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# Popular Epidemiology and Toxic Waste Contamination: Lay and Professional Ways of Knowing\*

PHIL BROWN

*Brown University*

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*Building on a detailed study of the Woburn, Massachusetts, childhood leukemia cluster, this paper examines lay and professional ways of knowing about environmental health risks. Of particular interest are differences between lay and professional groups' definitions of data quality, methods of analysis, traditionally accepted levels of measurement and statistical significance, and relations between scientific method and public policy. This paper conceptualizes the hazard-detection and solution-seeking activities of Love Canal, Woburn, and other communities as popular epidemiology: the process by which lay persons gather data and direct and marshal the knowledge and resources of experts in order to understand the epidemiology of disease, treat existing and prevent future disease, and remove the responsible environmental contaminants. Based on different needs, goals, and methods, laypeople and professionals have conflicting perspectives on how to investigate and interpret environmental health data.*

Medical sociology has long been concerned with differences between lay and professional ways of knowing (Fisher 1986; Roth 1963; Stimson and Webb 1975; Waitzkin 1989). Because of their different social backgrounds and roles in the medical encounter, clients and providers have divergent perspectives on problem definitions and solutions (Freidson 1970). Professionals generally concern themselves with disease processes, while laypeople focus on the personal experience of illness. For professionals, classes of disorders are central, while those who suffer the disorders dwell on the individual level (Zola 1973). From the professional perspective, symptoms and diseases universally affect all

people, yet lay perceptions and experience exhibit great cultural variation. Similarly, lay explanatory approaches often utilize various causal models that run counter to scientific notions of etiology (Fisher 1986; Freidson 1970; Kleinman 1980). Medical professionals' work consists of multiple goals, among which patient care is only one; patients are centrally concerned with getting care (Strauss et al. 1964).

The study of these contrasting perspectives has centered on clinical interaction and institutional settings. Some scholars have examined lay-professional differences in occupational health (Smith 1981), community struggles over access and equity in health services (Waitzkin 1983), and genetic screening (Rothman 1986). Yet medical sociology has scarcely studied environmental and toxic waste issues.

Recently, lay perceptions of environmental health have manifested themselves in a burgeoning community activism. Following the landmark Love Canal case (Levine 1982), the childhood leukemia cluster in Woburn, Massachusetts, has drawn attention to the lay-professional gap. Woburn residents were startled beginning in 1972 to learn that their children were contracting leukemia at exceed-

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ingly high rates. Affected families and community activists attempted to confirm the existence of a leukemia cluster and to link it to industrial toxins that leached into their water supply. They pursued a long course of action that led to a major community health study, a civil suit against W. R. Grace Chemical Corporation and Beatrice Foods, and extensive national attention.

Building on a detailed study of the Woburn case and utilizing data from other toxic waste sites, this paper discusses conflicts between lay and professional ways of knowing about environmental health risks. This discussion centers on the phenomenon of *popular epidemiology*, in which laypeople detect and act on environmental hazards and diseases. Popular epidemiology is but one variant of public participation in the pursuit of scientific knowledge, advocacy for health care, and public policy, as witnessed in such diverse cases as AIDS treatment, nuclear power development, and pollution control. The emphasis on ways of knowing makes sense because knowledge is often what is debated in struggles to win ownership of a social problem (Gusfield 1981, pp. 36–45).

In their popular epidemiological efforts, community activists repeatedly differ with scientists and government officials on matters of problem definition, study design, interpretation of findings, and policy applications. In examining the stages through which citizens become toxic waste activists, this paper emphasizes lay-professional differences concerning quality of data, methods of analysis, traditionally accepted levels of measurement and statistical significance, and relations between scientific method and public policy.

## STUDY BACKGROUND

There were two sets of interviews with the Woburn litigants. The first set was with eight families; open-ended questions were asked dealing with individual experiences with the toxic waste crisis, including personal and family problems, coping styles, and mental health effects. These interviews were conducted in 1985 by a psychiatrist and reanalyzed in 1988 for an earlier phase of this research (Brown 1990). This reanalysis involved both the researcher and the psychiatrist rereading the interview material several times, and then discussing the most promi-

nent themes. This process defined themes for discussion of the original, largely psychosocial, interviews. As well, it directed the creation of the interview schedule for the reinterview. For example, respondents in the original interviews expressed considerable anger at the corporations accused of contaminating the wells, and at the government officials investigating the disease cluster. This provided initial information on these important concerns, and directly yielded more specific reinterview questions.

The second set of interviews in 1988 (except for one family that did not wish to participate) comprised 20 open-ended questions on residents' perceptions of community activism, the litigation, government and corporate responsibility for toxics, and the relationship between lay and scientific approaches.<sup>1</sup> The first set of family interviews were taken down in writing. The second set of family interviews, as well as all interviews with other actors, were tape-recorded and transcribed.

Fourteen community activists, apart from the litigants, were also interviewed in 1990. In addition to basic personal data, respondents were asked 19 open-ended questions concerning toxic waste activism, knowledge about toxic wastes and their detection and remediation, attitudes toward corporate and governmental actors, and attitudes and participation in other environmental and political concerns. Between 1988 and 1991, the litigants' lawyer was interviewed, and other data were obtained from interviews with, formal presentations by, and official documents provided by state public health officials, federal environmental officials, and public health researchers. The interviews with public health officials sought responses to matters of lay-professional differences in methodology of, and interpretation of data from, both official and community health studies. Additional data came from legal documents, public meetings, and archival sources, and from research on other similar sites.

