Policy Issues in Environmental Health Disputes

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By PHIL BROWN, STEPHEN ZAVESTOSKI, BRIAN MAYER, SABRINA MCCORMICK, and PAMELA S. WEBSTER

ABSTRACT: This article compares the state of policies concerning three different diseases/conditions with putative environmental factors: asthma, breast cancer, and Gulf War–related illnesses. By comparing the state of four different types of policies—research funding, regulations, compensation/treatment, and citizen participation—the authors demonstrate the dynamic relationship between policies and health social movements. They identify four factors that shape policy for these three diseases: the science base supporting the environmental causation hypothesis, prevalence and perception of risk, the sources of support for the environmental causation hypothesis, and the strength of health social movements. All four factors contribute to policy outcomes, but they find the strength of health social movements to be particularly important for the three diseases they examine. In some cases, social movement activity can be more important than the strength of the science base in terms of policy outcome success.

Phil Brown is a professor of sociology and environmental studies at Brown University. He is currently examining disputes over environmental factors in asthma, breast cancer, and Gulf War–related illnesses as well as toxics reduction and precautionary principle approaches that can help avoid toxic exposures. Among his other research interests are gender, race, and class bias in the burden of environmental hazards, health social movements, and community responses to toxic waste contamination. He is the author of No Safe Place: Toxic Waste, Leukemia, and Community Action (Phil Brown and Edwin Mikkelsen) and coeditor of a collection, Illness and the Environment: A Reader in Contested Medicine. His third edition of Perspectives in Medical Sociology is widely used in colleges. Prior to studying health and the environment, he studied mental health policy, mental patients' rights, and clinical interaction in psychiatric settings. Among his publications from that work are The Transfer of Care: Psychiatric Deinstitutionalization and Its Aftermath and Mental Health Care and Social Policy (edited).

Stephen Zavestoski is an assistant professor of sociology at the University of San Francisco. His current research examines the role of science in disputes over the envi-
As environmentally induced diseases become more frequent in modern societies, there is a corresponding need to understand how social institutions deal with these diseases. Sufferers of environmentally induced diseases share an initial and often ongoing struggle to demonstrate the link between their condition and the purported environmental cause. In seeking to make this link, sufferers move between cultural, scientific, medical, and political institutions, with the ultimate goals of effectively treating their symptoms and preventing future incidences for themselves and others.

Achieving these goals means that sufferers of environmentally induced diseases have to fight for new or environmental causes of unexplained illnesses, the use of the Internet as a tool for enhancing public participation in federal environmental rule making, and citizen responses to community contamination. His work appears in journals such as Science, Technology & Human Values, Journal of Health and Social Behavior, and Sociology of Health and Illness and in the book Sustainable Consumption: Conceptual Issues and Policy Problems.

Brian Mayer is currently a graduate student in the sociology department at Brown University. His interests include environmental and medical sociology as well as science and technology studies. His recent projects include an investigation of the growth of the precautionary principle as a new paradigm among environmental organizations and a study of social movements addressing environmental health issues.

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Pamela S. Webster is an adjunct faculty member in the Department of Sociology at the University of Rhode Island in Kingston. Her research interests include sex differences in well-being and the interrelationships between health and the environment. She recently published research examining factors related to husbands' contribution to housework when their wives become newly impaired (with Susan M. Allen). She assisted in the coordination of A Just and Sustainable Future: Overcoming Barriers to Action, a series of public lectures and programs at the University of Rhode Island. Trained as a demographer, she teaches sociology of aging and sociology of the family.

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stronger policies that will guarantee them treatment and compensation, provide money for further research into the causes of their condition, and remove or reduce the causes, once identified. We explain how a variety of factors lead to policies that benefit some diseases and conditions with putative environmental causes more than others. We further show how the advantages and disadvantages of existing policies shape the strategies and resources of the health social movements (HSMs) that often emerge to advocate for stronger or newer policies. We do this by comparing the state of policies with respect to three different diseases/conditions\(^1\) that have putative environmental factors: asthma, breast cancer, and Gulf War–related illnesses.

We are interested in these three diseases because they are very prominent in the public eye, with much debate over identification, environmental causation, treatment, and lay involvement. Furthermore, research remains under public scrutiny in terms of funding, hypothesis formulation, research design, interpretation, and resultant regulation. In addition, social movements play a large role in disease identification, advocacy, and debates over environmental causation.

Finally, we are interested in environmentally induced diseases because they are unique in health policy and research for several reasons. Environmental causation is difficult to demonstrate since exposures are usually not controlled or easily measured in terms of quantity and location. Furthermore, multiple exposures are common, and there is not usually a signature disease for a specific agent. In some cases, for example, Gulf War–related illnesses, the symptoms are diffuse and fail to fall into the categories of diagnosis as defined by the biomedical model of disease. For those reasons, research capacity is weaker for environmentally induced diseases than for most other diseases, which subsequently results in much policy being shaped in the absence of scientific certainty.

In addition, even in cases where a disease has a solid funding and research base, for example, breast cancer, little of that funding goes toward research for environmental factors. When undertaken, the search for environmental causation often brings much resistance from government and industry because of its implicit challenge to the treadmills of production and consumption (Schnaiberg 1980; Bell 1998). Given government and scientific resistance to identifying environmental causes of disease, social movements often mobilize to push for policies that will guarantee research into suspected environmental causes, promise public involvement in the science and policy making related to the disease and its suspected environmental causes, regulate production processes that generate known causes, and provide compensation and treatment for those afflicted with the disease.

We organize our analysis of policy outcomes around four types of policies. Research policies include allocation of funds for both intramural and extramural research. Regulatory policies include legislation, official
regulations, and agency directives that put limits or restrictions on industry, health care providers, or others. When litigation results from regulation, we include it under regulation. Compensation/treatment includes the certification of diseases and conditions as legitimate for provision of health care services, alterations in health care surveillance, and the types of disability and compensation provided to sufferers. Citizen participation policies include measures that mandate a variety of types of lay involvement, including citizen participation on advisory boards and scientific review panels, and collaboration in research. While citizen participation is not a common outcome in policy studies, we include it here for two reasons. First, citizen participation is central to much of the activity around these diseases. Second, citizen participation is increasingly part of social policy, especially in the area of environmentally induced diseases (O’Fallon, Tyson, and Dearry 2000).

