such advocacy fashion, but in practice many do. They are acting to help create, modify, and present to the world the community narratives of grassroots and grassroots-related environmental health research and advocacy. Often, these narratives are untapped; qualitative researchers help the community to develop narratives. Gareth Williams (1984) writes about "narrative reconstruction," the ways that people reconstruct how they believe they "got" diseases. People often employ broader viewpoints than the biomedical model, some imputing a political and economic causality, others locating etiology in a nest of social relationships and in their own psychological makeup, others using a mystical explanation. Their goal is to produce a coherent self-analysis for their own narrative, thus providing a way to repair the rupture which disease causes in their relationship with the world.

This search for etiological explanation is central to contaminated communities; it occurs at both the individual and community level, and neither of those levels is possible without the community context. Lynn Nelson (1990) offers a valuable addition to this line of thought: it is communities or groups that acquire and possess knowledge, and that focusing on individuals in epistemology is inappropriate. Individuals "have" beliefs and they know, but only in a derivative sense. Their beliefs and their "knowing" depend on public language and the conceptual scheme it embodies, and what they know and believe is constrained by public standards of evidence. The primary epistemological agents are groups -- or more accurately, epistemological communities.

In the case of contaminated communities, fragmented knowledge regarding environmental hazards may be possessed by individuals, but the whole story is a community narrative. This meshes with the "standpoint" theory of Nancy Hartsock (1983) and holds that an accurate perspective on social life can only stem from members of oppressed groups, in this case meaning those from affected communities. Those "communities who know" have for a quarter-century been teaching social scientists how to tell communities' stories. The valuable legacy we have created in this field is possible because of acceptance by significant sectors of social science and life science professional organizations, but mostly because of acceptance from, and collaboration with, affected communities. Researchers need to find ways of building even further support from sympathetic federal agencies and programs, from private foundations, and from

scientists and their organizations. Scholars need to cement stronger alliances with community groups with whom we collaborate, since they can exert important influence on the funders. And researchers need to carefully document their methods, especially those that improve academic-community partnerships.

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