Material from all interviews, documents, meetings, and other sources was coded in two ways. First, codes were devised from prior knowledge gained from the first litigant interviews, from the themes that the litigant reinterview questions and other interview questions were expected to tap, and from existing literature on toxic waste sites.

Second, additional codes were identified after reading through the transcripts. In this second case, a number of codes were quickly apparent, such as the pride that citizens had in their nascent scientific abilities. The coding process therefore identified the beliefs and experiences of involved parties, enabling interpretations of those beliefs and experiences. In many instances, considerable congruence with other scholars' findings in case studies of toxic waste sites provided a degree of reliability.

In addition to this coding process, all data was examined in terms of its place in the historical/chronological development of the toxic waste crisis. While a clear line of unfolding events was previously apparent, the data culled from the detailed research allowed me to fill in fine-grained detail. This approach enabled me to create the stages model of popular epidemiology described in the next section. Here, too, other toxic waste studies offered support for the development of such a schema.

## LAY WAYS OF KNOWING

### *Popular Epidemiology*

Traditional epidemiology studies the distribution of a disease or condition, and the factors that influence this distribution. These data are used to explain the etiology of the condition and to provide preventive, public health, and clinical practices to deal with the condition (Lillienfeld 1980, p. 4). A broader approach, seen in the risk-detection and solution-seeking activities of Woburn and other "contaminated communities" (Edelstein 1988), may be conceptualized as *popular epidemiology*.

Popular epidemiology is the process by which laypersons gather scientific data and other information, and also direct and marshal the knowledge and resources of experts in order to understand the epidemiology of disease. In some of its actions, popular epidemiology parallels scientific epidemiology, such as when laypeople conduct community health surveys. Yet popular epidemiology is more than public participation in traditional epidemiology, since it emphasizes social structural factors as part of the causal disease chain. Further, it involves social movements, utilizes political and judicial

approaches to remedies, and challenges basic assumptions of traditional epidemiology, risk assessment, and public health regulation. In some cases, traditional epidemiology may reach similar conclusions as popular epidemiology. Yet scientists generally do not become political activists in order to implement their findings, despite exceptions such as Selikoff's work on asbestos diseases.

Popular epidemiology is similar to other lay advocacy for health care in that lay perspectives counter professional ones and a social movement guides this alternative perspective. Some lay health advocacy acts to obtain more resources for the prevention and treatment of already recognized diseases (e.g., sickle cell anemia, AIDS), while others seek to win government and medical recognition of unrecognized or underrecognized diseases (e.g., black lung, post-traumatic stress disorder). Still others seek to affirm the knowledge of yet-unknown etiological factors in already recognized diseases (e.g., DES and cervical cancer, asbestos and mesothelioma). Popular epidemiology is most similar to the latter approach, since original research is necessary both to document the prevalence of the disease and the putative causation.

From studying Woburn and other toxic cases (e.g., Couto 1986; Edelstein 1988; Krauss 1989; Levine 1982; Nash and Kirsch 1986), we observe a set of stages of citizen involvement. Participants do not necessarily complete a stage before beginning the next, but one stage usually occurs before the next begins:

- 1) A group of people in a contaminated community notice separately both health effects and pollutants.

- 2) These residents hypothesize something out of the ordinary, typically a connection between health effects and pollutants.

- 3) Community residents share information, creating a common perspective.

- 4) Community residents, now a more cohesive group, read about, ask around, and talk to government officials and scientific experts about the health effects and the putative contaminants.

- 5) Residents organize groups to pursue their investigation.

- 6) Government agencies conduct official studies in response to community groups' pressure. These studies usually find no association between contaminants and health effects.

7) Community groups bring in their own experts to conduct a health study and to investigate pollutant sources and pathways.

8) Community groups engage in litigation and confrontation.

9) Community groups press for corroboration of their findings by official experts and agencies.

*Lay Observations of Health Effects and Pollutants.* Many people who live at risk of toxic hazards have access to data otherwise inaccessible to scientists. Their experiential knowledge usually precedes official and scientific awareness, largely because it is so tangible. Knowledge of toxic hazards in communities and workplaces in the last two decades has often stemmed from lay observation (Edelstein 1988; Freudenberg 1984a; Frumkin and Kantrowitz 1987).

Although the first official action—closing Woburn's polluted wells—occurred in 1979, the Woburn water had a long history of problems. 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 Ann Anderson, whose son, Jimmy, had been diagnosed with acute lymphocytic leukemia in 1972.

*Hypothesizing Connections.* Anderson put together information during 1973–1974 about other cases by meetings with other Woburn victims in town and at the hospital where Jimmy spent much time. Anderson 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 (DiPerna 1985, pp. 75–82). Anderson's hypothesis mirrored that of other communities, where people hypothesize that a higher than expected incidence of disease is due to toxics.