Our emphasis on the social movements that emerge to challenge or press for new policies leads us to the diagram in Figure 1. In stage 1 of the figure, prior to a HSM’s mobilizing, a disease receives greater or lesser attention from policy makers as a result of the three factors. In stage 2, the three factors and the existing policies from stage 1 influence whether an HSM will emerge and the characteristics and strategies it will adopt. HSMs then become a fourth factor, in tandem with the first three, to continue to shape future policy making. The significance of HSMs is that often they are able to promote policies even in the absence of support from one or more of the first three factors. For example, environmental breast cancer activists lack a strong science base supporting the environmental causation hypothesis, but they can nevertheless mobilize the support of physicians, scientists, and policy makers who find such a hypothesis plausible and worth investigating. The entry of social movements into the policy arena does not always occur. But when it does, we need to understand how the movements are shaped by existing policies and how they are enabled or constrained in their attempts to pass stronger legislation. Such an understanding requires a view of the relationship between HSMs and policies as dynamic rather than occurring in a linear causal fashion. Figure 1 helps conceptualize such a dynamic relationship.

After describing our methods in the next section, we review the policies that exist in each of the four policy-type categories for the three diseases. These are summarized in Table 1. Next, we explain the variation in the types, levels, and successes of policies across the three diseases in terms of the factors identified in Figure 1: the science base supporting the environmental causation hypothesis, public awareness and perception of risk of the disease, the sources of support for the environmental causation hypothesis, and the strength of the HSMs mobilized to lobby for new policies.

During our discussion of the types of policies and the factors shaping them, we move back and forth between policies that existed prior to
any mobilized effort to address the disease and policies that emerged after sufferers of an environmental illness organized themselves and lobbied for new or stronger policies. Our intent is not to argue that some groups or movements are more successful than others at passing policies or that certain factors cause policy outcomes. Rather, we try to illustrate the dynamic relationships among existing policies, medical and scientific institutions, political institutions, and the sufferers of environmental illness.

METHOD

For each of the three diseases, we studied a research site that was conducting investigations into environmental causation: Silent Spring Institute in Newton, Massachusetts, on breast cancer; the Boston Environmental Hazard Center in Boston on Gulf War illnesses; and Alternatives for Community and Environment in Boston on asthma. While the first two organizations were expressly set up to conduct public health research, Alternatives for Community and Environment’s research involvement is a small part of its larger mission of environmental-justice-based community organizing. In all three cases, social movement pressure had been central to the formation of and motivation for research on environmental causation. These three sites were vehicles for larger exploration of the three diseases, and we expanded our observation and interviewing to other sites involved in these areas.

We conducted interviews with activists and researchers involved in the above-mentioned sites (breast cancer, 36; asthma, 18; and Gulf
TABLE 1
CURRENT STATE OF POLICIES FOR ASTHMA, BREAST CANCER, AND GULF WAR ILLNESS

<table>
<thead>
<tr>
<th>Regulatory policy</th>
<th>Asthma</th>
<th>Breast Cancer</th>
<th>Gulf War Illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clean Air Act/National Ambient Air Quality Standards, diesel bus reduction in Boston</td>
<td>Endocrine Disruptor Screening and Testing Advisory Committee</td>
<td>Anthrax vaccination policy lifted</td>
<td></td>
</tr>
<tr>
<td>DoD predeployment health monitoring</td>
<td>DoD required to adhere to Food and Drug Administration human subjects regulations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Research funding policy</td>
<td>Environmental Protection Agency research on particulates</td>
<td>DoD Breast Cancer Research Program</td>
<td></td>
</tr>
<tr>
<td>NIH, Centers for Disease Control and Prevention</td>
<td>NIH, National Cancer Institute Breast Cancer and Environmental Research Act of 2001 funding</td>
<td>Persian Gulf War Veterans Act</td>
<td></td>
</tr>
<tr>
<td>Department of Housing and Urban Development Healthy Homes project</td>
<td>Long Island Breast Cancer Study Project (joint NIH/DoD)</td>
<td>Veterans Administration and DoD funding of internal research</td>
<td></td>
</tr>
<tr>
<td>Children’s Environmental Health Centers</td>
<td>Massachusetts state funding for Silent Spring Institute</td>
<td>Environmental Hazards Research Centers</td>
<td></td>
</tr>
<tr>
<td>National Institute of Allergy and Infectious Diseases</td>
<td>Allocation of tax money to research through voluntary check-off box</td>
<td>Institute of Medicine, Centers for Disease Control, President’s Advisory Committee</td>
<td></td>
</tr>
<tr>
<td>Citizen participation</td>
<td>National Institute of Environmental Health Sciences Community-Based Participatory Research Community Outreach Education Project (community involvement in educational programming, not research)</td>
<td>Consumer advocates on advisory panels in DoD research</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Long Island Breast Cancer Study Project participation requirements</td>
<td>Informal, none required</td>
<td></td>
</tr>
<tr>
<td></td>
<td>NIH-funded Breast Cancer Centers of Excellence participation requirements</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Silent Spring Institute organizational citizen participation policy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Costs of prevention (e.g., hypoallergenic products) not covered</td>
<td>Endocrine Disruptor Screening and Testing Advisory Committee</td>
<td>Veterans Programs Enhancement Act</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Persian Gulf War Veterans Act</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Veterans Millennium Health Care and Benefits Act</td>
<td></td>
</tr>
</tbody>
</table>

NOTE: DoD = Department of Defense; NIH = National Institutes of Health.

War–related illnesses, 23), as well as other activists and researchers in these fields. We also collected and analyzed policy-related government
documents in each of the disease areas. Ethnographic observations (38) were also conducted to supplement these data. While the interviews were the primary source of analysis, the observations provided a broader contextual picture. Printed materials from each organization were collected to better understand their activities that have shaped policy.

ASTHMA

Asthma represents a case where existing legislation provides a substantial head start to illness sufferers or their advocates who are working to pass new or stronger pieces of legislation. It is these existing policies—in the case of asthma, the Clean Air Act—that create a context within which illness groups develop strategies of action. The activist groups we examined, for example, had the luxury of overlooking policies to guarantee research funding. Instead, they primarily focused on local-level transit and housing policies that would result in a cleaner environment and cleaner air to breathe.

Research funding policy

Community and environmental groups that increasingly focus their attention on the environmental causes of asthma, especially in inner-city areas, are able to devote many of their resources toward passing regulatory policies that will clean up the air in their communities. This is a result of the Clean Air Act, which not only creates standards for air quality but also demands that those standards be based on the most recent scientific evidence. In fact, the Environmental Protection Agency (EPA) is required by law to provide scientific evidence when defining the National Ambient Air Quality Standards (NAAQS). In addition, the Clean Air Act explicitly states that air pollution standards cannot be based on cost-benefit analyses but rather must be based only on the best science available at the time. With federal legislation driving a large amount of the research into air pollution’s respiratory effects, organizations advocating for cleaner air in inner-city areas plagued by asthma need not devote extensive resources to passing legislation that would produce further research.