*Creating a Common Perspective.* Anderson sought to convince the family minister, Bruce Young, that the water was somehow responsible, although he at first supported her husband's wish to dissuade her. The creation of a common perspective was aided by a few significant events. In 1979, builders found 184 55-gallon drums in a vacant lot; they called the police, who in turn summoned the state Department of Environmental Quality Engineering (DEQE). When water samples were then taken from a number of municipal

wells, Wells G and H showed high concentrations of organic compounds known to be animal carcinogens, especially trichloroethylene (TCE) and tetrachloroethylene (PCE). EPA recommends that the TCE be zero parts per billion and sets a maximum of 5 parts per billion; Well G had 40 times that concentration. As a result, the state closed both wells (Clapp 1987; DiPerna 1985, pp. 106–8).

In June 1979, just weeks after the state closed the wells, a DEQE engineer driving past the nearby Industri-Plex construction site thought he saw violations of the Wetlands Act. A resultant EPA study found dangerous levels of lead, arsenic, and chromium, yet EPA told neither the town officials nor the public. The public only learned of this months later, from the local newspaper. Reverend Young, initially distrustful of Anderson's theory, came to similar conclusions once the newspaper broke the story. Working with a few leukemia victims he placed an ad in the Woburn paper, asking people who knew of childhood leukemia cases to respond. 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.

*Looking for Answers from Government and Science.* The data convinced Dr. Truman, who called the Centers for Disease Control (CDC). The citizens persuaded the City Council in December 1979 to ask the CDC to investigate formally. Five days later, the Massachusetts DPH reported on *adult* leukemia mortality for a five-year period, finding a significant elevation only for females. This report was cited to contradict the residents' belief in the existence of a childhood leukemia cluster.

*Organizing a Community Group.* In January 1980, Young, Anderson, and 20 others (both litigants and non-litigants) formed For a Cleaner Environment (FACE) to solidify and expand their efforts (DiPerna 1985, pp. 111–25). FACE pursued all subsequent negotiations with local, state, and federal agencies. It campaigned to attract media attention, and made connections with other toxic waste groups.

Community groups in contaminated communities provide many important functions. They galvanize community support, deal with government, work with professionals, engage in health studies, and provide social and

emotional support. They are the primary information source for people in contaminated communities, and often the most—even the only—accurate source (Gibbs 1982; Edelstein 1988, p. 144). Through their organization, Woburn activists report pride in learning science, protecting and serving their community, guaranteeing democratic processes, and personal empowerment.

*Official Studies Are Conducted by Experts.* In May 1980 the CDC and the National Institute for Occupational Safety and Health sent Dr. John Cutler to collaborate with the DPH on further study. By then, the Woburn case had national visibility due to national newspaper and network television coverage. In June 1980 Senator Edward Kennedy asked Anderson and Young to testify at hearings on the Superfund, providing further important public exposure. Five days after Jimmy Anderson died, the CDC/DPH study was released in January 1981, 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 (e.g., medical histories, parental occupation, environmental exposures) that differentiated victims from nonvictims. Lacking environmental data prior to 1979, no linkage could be made to the water supply (Parker and Rosen 1981). That report helped bolster community claims of a high leukemia rate, although the DPH argued that the data could not implicate the wells. Cutler and his colleagues argued that in addition to the absence of case-control differences and the lack of environmental water exposure data, the organic compounds in the wells were known as animal, but not human, carcinogens (Condon 1991; Cutler et al. 1986; Knorr 1991).

The government agencies and their scientific experts worked to maintain their "ownership" of the problem by denying the link with toxics, and by maintaining control of problem solution (Gusfield 1981, pp. 10–15). Activists struggled to solidify their claim to ownership of the problem, to redefine causal responsibility, and to take on political responsibility. While epidemiologists admit to the uncertainties of their work, their usual solution is to err on the side of rejecting environmental causation, whereas community residents make the opposite choice.

*Activists Bring in Their Own Experts.* The

activists had no "court of appeals" for the scientific evidence necessary to make their case. It became FACE's mission to obtain the information themselves. The conjuncture of Jimmy Anderson's death and the DPH's failure to implicate the wells led the residents to question the nature of official studies. They received help when Anderson and Young presented the Woburn case to a seminar at the Harvard School of Public Health (HSPH). Marvin Zelen and Steven Lagakos of the Department of Biostatistics became interested. Working with FACE members, they designed a health study, focusing on birth defects and reproductive disorders widely considered to be environmentally related. The biostatisticians and activists teamed up in a prototypical collaboration between citizens and scientists (Lagakos 1987; Zelen 1987). The FACE/HSPH study was more than a "court of appeals," since it transformed the activists' search for credibility. They no longer had to seek scientific expertise from outside; now they were largely in control of scientific inquiry.

Sources of data for the Woburn health study included information on 20 cases of childhood leukemia (ages 19 and under) diagnosed between 1964 and 1983, the DEQE water model of Wells G and H, and the health survey. The survey collected data on adverse pregnancy outcomes and childhood disorders from 5,010 interviews, covering 57 percent of Woburn residences with telephones. The researchers trained 235 volunteers to conduct the survey, taking precautions to avoid bias<sup>2</sup> (Lagakos, Wessen, and Zelen 1984).

*Litigation and Confrontation.* During this period, the DEQE'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. DEQE's March 1982 report thus determined that 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 for waste disposal practices that led to water contamination and disease. A smaller company, Unifirst, was also sued but quickly settled before trial (Schlichtmann 1987). In July 1986 a federal district court jury found that Grace had negligently dumped chemicals; Beatrice Foods was absolved. An \$8 million out-of-court settlement with Grace

was reached in September 1986. The families filed an appeal against Beatrice, based on suppression of evidence, but the Appeals Court rejected the appeal in July 1990, and in October 1990 the United States Supreme Court declined to hear the case (Brown 1987, 1990; Neuffer 1988).

The trial was a separate but contiguous struggle over facts and science. Through consultant physicians, immunologists, epidemiologists, and hydrogeologists, the families accumulated further evidence of adverse health effects. The data were not used in the trial, which never got to the point of assessing the causal chain of pollution and illness. Nevertheless, the process made the residents more scientifically informed.

*Pressing for Official Corroboration.* In February 1984 the FACE/Harvard School of Public Health data were made public. Childhood leukemia was found to be significantly associated with exposure to water from Wells G and H. Children with leukemia received an average of 21.2 percent of their yearly water supply from the well, compared to 9.5 percent for children without leukemia. Controlling for risk factors in pregnancy, the investigators found that access to contaminated water was associated with perinatal deaths since 1970, eye/ear anomalies, and CNS/chromosomal/oral cleft anomalies. With regard to childhood disorders, water exposure was associated with kidney/urinary tract and lung/respiratory diseases (Lagakos et al. 1984). If only the children that were in-utero at the time of exposure were studied, the positive associations were even stronger (Lagakos 1987).

Due to lack of resources, this study would not have been possible without community involvement. Yet this lay involvement led professional and governmental groups—the DPH, the Centers for Disease Control, the American Cancer Society, the EPA, and even the Harvard School of Public Health Department of Epidemiology—to charge that the study was biased. The researchers conducted extensive analyses to demonstrate that the data were not biased, especially with regard to the use of community volunteers as interviewers.<sup>2</sup> Still, officials argued that interviewers and respondents knew the research questions, respondents had potential recall bias, and the water model measured only household supply rather than individual consumption (Condon 1991; Knorr 1991).

Thus, although activists expected the results to bring scientific support, they saw only criticism.

Having laid out the stages of popular epidemiological involvement, the main lay-professional disputes will now be described. These stages include lay participation, standards of proof, constraints on professional practice, quality of official studies, and professional autonomy.

## PROFESSIONAL WAYS OF KNOWING

Sociologists of science note that despite the existence of competing paradigms and models in any science, there is nevertheless a mainstream canon of knowledge, interpretation, and causal reasoning (Aronowitz 1988; Dickson 1984). The discussion here of professional ways of knowing refers to that mainstream. This does not mean that there is a monolithic worldview; there are indeed alternative voices. Yet a dominant mainstream approach permits us to make generalizations.

Traditional science contains a narrowly circumscribed set of assumptions about causality, the political and public role of scientists, and corporate and governmental social responsibility (Ozonoff and Boden 1987). Political-economic approaches argue that scientific inquiry is tied to corporate, political, and foundation connections that direct research and interpretation toward support for the status quo (Aronowitz 1988; Dickson 1984). It is useful to draw on both the political-economic perspective, which provides a social context for science, and the ethnomethodological/constructivist perspective, which shows us the internal workings of the scientific community (e.g., Latour 1987). There is a dynamic relationship between these two approaches—social movement actions provide the impetus for new scientific paradigms, and those new paradigms in turn spawn further social movement action.

The critics of the Woburn health survey did not represent *all science*, since residents received help from scientists who supported community involvement and believed that contaminated communities fail to receive fair treatment. Often such scientists have worked without compensation. Some began as critics of mainstream approaches, while others became critical only during the investigation.

Some believed in a different causal paradigm, and some were critical of prevailing canons of significance levels. Others simply believed they could conduct better studies than official agencies.

Lay pressure for a different scientific approach is not directed at "pure" science. In environmental health, we are dealing with *combined* government/professional units, e.g., DPH, EPA, and CDC. The end goal for activists is mainly acceptance by *government agencies*, since they have the power to act. At the same time, activists seek to become "popular scientists" who can win the support of scientific experts for the sake of knowledge.

### *Popular Participation and the Critique of Value-neutrality*

Activists disagree that epidemiology is a value-neutral scientific enterprise conducted in a sociopolitical vacuum. Critics of the Woburn health study argued that the study was biased by the use of volunteer interviewers and by prior political goals. Those critics upheld the notion of a value-free science in which knowledge, theories, techniques, and applications are devoid of self-interest or bias. Such claims are disputed by the sociology of science, which maintains that scientific knowledge is not absolute, but rather is the subject of debate among scientists (Latour 1987). Scientific knowledge is shaped by social forces such as media influence, economic interest, political pressure, and social movement activism (Aronowitz 1988; Dickson 1984). On a practical level, scientific endeavors are limited by financial and personnel resources (Goggin 1986; Nelkin 1985); lay involvement often supplies the labor power needed to document health hazards. Science is also limited in the method(s) it uses to identify problems worthy of study. As an academic and official enterprise, science does not take its direction from the lay public.