Despite the Clean Air Act’s guarantee of ongoing science into the health effects of air pollution, much of this research is on respiratory conditions other than asthma. In addition, in agencies other than EPA that fund asthma research, much of the research is on indoor causes of asthma or on asthma treatments rather than environmental causes. For example, the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), and the Department of Housing and Urban Development also fund asthma research. However, the funding provided by agencies like NIH typically goes to treatment rather than etiological studies. A recent study by the Pew Environmental Health Commission shows that 71 percent of NIH asthma grants go to pathophysiology/treatment studies, while only 17 percent go to etiological
studies. Of that 17 percent, roughly two-thirds are directed toward environmental factors (Pew Environmental Health Commission 2000).

Besides funding external research projects, federal agencies also conduct intramural research. Both the National Institute of Environmental Health Sciences (NIEHS) and the National Institute of Allergy and Infectious Diseases, located within the NIH, have several research programs focused on the diagnosis and prevention of asthma. It is not possible to calculate the amount of intramural funding on research for environmental factors in asthma, since much of the research touches on the environment indirectly. For instance, the NIEHS Children’s Environmental Health Centers carry out a wide variety of research, service, and education, but it is difficult both to separate out those diverse activities and to calculate the amount that goes to environmental asthma research.

Compensation/treatment

One significant issue in asthma treatment is whether Medicaid and insurance will cover antiallergy products (e.g., pillow and mattress covers, air purifiers) and remediation of household factors contributing to asthma (e.g., mold, carpets). At present, such expenses are not covered, with the exception of a small number of intervention programs. As for treatment, most individuals with asthma have access to health care that allows them to manage their condition. But the higher rate of asthma-related hospitalization in inner-city populations suggests there are not adequate policies to guarantee treatment for those subject to more frequent triggers such as diesel exhaust. Rather than spurring activism around better treatment for inner-city and minority asthma sufferers, these inequitable impacts have led many community organizations to take on the root cause of increased asthma attacks in their communities—poor air quality.

Regulatory policy

The most prominent form of regulatory policy affecting asthma is the 1970 Clean Air Act and its 1990 amendments. The Clean Air Act authorizes the EPA to establish NAAQS to protect public health and the environment. The goal of the NAAQS is to set maximum pollutant standards every five years based on current scientific knowledge. Although the Clean Air Act is a federal law, NAAQS are created on a state-by-state basis.

Recent controversy has sparked a heated debate about the power plants that were already in operation when the Clean Air Act was passed in 1970. Assuming these power plants would eventually be closed, they received a grandfather clause that provided exemption from the strict air emission regulations. The current controversy centers on lawsuits filed by the Clinton administration against power plants that were exempt from the original Clean Air Act but failed to upgrade their emission controls to meet new air quality standards when they modernized their plants as required by the new law. Attorney General Ashcroft has agreed to pursue the lawsuits, but other parties in the Bush
administration and their allies in the energy industry continue to challenge the Clean Air Act regulations.

At the local level, regulatory bodies are working to meet demands from resident activists to improve urban pollution problems that contribute to asthma. In Boston, regional authorities responded to an activist group’s efforts and closed a bus depot the activists felt was sited unjustly in a poor or minority neighborhood. Similarly, the Massachusetts Bay Transit Authority responded to asthma activists’ charges of “transit racism,” wherein more than $12 billion were being spent on the Big Dig highway project while the Massachusetts Bay Transit Authority refused to spend $105 million to purchase newer, cleaner buses to reduce pollution from diesel exhaust. In 2000, the Massachusetts Bay Transit Authority agreed not to buy any new conventional diesel buses, to implement an alternative fuel prototype program, and to participate in a public process for service improvements.

At the federal level, the EPA’s attempt in 1996 to tighten the restriction of ozone in the NAAQS resulted in a legal challenge from the American Trucking Association. The U.S. Court of Appeals for the District of Columbia ruled against the EPA, arguing that it had unconstitutionally exercised authority. The Supreme Court overturned the decision by the Court of Appeals in 2001. The fact that the implementation of the new NAAQS is still awaiting approval demonstrates the difficulty of implementing policies that restrict industries that are typically protected from such restrictions by both Democratic and Republican administrations. Given the high stakes involved in federal regulatory air pollution policies, as the movement to address the inequitable impacts of asthma in inner cities emerged, it focused on local issues it could achieve within the existing policies.

Citizen participation

The NIEHS, CDC, and EPA all fund asthma projects that involve the community. An example of citizen participation in asthma research is the NIEHS’s Community-Based Participatory Research project that funds prevention- and intervention-hypothesis-driven research but mandates community involvement in the process. There are five Centers for Children’s Environmental Health and Disease Prevention cofunded by the NIEHS, CDC, and EPA that include or focus on asthma as a major area of study in conjunction with Community-Based Participatory Research projects. One example of these centers is the Columbia Center for Children’s Environmental Health in New York, which works in collaboration with the activist group West Harlem Environmental Action. West Harlem Environmental Action has published several articles in which community members were co-investigators and/or actually involved in collection of data (Northridge et al. 1999). The NIEHS has created the Environmental Justice: Partnership for Communications program to support academic-community collaboration on research and education. Some of these collaborations address
asthma and are mandated to include the community in their projects and also sometimes involve lay partners in research (NIH 2000). The Community Outreach Education Projects were developed as an aspect of NIEHS Environmental Health Science Grant Centers to incorporate multidisciplinary research in an existing research setting. While community involvement is only mandated for developing educational programming, some of the projects include a community component in research.

A number of researchers have pointed to the long history of public participation models that were used to co-opt community involvement or to pay only lip service to meaningful participation (Hollander 1984; Sclove 1995). It is important to note that the examples we are speaking of do not fall into that category. They are indeed very meaningful approaches to citizen involvement, as can be seen in the opinions of lay people and can be detected in the effectiveness of these approaches in terms of challenging traditional scientific and governmental action.

BREAST CANCER

In addition to benefiting from pre-existing policies, HSMs can benefit from the efforts of movements or groups that came before them. The benefits of successes of the broader breast cancer movement, for example, have been reaped by the environmental breast cancer movement (EBCM). The breast cancer movement also represents an example of how movement success can result in functional differentiation. As a result of this differentiation, the mainstream breast cancer movement continues to focus on policies aimed at diagnosis and treatment while the EBCM focuses more on securing funding to investigate possible environmental causes of breast cancer. We discuss both efforts.