Toxic waste activists see themselves as correcting problems not dealt with by the established scientific community. The centrality of popular involvement is evident in the women's health and occupational health movements that have been major forces in pointing to often unidentified problems and working to abolish their causes. Among the

hazards and diseases thus uncovered are DES, Agent Orange, asbestos, pesticides, unnecessary hysterectomies, sterilization abuse, and black lung (Berman 1977; Rodriguez-Trias 1984; Scott 1988; Smith 1981). In these examples and in Woburn, lay activists are not merely research assistants to sympathetic scientists, but often take the initiative in detecting disease, generating hypotheses, pressing for state action, and conceiving and overseeing scientific studies.

### *Standards of Proof*

Many scientists and public health officials emphasize various problems in standards of proof, ranging from initial detection and investigation to final interpretation of data. Assessment of public health risks of toxic substances involves four steps. Hazard identification locates the existence and extent of toxics. Dose response analysis determines the quantitative effects of the substance. Exposure assessment examines human exposure to the substances. Risk characterization integrates the first three steps in order to estimate the numbers of people who will be affected and the seriousness of the effects. From the scientific point of view, there is considerable uncertainty about each of these steps (Upton, Kneip, and Toniolo 1989).

Scientists and officials focus on problems such as inadequate history of the site, lack of clarity about the contaminants' route, determination of appropriate water sampling locations, small numbers of cases, bias in self-reporting of symptoms, obtaining of appropriate control groups, lack of knowledge about characteristics and effects of certain chemicals, and unknown latency periods for carcinogens (Condon 1991; Knorr 1991). Epidemiologists usually do not choose the research questions they think are amenable to study based on clear hypotheses, firmer toxicological data, and adequate sample size. Rather, they respond to a crisis situation, engaging in "reactive epidemiology" (Anderson 1985). Traditional approaches also tend to look askance at innovative perspectives favored by activists, such as the importance of genetic mutations, immune dysregulation markers, and non-fatal and non-serious health effects (e.g., rashes, persistent respiratory problems) (Gute 1991; Ozonoff and Boden 1987).



For public health officials, disputes over health studies arise from shortcomings in knowledge about toxic waste-induced disease. A DPH official involved in Woburn for over a decade reflected on the vast changes in knowledge, personnel, and attitudes over that period. At first, public health researchers knew little about investigating clusters; environmental epidemiology was a new field; the state had few qualified scientists; and officials did not know how to involve the public. The DPH was trying out new approaches as they proceeded, without clearly established protocols (Condon 1991).

Activists view scientists as too concerned with perfection in scientific study. Residents believe that there have been visible health effects, clear evidence of contamination, and strong indications that these two are related. From their point of view, the officials and scientists are hindering a proper study, or are hiding incriminating knowledge. Residents observe corporations denying their dumping of toxic waste and that such substances have health effects. When public health agencies fail to find adverse health effects, many people view them as supporting corporate polluters. While residents agree with officials that cluster studies and environmental health assessment are new areas, they believe the agencies should spend more effort on residents' perceptions of crucial matters.

The level of statistical significance required for intervention is a frequent source of contention. Many communities that wish to document hazards and disease are stymied by insufficient numbers of cases to achieve statistical significance. Some professionals who work with community groups adhere to accepted significance levels (Lagakos et al. 1984), while others argue that such levels are as inappropriate to environmental risk as to other issues of public health, such as bomb threats and epidemics (Paigen 1982). Ozonoff and Boden (1987) distinguish statistical significance from public health significance, since an increased disease rate may be of great public health significance even if statistical probabilities are not met. They believe that epidemiology should mirror clinical medicine more than laboratory science, by erring on the safe side of false positives.

Hill (1987) argues that even without statistical significance we may find a clear association based on strength of association;

consistency across persons, places, circumstances, and time; specificity of the exposure site and population; temporality of the exposure and effect; biological plausibility of the effect; coherence with known facts of the agent and disease; and analogy to past experience with related substances. Pointing to the above as well as to more "provable" experimental models and dose-response curves, Hill argues that there are no hard and fast rules for establishing causality. Given the potential dangers of many classes of materials, he believes that often it is wise to restrict a substance to avoid potential danger.

Epidemiologists prefer false negatives to false positives—i.e., they would prefer to claim falsely that an association between variables does not exist when it does than to claim an association when there is none. This burden of proof usually exceeds the level required to argue for intervention. As Couto (1986) observes:

The degree of risk to human health does not need to be at statistically significant levels to require political action. The degree of risk does have to be such that a reasonable person would avoid it. Consequently, the important political test is not the findings of epidemiologists on the probability of nonrandomness of an incidence of illness but the likelihood that a reasonable person, including members of the community of calculation [epidemiologists], would take up residence with the community at risk and drink from and bathe in water from the Yellow Creek area or buy a house along Love Canal.

Indeed, these questions are presented to public health officials wherever dispute occurs between the citizen and official perceptions. Beverly Paigen (1982), who worked with laypeople in Love Canal, clearly believes that standards of evidence are value-laden:

Before Love Canal, I also needed a 95 percent certainty before I was convinced of a result. But seeing this rigorously applied in a situation where the consequences of an error meant that pregnancies were resulting in miscarriages, stillbirths, and children with medical problems, I realized I was making a value judgment . . . whether to make errors on the side of protecting human health or on the side of conserving state resources.

This dispute suggests the need for a more interactive approach to the *process* of scientific knowledge-making. Applying Latour's (1987) "science in action" framework, the real meaning of epidemiological "fact" cannot be seen until the epidemiologist experiences the citizenry and the problem being studied. Conversely, the public has no clear sense of what epidemiology can or cannot do for them until they or their neighbors are part of a study sample. In addition, both parties' perceptions and actions are jointly produced by their connections with other components, such as media, civic groups, and politicians. Latour's method bids us to ask this question of epidemiological research: for *whose* standards, and by what version of *proof* is a "standard of proof" determined and employed?

#### *Institutional Constraints on Professional Knowledge and Action*

Professional knowledge formation is affected by various institutional constraints. Professionals rarely view public initiatives as worthy of their attention. Laypeople have fewer scientific and financial resources than government and corporations (Paigen 1982). Without an ongoing relationship with the community, professionals enter only as consultants at a single point, and are unlikely to understand the larger framework of lay claims-making.

University-based scientists, a potential source of aid, frequently consider applied community research to be outside the regular academic reward structure (Couto 1986). Further, universities' increasing dependency on corporate and governmental support has made scholars less willing to challenge established authority (Goggin 1986). Grant support from federal agencies and private foundations is less likely to fund scholars who urge community participation and who challenge scientific canons and government policy.

Scientists often ally themselves with citizen efforts because they see flaws in official responses. Challenging state authority sometimes leads them to be punished as whistleblowers. When Beverly Paigen, a biologist at the New York State Department of Health (DOH), aided Love Canal residents' health studies, she was harassed by her superiors.

The DOH withdrew a grant application she had written without telling her, and refused to process an already funded grant. She was told that due to the "sensitive nature" of her work, all grants had to go through a special review process. Her professional mail was opened and taped shut, and her office was entered and searched at night. Paigen's state tax was audited, and she saw in her file a clipping about her Love Canal work. Later, the state tax commissioner apologized to her. Two officials in the regional office of the Department of Environmental Conservation were demoted or transferred for raising questions about the state's investigation (Paigen 1982). Similar cases have been documented elsewhere (Freudenberg 1984a, p. 57).

#### *Quality and Accessibility of Official Data*

Massive complaints in Massachusetts about the state's response to lay concerns over excess cancer rates in 20 Massachusetts communities (including Woburn) led to state senate (Commonwealth of Massachusetts 1987) and university (Levy et al. 1986) investigations, which found that the DPH studies were poorly conceived and methodologically weak. Most lacked a clear hypothesis, failed to mention potential exposure routes, and as a result rarely defined the geographic or temporal limits of the population at risk. Methods were presented erratically and inconsistently, case definitions were weak, environmental data were rarely presented, and statistical tests were inappropriately used (Levy et al. 1986). Frequently, exposed groups were diluted with unexposed individuals, and comparison groups were likely to include exposed individuals (Ozonoff and Boden 1987). This situation is striking, since the damaging effects of the poor studies and nonresponsiveness to the community led to the resignation of the public health commissioner, Bailus Walker, then head of the American Public Health Association (Clapp 1987).

State agencies are often unhelpful. A survey of all 50 states' responses to lay cancer cluster reports found an estimated 1,300–1,650 such reports in 1988, clearly a large number for agencies already short-staffed. Many state health departments discouraged informants, in some cases requesting extensive data before they would go further. Rather

than deal specifically with the complaint, many health departments 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).

Officials may withhold information on the basis that it will alarm the public (Levine 1982), that the public does not understand risks, or that it will harm the business climate (Ozonoff and Boden 1987). Many scientists oppose public disclosure on the grounds that laypersons are unable to make rational decisions (Krimsky 1984). Toxic waste activists often are called "anti-scientific" when in fact they may simply work at science in a nontraditional manner. Indeed, these activists express support for scientists as important sources of knowledge (Freudenberg 1984b). FACE activists report that they have become highly informed about scientific matters, and are proud of it.

A cardinal assumption of science is that its truth and validity are affirmed by widespread recognition of the findings through open access to data among members of the scientific community. Yet the Massachusetts cases were not even shared with all appropriate scientists. Local health officials typically heard of elevated cancer rates through the media, rather than from state health officials. The EPA began a secret investigation of the Woburn data, leaving out researchers and Woburn residents who had already been involved in many investigations. Formed in 1984, the study group's existence was only discovered in 1988 (Kennedy 1988). The EPA did not view this as secrecy, but merely an internal "tell us what you think of this thing" (Newman 1991).

### *Professionalism, Controversy, and Information Control*

It is particularly ironic that epidemiology excludes the public, since the original "shoe-leather" work that founded the field is quite similar to popular epidemiology. Woburn residents' efforts are very reminiscent of John Snow's classic study of cholera in London in 1854, where that doctor closed the Broad Street pump to cut off contaminated water. Yet modern epidemiology has come far from

its original shoe-leather origins, turning into a laboratory science with no room for lay input.

The combination of epidemiologic uncertainty and the political aspects of toxic waste contamination leads to scientific controversy. According to Latour (1987, p. 132), rather than a "diffusion" of ready-made science, we must study how "translations" by many parties of undecided controversies lead to a consensual reality. From the point of view of traditional epidemiologists, citizens' translations hinder consensual production of science. Yet, in fact, the scientific community is itself disunified on most issues of environmental epidemiology, and laypeople are partaking in the related consensual production.