Research funding policy

As recently as the 1970s, physicians relied on nearly eighty-year-old research in justifying mastectomies as the most effective treatment of breast cancer. Given the complete absence of any alternative research, the breast cancer movement first passed legislation requiring women’s informed consent before mastectomies could be performed. Next, the movement shifted its attention to securing funding for additional research into detection, treatments, and less so, causes. Thirty years later, the EBCM has taken up the effort to secure research funding, this time to study the potential environmental causes of breast cancer. The EBCM, although national, has been shaped by the strength of activists in three areas of high cancer rates: Long Island, New York; California’s Bay Area; and Cape Cod and Newton in Massachusetts. Activists in these areas have succeeded in getting funding for a large amount of locally based research while staying involved in the effort to pass federal legislation. Yet while federal breast cancer research has increased dramatically as a result of the broader breast cancer movement, less than 3 percent of the money ($800 million in 2001) has been directed toward
finding environmental connections to breast cancer (Breast Cancer Fund 2002).

An example of the success of local area activism is the Silent Spring Institute, founded by the Massachusetts Breast Cancer Coalition in 1994. The institute serves as a research organization focused on studying breast cancer by bringing together activists and scientists to develop research and to educate the public about possible environmental causes of breast cancer. Initially, the funding came from the Massachusetts legislature, which granted $3.6 million for a three-year study. Later, the scope of the investigation was broadened considerably, and the second wave of data collection was recently completed. Silent Spring Institute’s investigation has unusual breadth, collecting environmental samples of dust, soil, and air directly from women’s homes. Silent Spring Institute also examines historic and current patterns of land use and proximity to geographical features such as golf courses and cranberry bogs (which utilize pesticides).

At the national level, Congress directed the Department of Defense’s (DoD’s) involvement in a breast cancer research program beginning in 1992. The National Breast Cancer Coalition attributes this breakthrough to its $300 Million More campaign, which was designed to increase federal funding for breast cancer research. Congress has appropriated more than $1 billion to the breast cancer research program since its inception. In 2001, the congressional appropriation for the breast cancer research program was $175 million, but it was cut to $124 million in 2002. The DoD program is unusual in the extent to which social activists have successfully shaped the process, not only in terms of level of funding but also in the overall structure of the system and the allocation of funds (e.g., more than 90 percent of the funds went directly to research grants).

The Stamp out Breast Cancer Program, another successful policy effort, is centered on a breast cancer stamp whose net proceeds above the cost of postage are designated for research purposes. It has raised at least $21 million from the sale of 305 million stamps (as of June 2001) in less than three years (http://www.winabc.org). The authorization for the breast cancer stamp, the only extra-postage stamp in existence, has been extended until July 2002, and a bill to reauthorize it until 2008 has been proposed (H.R. 2725). The success and popularity of the program and the role of citizens has been important to its reauthorization. The stamp also demonstrates the tension within the diversified breast cancer movement. For example, EBCM activists have attempted to get revenue from the breast cancer stamp moved from NCI to NIEHS, where it would be put toward more research into environmental causes.

More than $3 billion has been spent on intramural breast cancer research at NIH. While breast cancer activists applaud the importance of research, they also question whether the money is being invested wisely. The National Breast Cancer Coalition is urging Congress and the administration to explore the
question of whether changes may be needed in the grant mechanisms and the research structure at NIH and the National Cancer Institute. Activists are calling for external monitoring of the NIH and believe the public should design and participate in an oversight process that will track how the money is being spent and whether it is being spent well (National Breast Cancer Coalition 2001).

One last important development in research funding is the proposed legislation called the Breast Cancer and Environmental Research Act of 2001 (S. 830/H.R. 1723). The proposal would authorize the NIEHS to establish multidisciplinary, multi-institutional research centers to study environmental factors that may be related to the development of breast cancer. Specifically, $30 million per year in fiscal years 2002 to 2007 could be used to develop and operate no more than eight centers nationally. Activist organizations such as the National Breast Cancer Coalition support such legislation and are pleased with the number of cosponsors who have signed onto the bill to date.

**Compensation/treatment**

Changes to increase the number of women receiving treatment occurred at both the state and national level. EBCM activists, along with activists from the mainstream movement, were active in pushing California to take important steps toward guaranteeing treatment to everyone diagnosed with breast cancer. California’s 2000-2001 budget earmarked $20 million for breast cancer treatment for low-income uninsured and underinsured individuals. Shortly thereafter, former president Clinton signed into law the Breast and Cervical Cancer Prevention and Treatment Act of 2000. This law gives states the option of making medical assistance for breast- and cervical-cancer-related treatment services available to certain uninsured low-income women screened and found to have breast or cervical cancer under a federally funded screening program. As of December of 2001, forty-one states had opted into the program and/or had passed legislation adopting the new Medicaid option to expand eligibility to uninsured women.

**Regulatory policy**

Few regulatory policies exist in the area of breast cancer and environmental risk factors. This may be due in part to the equivocal state of research on breast cancer and the environment. One important exception came in 1996. At that time, provisions of both the 1996 Food Quality Protection Act and the reauthorization of the Safe Drinking Water Act called for the creation of a screening and testing program at the EPA that would provide information about possible endocrine effects of certain chemicals on human health, including pesticides, industrial chemicals, and environmental contaminants. The Endocrine Disruptor Screening and Testing Advisory Committee brought together representatives from industry, government, environmental and public health groups (including the National Breast Cancer Coalition), and academia to
deliberate for two years to design this program. While the Endocrine Disruptor Screening and Testing Advisory Committee’s 1998 recommendations were a large achievement, they still failed to include low-dose testing and a focus on early developmental disorders. Many observers believe the Endocrine Disruptor Screening and Testing Advisory Committee’s recommendations have not been implemented at the level necessary to study the many endocrine disrupters that are known (Baltz 1999). Critics of the current chemical-by-chemical regulatory approach might have predicted this, noting that the size of the task is too large and resources required are too great. Moreover, the task grows harder every year as 2,000 to 3,000 new chemicals appear on the market. According to Thornton (2001, 15), preventive action will require policies that address chemical classes and that are focused on the sources of chemical contamination. Future agency directives may be more successfully implemented by focusing on chemical classes rather than on health effects.