In this struggle, citizens use controversy to demystify expertise and to transfer problems from the technical to the political arena (Nelkin 1985). This redefinition of the situation involves a lay approach to "cultural rationality" as opposed to the scientific establishment's "technical rationality" (Krimsky and Plough 1988). This form of struggle was described earlier, in reference to when residents ask officials whether they would live in and drink water from the contaminated community. We also may view gender differences as representative of differing rationalities. Women are the most frequent organizers of lay detection, partly because they are the chief health arrangers for their families, and partly because they are more concerned than men with local environmental issues (Blocker and Eckberg 1989; Levine 1982). From this perspective, women's cultural rationality is concerned with who would be willing to drink local water, and how their families experience daily life.

### BAD SCIENCE, GOOD SCIENCE, POPULAR SCIENCE

One way to look at official support for lay involvement is to view it as simply "good politics," whereby the government provides a formal mechanism for citizen participation in such areas as Environmental Impact Statements and Recombinant DNA Advisory Panels. However, public participation was limited in these cases to minor roles on panels that already had an official agenda (Jasanoff 1986; Krimsky 1984).

But as we observe in popular epidemiology, lay involvement is not merely "good

politics." It is also "good science," since it changes the nature of scientific inquiry. This involves four elements addressed throughout:

1) Lay involvement identifies the many cases of "bad science," e.g., poor studies, secret investigations, failure to inform local health officials.

2) Lay involvement points out that "normal science" has drawbacks, e.g., opposing lay participation in health surveys, demanding standards of proof that may be unobtainable or inappropriate, being slow to accept new concepts of toxic causality.

3) The combination of the above two points leads to a general public distrust of official science, thus pushing laypeople to seek alternate routes of information and analysis.

4) Popular epidemiology yields valuable data that often would be unavailable to scientists. If scientists and government fail to solicit such data, and especially if they consciously oppose and devalue it, such data may be lost.

We see these four elements in many contaminated communities, but in Woburn the lay contribution to scientific endeavor has been exceptional. The Woburn case was the major impetus for the establishment of the state cancer registry (Clapp 1987). Activism also has contributed to increasing research on Woburn: the DPH and CDC are conducting a major five-year reproductive outcome study of the city, utilizing both prospective and retrospective data, and citizens have a large role in this process. The DPH is conducting a case-control study of leukemia, and an MIT study will study genetic mutations caused by trichloroethylene (TCE), to investigate their role in causing leukemia (Latowsky 1988).

Popular epidemiology can sway government opinion over time, especially when activists doggedly stick to their own work while constantly participating with official bodies. The since-retired DPH Commissioner who took office in 1988, Deborah Prothrow-Stith, asked for a more official relationship with FACE. Upon visiting Woburn, the commissioner said she was "struck with how epidemiology is dependent on the role the public plays in bringing these things to light" (Mades 1988). A DPH official in 1990, going over the chronology of events, noted that the FACE/Harvard School of Public Health study found positive associations between well

water and adverse reproductive outcomes, a position the DPH avoided for the preceding six years since the study was published (Kruger 1990). Other officials now view the study as an important source of research questions and methods that informs the ongoing official studies, as well as a prompt to government action. Indeed, they expect that the new studies may show evidence of adverse health effects (Condon 1991; Knorr 1991).

Popular epidemiologists also provide continuity in the scientific process. As a leading activist stated, "We have been the institutional memory of studies in Woburn. We have seen agency heads come and go. We have seen project directors come and go. Our role has been to bring those efforts together and to help the researchers investigate what was going on all throughout the area." (Latowsky 1990). To understand the significance of that position, we may observe that as late as 1990 an EPA Remedial Project Manager for the Woburn site could hear a question, "Is the leukemia cluster a cause for urgency of cleanup?" and respond that "Our investigation is not concerned with the cluster of leukemia. It's really irrelevant. We're on a schedule based on our regulations" (Newman 1990). While EPA does not consider its responsibilities to include cluster detection (Newman 1991), all elements are related for residents.

Ozonoff (1988) sums up the Woburn impact:

In hazardous waste, three names come up—Love Canal, Times Beach, and Woburn. Woburn stands far and above them all in the amount of scientific knowledge produced. All over the country, Woburn has put its stamp on the science of hazardous waste studies.

Of particular value is the discovery of a TCE syndrome involving three major body systems—immune, cardiovascular, and neurological—which is increasingly emerging in other TCE sites.

#### *How Do We Know if Lay Investigations Provide Correct Knowledge?*

It is obviously necessary to evaluate the correctness of findings that result from popular epidemiology. Such knowledge is not

"folk" knowledge with an antiscientific basis. In most cases, popular epidemiology findings are the result of scientific studies involving trained professionals, even if they begin as "lay mapping" of disease clusters without attention to base rates or controls. Indeed, lay-involved surveys are sometimes well-crafted research with defensible data. Laypeople may initiate action and even direct the formulation of hypotheses, but they work *with* scientists, not in place of them. Thus, the end results can be judged by the same criteria as any study. However, since all scientific judgments involve social factors, there are no simple algorithms for ascertaining truth. Scientific inquiry is always full of controversy; what is different here is that laypeople are entering that controversy.

Public health officials worry that some communities might exaggerate the risks of a hazard, or be wrong about the effects of a substance. Yet if this occurs, it must be seen in context: community fears are too often brushed aside and data has been withheld. Given the increasing cases (or at least recognition of those cases) of technological disasters, drug side effects, and scientific fraud, public sentiment has become more critical of science. In response, lay claims may be erroneous. But this is the price paid for past failures and problems, and is a countervailing force in democratic participation (Piller 1991). Exaggerated fears may be understood as signs of the need to expand public health protection, rather than justifications to oppose lay involvement. Even if a community makes incorrect conclusions, their data base may still remain useful for different analyses. As mentioned before, the DPH disagrees with the Harvard/FACE conclusions, yet they are now testing those same relationships in their own study.

Even if they do not exaggerate claims, lay investigators may pursue specific inquiries with their own agenda in mind. For example, they may emphasize certain health data and minimize other reports. This may stem from the salience of certain hazards or diseases, the population affected (especially children), and the dynamics between residents and corporate and governmental actors. Citizens' efforts are typically more avowedly political and media-oriented, since their lack of power compels them to mobilize mostly in public rather than scientific venues.

## CONCLUSION

### *Limitations of This Study*

Despite the triangulation of various forms of data, this study is based on a single site. The laypeople who played such a major role may be a unique group in their abilities and tenacity, leading them to be at the forefront of challenges to official science. As well, the Woburn activists are one of the few groups to find such high-quality scientific collaboration. To the extent that these activists and their scientific colleagues are unique, parts of the Woburn experience may not be widely generalizable to other toxic waste sites. The literature does tell us that some parts of the Woburn experience are indeed common to other sites, especially the challenge to, and distrust of, scientific and governmental elites. Those parts that are perhaps less generalizable are the successful application of health survey techniques, and eventual acceptance of activists' role by public health agencies. Lastly, both the study of the existence of disease clusters and the causal role of toxic substances are in their early stages of development. The intense conflicts over these issues may make it difficult to judge the validity of research methods, results, and interpretation.

### *Causes and Implications of Popular Epidemiology*

Popular epidemiology stems from the legacy of health activism, growing public recognition of problems in science and technology, and the democratic upsurge regarding science policy. This paper has pointed to the difficulties faced by communities due to differing conceptions of risk, lack of resources, poor access to information, and unresponsive government. In popular epidemiology, as in other health-related movements, activism by those affected is necessary to make progress in health care and health policy. In this process a powerful reciprocal relationship exists between the social movement and new views of science. The striking awareness of new scientific knowledge, coupled with government and professional resistance to that knowledge, leads people to form social movement organizations to pursue their claims-making. In turn, the further development of social movement organiza-

tions leads to further challenges to scientific canons. The socially constructed approach of popular epidemiology is thus a result of both a social movement and a new scientific paradigm, with each continually reinforcing the other.

Dramatically increasing attention to environmental degradation may make it easier for many to accept causal linkages previously considered too novel. Further, this expanding attention and its related social movements may lead to the identification of more disease clusters. This then could lead to the reevaluation of problems of low base rates in light of how other sciences (e.g., physics, paleontology) conduct research on low base-rate phenomena. As well, growing numbers of similar cases containing small sample sizes and/or low base-rate phenomena may allow for more generalizability. These increasing cases also produce more anomalies, allowing for a paradigm shift.

Causal explanations from outside of science also play a role. Legal definitions of causality, developed in an expanding toxic tort repertoire, are initially determined by judicial interpretation of scientific testimony. Once constructed, they can take on a life of *their own*, directing public health agencies and scientists to adhere to scientific/legal definitions that may or may not accord completely with basic science. At the least, they set standards by which scientific investigations will be applied to social life (e.g., court-ordered guidelines on claims for disease caused by asbestos, nuclear testing, DES).

Lay and professional approaches to knowledge and action on environmental health risks are structurally divergent, much as Freidson (1970) conceives of the inherent differences and conflicts between patient and physician. Yet just as modern efforts from both medicine and its clientele seek an alternate model, so too does popular epidemiology offer a new path. Popular epidemiology offers a bridge between the two perspectives, a bridge largely engineered and constructed by lay activists, yet one with the potential to bring citizens and scientists together.

## NOTES

1. The *interview* included questions such as: "What has the progress of the Woburn situation taught you about the nature of environmental hazards?", "Did you know what you were

getting at when you filed the suit?", "Do you expect you or your family will have any future health problems as a result of the Woburn pollution from Wells G and H?" A complete interview guide is available from the author.

2. The researchers conducted extensive analyses to demonstrate that the data were not biased. They found no differences when they compared baseline rates of adverse health effects for West Woburn (never exposed to Wells G and H water) and East Woburn (at a period prior to the opening of the wells). They examined transiency rates to test whether they were related to exposure and found them to be alike in both sectors. Other tests ruled out various biases potentially attributable to the volunteer interviewers (Lagakos et al. 1984).

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**Phil Brown** is professor of sociology, Brown University. His research interests are community responses to toxic wastes, physician involvement in identifying toxic waste-induced disease, class and gender differences in toxic waste activism, self-care beliefs and practices of elderly people, diagnostic issues in psychiatry, and interaction in mental health settings.