Recently, the CDC collected the first national data on human exposure to environmental chemicals, which eventually may lead to an improved understanding of environmental health effects (CDC 2001). When the first report from these data was released last April, it was called a “milestone in biomonitoring” (Vastag 2001). While this is an important step, exposures that occur prior to adulthood or that leave no biological markers may also be very important. For now, the paucity of regulatory policy is at least in part a reflection of the underdeveloped scientific base in this area.

Citizen participation

Citizen participation is very much a part of research on environmental factors in breast cancer. The federal government implemented citizen participation requirements for the Long Island studies and for the DoD breast cancer research program. The Silent Spring Institute bases all its activities on a citizen participation model, and California activists achieved mandated citizen participation in state-funded research. Activists are more likely to gain access to the research process when they have acquired a substantial amount of expert knowledge. Yet as we discuss later, the case of Gulf War veterans demonstrates that the level of expertise among disease activists is not always a good indicator of whether the activists will succeed at forging policies that allow them to participate in scientific research.

EBCM activists were some of the first to demand and receive government approval for citizen participation in research. As a result, advocate participation has been mandated in the DoD Breast Cancer Research Program. For the Long Island Breast Cancer Study Project, the first major study motivated by activists to investigate environmental causation, the federal government granted $32 million to conduct several different types of studies, all of which were to be advised in a variety of ways by activists. The Silent Spring Institute was also formed and continues to be shaped by activist involvement. It
exemplifies the way that activists and scientists can work together to achieve their respective agendas. Since the DoD program was the first major federal program that mandated citizen involvement, it is likely that its success, to which government officials attest, has influenced the increasing implementation of this type of collaboration. Citizen participation has recently been mandated in the new Breast Cancer Centers of Excellence, multidisciplinary institutes studying breast cancer with advising by advocates. While these, along with the general breast cancer research program, are not specifically focused on environmental causation, they do provide an avenue through which activists can share their perspectives on potential environmental causation.

Another program that institutionalizes public involvement in research is NIH's Consumer Advocates in Research and Related Activities program. NIH is recruiting 150 advocates who can serve multiple functions including advocating for and setting research priorities, participating in early design efforts of clinical trials, advocating and evaluating clinical trials, identifying research gaps, peer reviewing research, and other programmatic activities. Mentors, orientation, and training are provided. Selection of advocates is based on a ranking of applications according to the following criteria: membership in a cancer-related group, ability to offer a perspective beyond his or her own, leadership qualities, interest, familiarity or training in cancer-related concerns, and ability to work as a team player.

Finally, the Breast Cancer and Environmental Research Act mentioned previously would require the grant review process to involve consumers in decision making, and the bill would require each center to establish and maintain collaborations with local community organizations, particularly those that represent women with breast cancer.

Although breast cancer activists do not have the equivalent of asthma activists' Clean Air Act, EBCM activists in particular have benefited from the strength of the mainstream breast cancer movement. Because of the mainstream movement's attention to treatment issues, the EBCM has been able to focus on policies that would guarantee funding for research into the environmental causes of breast cancer.

GULF WAR–RELATED ILLNESSES

Gulf War veterans, unlike breast cancer or asthma activists, have struggled within a policy-making context that is heavily shaped by the power wielded by the DoD. On the other hand, early in their fight to get the government to treat and compensate them, veterans benefited from the status that military veterans are accorded in American society. This status, and the congressional support it generated, has resulted in quite a few policies both to provide compensation for Gulf War veterans and to protect soldiers in future wars. Yet as we discuss below, all of this support has failed to produce the scientific evidence that would justify further or stronger policies. This is
due, in part, to the failure of the movement to differentiate into one component that focuses on policies designed to generate a scientific base and another component focusing on compensation and treatment issues.

Research funding policy

Research on Gulf War illnesses has been supported through executive orders, congressional legislation, and internal policy decisions. Between 1994 and 2000, the federal government spent approximately $155 million for Gulf War research. This money funded 192 basic and applied research projects. In addition to the competitive grants made available by the Veterans Administration (VA) and DoD, the VA has contracted with private research firms such as RAND to conduct reviews of scientific literature. Veterans have not simply pushed for additional funding of research but in some cases, they have applied pressure to ensure that certain researchers would be the recipients of that money. Various researchers we interviewed remarked that studies by Robert Haley and Garth Nicholson, for example, received federal funding even though government scientists did not believe the research they proposed was promising or even methodologically sound.

Intramural research has also been supported. For example, in 1997, the undersecretary for health at the VA requested that the Institute of Medicine conduct a review of the peer-reviewed scientific literature on depleted uranium used in munitions, sarin nerve gas, and pyridostigmine bromide, a nerve gas antidote. This request was later turned into a legislative mandate when Congress passed the Veterans Programs Enhancement Act of 1998 and the Persian Gulf War Veterans Act of 1998. This study was released in 2000 and has been used to justify future research priorities.

Intramural research also resulted in the 2001 study by the VA and DoD that linked service in the Gulf to amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease. This study was launched after veterans voiced concerns about a perceived disproportionate number of cases of ALS. The VA initially denied veterans were suffering from ALS at a higher rate than the general population, but the preliminary results of an epidemiological analysis now suggest otherwise, and the VA has promised to offer immediate compensation and benefits to any Gulf War veteran diagnosed with ALS (Stolberg 2001).

On the other hand, distrust of the government has led veterans to be suspicious of much of the research conducted by the VA and DoD. The exception to this is the three Environmental Hazards Research Centers, located in VA Medical Centers in Boston, Massachusetts; East Orange, New Jersey; and Portland, Oregon, created by the VA in 1995. Although these centers have since lost much of their funding, they were significant in their involvement of veterans on community advisory boards and in other stages of the research process (Brown et al. 2001).
Compensation/treatment

An important issue regarding Gulf War illnesses has been the attempt to guarantee compensation and benefits for veterans with undiagnosed symptoms. Due to a VA policy that requires a service-linked diagnosis in order to receive compensation and benefits, veterans whose symptoms have gone undiagnosed have not received the care they would like. Their first success was with the Persian Gulf War Veterans’ Benefits Act of 1994, which was intended to provide for the payment of compensation to veterans suffering from a chronic disability resulting from an undiagnosed illness that manifested itself within the period required by existing regulations. But the secretary of veterans affairs interpreted the legislation so as to limit compensation to veterans with illnesses that could not be attributed to any known clinical diagnosis. As a result, veterans whose symptoms appeared similar to chronic fatigue syndrome, for example, and who received such a diagnosis, could not receive compensation. Under the Persian Gulf War Illness Compensation Act of 2001 (H.R. 612), which was referred to the Committee on Veteran Affairs in the House of Representatives in February 2001, “undiagnosed illness” is redefined so that veterans can still receive compensation even if the etiology of their symptoms cannot be identified. H.R. 612 would also extend the presumptive period for undiagnosed illnesses to 2011, which would guarantee veterans continued coverage during the intervening years even if their illnesses are not service connected.

In 1999, the Veterans Millennium Health Care and Benefits Act extended for four years the requirement that the VA operate a program to evaluate the health status of Gulf War veterans’ dependents and ensured that those who are sick but remain non–service connected will maintain eligibility for VA health care. Other legislation has included the Veterans Programs Enhancement Act of 1998. The December 2001 findings on ALS were so prominent, representing the first known causal connection to disease and Gulf War exposure, that even prior to the scientific publication of the data, the VA immediately offered full disability status to any Gulf War veteran with the disease. While this may be seen as a victory in one sense, some observers familiar with Gulf War illness research raise the possibility that this apparently munificent policy was an easy decision to make since ALS affects very few people and is therefore not costly.

Regulatory policy

Because research has failed to provide a clear understanding of the etiology of Gulf War–related illnesses, few regulatory policies have resulted. With asthma, for example, scientific research is constantly identifying new triggers or discovering lower thresholds of known triggers; this allows policy makers to create new regulations and strengthen old ones. With Gulf War–related illnesses, researchers have attempted, but failed, to find links between veterans’ symptoms and nerve agents, vaccines, depleted uranium, oil well smoke, and other agents.
Nevertheless, some regulatory policies have resulted from the efforts of Gulf War veterans. When veterans of the Gulf War began asking whether their symptoms could be related to a vaccination they had received for the anthrax virus, repercussions were felt throughout the military. Policies that required soldiers to take the vaccine have since been challenged as more and more military personnel refused to be inoculated. Perhaps more significantly, the numbers of reservists began dwindling as more and more enlisted personnel and officers announced they would rather leave their posts than be required to take the vaccine (Ricks 2000). Since the 11 September terrorist attacks and anthrax contamination, however, there has been more support for such vaccines.

Another significant outcome, partly boosted by the Institute of Medicine's recommendation, is a DoD policy to improve predeployment health monitoring. But despite this having been in place after the Gulf War, it was not implemented successfully in the Balkan peacekeeping action or in the Afghanistan war. In a recent report, the General Accounting Office questioned the VA's ability to carry out its mission while the DoD continues to fail to implement a comprehensive health monitoring system (General Accounting Office 2002). The Institute of Medicine also concluded that to monitor the health of its forces, the DoD must develop a more accurate roster of deployed service members (General Accounting Office 2002). The ability of the VA to serve veterans is limited by the DoD's ability to provide accurate health information during active service. The Gulf War revealed the need for better medical surveillance, and while the steps the DoD is taking may be small and problematic, they do represent an improvement in the current system and hence a positive policy outcome. In the other example of regulatory policy, the DoD is no longer able to use military personnel as research participants without their knowledge.

Citizen participation

It took veterans some time before realizing the importance of participating in the review of research proposals and in research design itself. In 1993, VA Secretary Jesse Brown established the Persian Gulf Expert Scientific Committee, consisting of scientific experts and representatives from veterans service organizations. The committee advises the VA on clinical, research, and compensation issues for Persian Gulf veterans. One outcome of this committee's work is the recommendation that all researchers receiving federal money include veteran representatives on their community advisory board. But this recommendation has not always been followed, and veterans have failed to participate to the extent that breast cancer activists have, despite the high level of expertise many veterans have acquired with respect to the science underlying much research.
EXPLANATIONS OF VARIATION IN POLICY OUTCOMES

From the previous review of the policy outcomes for each of the three diseases, it becomes clear that the levels and types of policies vary quite drastically. These differences are apparent in our summary of the existing policies in each of the four policy-type categories in Table 1. In the remainder of this section, we discuss four factors that help to explain this variation. These are summarized in Table 2.

Table 2 includes the strength of HSMs as one of the factors that explain the variation in policies. But HSMs themselves are shaped by the first three factors in Table 2. Consequently, we describe these three factors in terms of the challenges an HSM might face in legitimating its claims of environmental causation. To gain public and especially medical acceptance of an environmental causation hypothesis, supporting scientific evidence must be produced. Therefore, the science base for environmental causes is the first factor we discuss. Since the science base for environmental illnesses is typically not strong, the next step of an HSM is to generate additional scientific evidence to warrant new research. With an adequate science base, HSMs might focus more on regulatory policies, as in the case of asthma, or treatment and compensation policies, as with Gulf War–related illnesses.

HSMs may struggle to find institutional support, or even media or public support, if our second factor, the public awareness and perception of risk of the disease, does not appear serious enough. For example, affected populations that are not particularly vulnerable may not get public empathy, and affected populations that lack adequate wealth and resources to mobilize may not be able to raise public awareness and perception of risk. The more public awareness there is, and the greater the perception that there is a widespread risk, the more likely HSMs are to marshal the resources necessary to push through new health policies. Finally, the HSM may be more successful if it gets support for environmental causation hypotheses from important sources. Activists cannot produce scientific evidence in support of an environmental causation hypothesis alone. They need the support of scientific researchers, physicians, and politicians.

At the same time, the strength of HSMs is dependent on the same factors. Weakness in one of the factors, however, is often compensated for with strengths in other factors. For example, there is a relatively weak science base for the environmental causation hypothesis for breast cancer. But due to the mortality rate of the disease, especially compared to asthma, for example, and the perceived vulnerability of the afflicted population (i.e., women and, more specifically, mothers), breast cancer activists have had many policy successes. Gulf War veterans, like asthma sufferers, experience low mortality. But veterans have benefited from extensive support from a small group of politicians. This
<table>
<thead>
<tr>
<th>Science base for environmental causes</th>
<th>Asthma</th>
<th>Breast Cancer</th>
<th>Gulf War–Related Illnesses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strong for environmental triggers (e.g., particulate matter, allergens); weak for environmental causes (though pollution's cause of other respiratory disease is known)</td>
<td>Weak for environmental causes (but strong theoretical reasons to suspect environment)</td>
<td>Weak; some evidence of increased amyotrophic lateral sclerosis, but no Gulf War–related illness symptoms conclusively linked to environment</td>
<td></td>
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</tbody>
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<tr>
<th>Prevalence and public perception of risks</th>
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<tbody>
<tr>
<td>Widespread and increasing among children (disproportionately affecting inner-city children); higher rates of hospitalization and days of work or school missed in inner-city populations; seen as condition that could affect anyone; high prevalence and high public awareness</td>
<td>Highest rates in white women of high socioeconomic status; increasing morbidity but decreasing mortality due to improved detection and treatments; highest mortality in black women; seen as disease that can affect any woman; family history perceived as primary risk factor</td>
<td>Symptoms emerged over time, but limited to men and women who served in Gulf War; high morbidity among those who served, but low mortality; condition seen as isolated to war; decreasing awareness due to isolated occurrence in 1991 Gulf War</td>
</tr>
</tbody>
</table>

| Sources of support for environmental causation hypotheses | Scientists, Environmental Protection Agency; some physicians and public health professionals; environmental justice activists; substantial academic research and foundation support (e.g., American Lung Association, Asthma and Allergy Foundation of America, Pew Health Track), though little research on environmental causes | Scientists; activists; some in Congress; substantial academic research and foundation support (e.g., American Cancer Society), though little research on environmental causes | Activists; less so scientists; little academic research or foundation support; symptomology like chronic fatigue syndrome, multiple chemical sensitivity (few resources for study of those diseases) |

| Strength of health social movement | Strong, though not exclusive to health-related issues (rather environmental justice more broadly) | Strong, both in broader breast cancer movement and environmental breast cancer movement | Once strong, but now waning |
support has strengthened the movement and its ability to push through legislation guaranteeing treatment and compensation. In the following sections, we discuss each of the first three factors from Table 2 in light of their impacts on policy and HSMs.

Science base for environmental causes

The first limiting factor in creating environmental health policy is the strength of the science base for environmental causes. For many environmental illnesses, the link between the environment and the disease is a matter of scientific contention. Although some scientists may find evidence of that link, the relationship between the environment and human health is debated in scientific forums. Policy makers are therefore unable to create strong policies in the absence of strong scientific evidence. HSMs that focus on environmental illnesses with a strong scientific base are more likely to advocate for regulations, whereas HSMs without that strong scientific base must first work to establish one.

Asthma activists have benefited from a strong science base that demonstrates environmental factors such as particulate matter and allergens can trigger asthma attacks. There is much less evidence that the same factors cause asthma, although pollution is known to cause other respiratory diseases.

Although substantial scientific evidence suggests that air pollution causes respiratory problems, politics always plays a part in policy making. The strength of the science identifying environmental triggers of asthma, and the growth of public advocacy for more science, has engendered powerful corporate opposition. Fossil-fuel-based industries find it important to counter the policy implications of particulates research. This struggle for scientific legitimacy is played out in many settings including Congress and the courts and in the funding of new research projects.

The exchange between the EPA and the District of Columbia Court of Appeals reflects what has emerged as the most contested area of air pollution and public health impacts. Following the new standards set in 1997, the National Research Council (1997) conducted a study leading to the proposal for tighter standards set forth in Research Priorities for Airborne Particulate Matter. Opponents of the more stringent measures argued against the costs of implementation and argued that the study was based on "junk science," supported by "hidden data" unavailable to challengers. The EPA responded to the charges of hidden data by asking the Health Effects Institute to reanalyze the data. Although the Health Effects Institute reaffirmed the findings, a major political struggle over access to scientific data used in government policy emerged. Senator Richard Shelby (a Republican from Alabama) added a provision to a 1999 appropriations bill that instructed the Office of Management and Budget to revise circular A-110 to ensure that all data produced with a federal grant would be made available to the public through the Freedom of Information Act. These challenges to the EPA’s policy making
demonstrate that a strong science base is not always adequate. When powerful interests oppose a policy, they often have a variety of strategies for preventing its passage and implementation, regardless of the scientific justifications (Greenhouse 2001).

The conflict over policy outcomes is not limited to government and industry. In 1994, the American Lung Association sued the EPA for failing to set new NAAQS every five years as mandated by the Clean Air Act. Other private organizations such as the Natural Resources Defense Council and the Pew Environmental Health Commission have been involved in shaping policy outcomes. These examples demonstrate that a strong science base is helpful, but not sufficient, in passing health policy.

But because HSMs so often rely on scientific evidence to make their case for policy change, many adopt innovative strategies of participation in research processes as a way of ensuring that the desired type of research gets done. On the local level, for example, asthma activist groups use their collaborations with scientists to shape the direction new policies will take. Both Alternatives for Community and Environment in Boston and West Harlem Environmental Action in New York seek to win public debates over the role of air pollution in triggering asthma by influencing the way in which science is done. Although their work is local, the cumulative impact of community collaborations with scientific research has national implications. The trend in research funding to include provisions requiring community participation in scientific research has led to new avenues of study, such as the health effects of diesel exhaust, which was promoted by West Harlem Environmental Action through its alliance with Columbia's Division of Environmental Health Sciences.

In the case of breast cancer, there is a strong science base in terms of detection and treatment. But less is known of causes in general, and even less in terms of environmental factors. In the face of this weak science base, the mainstream movement continues to push for policies that address detection and treatment and, to some extent, policies that will provide funding for research into genetic and lifestyle factors. The EBCM, on the other hand, focuses on policies that will provide funding for research into environmental causes.

Long Island breast cancer activists were able to forge strong connections with Republican politicians, most notably former senator Alphonse D'Amato (a Republican from New York), and this support led to a government public hearing that included the CDC, EPA, and National Cancer Institute. This alliance enabled the passage of the bill that planned and funded the Long Island Breast Cancer Study Project through the National Cancer Institute. Bay Area and Massachusetts activists found allies in state legislatures for their funding initiatives. EBCM activists have also relied on unique approaches to involve themselves in the research process.

Gulf War veterans also deal with a lack of significant scientific evidence linking their symptoms to
environmental causes. Like EBCM activists, they have relied on political pressure to demand the funding necessary to investigate the environmental factors they suspect are causing their symptoms. Unlike the EBCM, veteran activists have not been successful at establishing positive relationships with scientists that allow them to participate in the scientific process. Veteran activists, like EBCM activists, tend to be highly knowledgeable about the science behind their disease, but this knowledge has resulted in a contentious relationship with scientists instead of the cooperative one the breast cancer movement enjoys.

Public awareness and perception of risks

Even without a strong science base or institutional support, HSMs may be able to mobilize scientific research and even policy if the morbidity and mortality rates of the disease seriously affect particular populations. For example, asthma is currently a widespread condition that is increasing among children, especially among inner-city children. But because it has a low mortality rate, it is not perceived as a serious condition that warrants swift and broad policy changes. In fact, if it were a greater problem among suburban middle- and upper-middle-class children, there might be greater attention paid to the causes. The fact that inner-city populations are more likely to be hospitalized and to miss days of work or school suggests that increasing socioeconomic status improves a person’s ability to manage asthma by purchasing allergy control supplies and equipment.

Breast cancer, though not as pervasive as asthma, is also on the increase. In addition, its higher mortality rate makes it a disease that policy makers see as warranting new policy. The breast cancer movement has benefited from the perception that innocent women, and more particularly mothers, are being taken by this indiscriminate disease. For all individuals, although morbidity is increasing, the rates of mortality are decreasing due to improvements in detection and treatment. While the highest rates of breast cancer occur in white women of high socioeconomic status, African American women experience higher rates of mortality due to the disease. Gulf War–related illnesses, on the other hand, have a relatively high rate of morbidity among those who served in the Gulf, but a low mortality rate. The initial high morbidity drew attention to Gulf War–related illnesses, but their low mortality has hampered veterans’ abilities to keep public attention focused on their condition.

Public awareness of a disease, and the public’s perception of its relative risk, affect whether HSMs can tap into populations beyond the affected population when mobilizing supporters. Asthma, for example, is seen as a disease that could afflict anyone. Most people know someone with asthma and are aware of the triggers and approaches to managing an asthma attack. But asthma is also a disease that people believe they have little risk of getting if they did not get
it during childhood. Some people perceive the risk of asthma to be greater for those who live in "dirty conditions." To the extent that such a perspective places blame on the individual, there is less sympathy for asthma sufferers. Breast cancer shares the widespread awareness of asthma and is likewise seen as a disease that can afflict anyone, at least any woman. To get funding for research into environmental causes, the EBCM has had to overcome the perception that genetics and lifestyle choices are the primary risk factors. Gulf War veterans have struggled the most, since their condition is seen as isolated to the war environment. Veterans have been unable to keep Gulf War–related illnesses in the media and thereby the public consciousness.

Sources of support for environmental causation hypotheses

Finally, HSMs pushing for policies that would address environmentally related diseases must have allies who support the environmental causation hypothesis. Asthma activists benefit from a scientific community that has largely embraced the plausibility of the notion that air pollution can cause asthma and other respiratory problems. Even physicians and public health officials share the perspective. As previously mentioned, the Clean Air Act mandates that scientific evidence exists to justify updates in the National Ambient Air Quality Standards. As a result, asthma activists can shift attention from research-related policies to regulatory policies such as those that Alternatives for Community and Environment has achieved.

Breast cancer activists have some allies in the scientific community, but the infrastructure that has been constructed for conducting research into genetic and lifestyle factors creates a certain amount of inertia. Even those scientists who are investigating environmental causes of breast cancer, such as those at the Silent Spring Institute whom we interviewed, report that such work, especially when it involves lay advocates, is not always respected by their peers. As mentioned earlier, breast cancer activists have relied more heavily on political support. From female politicians to male politicians whose wives have experienced breast cancer, breast cancer activists have been able to mobilize a core set of political allies to work toward passing legislation that can begin to create the infrastructure to support environmental causation research.

Gulf War veterans have had the fewest allies. Initially, veterans succeeded in getting President Clinton to create the President's Special Oversight Board, getting invitations to testify before Congress, and in getting the unyielding support of several representatives, including Christopher Shays and Bernard Sanders. But appointed government officials in the DoD, VA, and other agencies have been less likely to offer vocal support of veterans. A few of the scientists who have spent the last eight years researching Gulf War–related illnesses told us in interviews that their commitment to finding the cause of Gulf War–related illnesses is related to their sense of injustice for
the veterans. Nevertheless, even these sympathetic scientists report having experienced tension working with veterans who want answers quickly and do not respect the slow process of accumulating scientific knowledge.

Several organizations focus much attention and many resources on asthma, for example, the American Lung Association and the American Academy of Allergy, Asthma and Immunology. Although these organizations fund much research on asthma, little of that money goes specifically to the investigation of environmental causes of asthma. The breast cancer movement experiences a similar dilemma. Although there is support from organizations such as the American Cancer Society, little attention is paid to environmental causes. Gulf War veterans, on the other hand, have not benefited much from such organizations. Organizations that support sufferers of Chronic Fatigue Syndrome and Multiple Chemical Sensitivity have attempted to support veterans, but the lack of any institutional infrastructure for these conditions means they have little to offer Gulf War veterans.

These three factors—the science base supporting the environmental causation hypothesis, public awareness and perception of risk of the disease, and the sources of support for the environmental causation hypothesis—combine in a variety of ways. HSMs' policy successes are not dependent on any of them, but they certainly stand to benefit to the extent that they can manipulate these factors to their advantage. In Table 2, we summarize some of the impacts the three factors have had on the three diseases we have been discussing.

The relative importance of HSMs

In this concluding section, we explain how social scientists can examine HSMs' effects on policy outcomes. We also offer an approach for extending our findings with respect to HSMs, focusing on diseases with putative environmental causes and other types of disease.

There is no simple algorithm for how HSMs and other factors interact to yield diverse policy outcomes. If anything, we must be attuned to the necessity of evaluating the complexity of each disease on an individual basis. For asthma, we see a strong regulatory policy in the form of the Clean Air Act, but this legislation existed before asthma activism emerged. There is considerable research and a high degree of mandated and actual citizen participation. Despite general coverage of asthma treatment, there is little provision of hypoallergenic products. These policy outcomes result from a strong science base, firm institutional support, and widespread public awareness. Support for environmental causation (including triggers, not necessarily causes) has grown, yet the low mortality has not put asthma high on many agendas. The social movement for asthma education and prevention is local, often based in environmental justice groups that are frequently allied with university research centers. It is a growing social movement but not nearly as powerful as the nationally
and locally centered breast cancer movement, and hence the social movement support has not yielded significantly additional policy benefits. We should note that it is easier to get research policy than regulatory policy (Baltz 1999). Research policy is less far-reaching and can be very ephemeral, whereas regulatory policy has to demonstrate economic impacts and be approved by the Office of Management and Budget.

For breast cancer, we see no major regulatory policy, but we do see considerable research funding growth, a high degree of citizen participation, and major effects on detection and treatment. This occurs in the context of strong institutional support and despite a weak science base for environmental causation. The high morbidity and mortality and broad public awareness have been powerful features in bringing breast cancer issues to the nation. Nevertheless, there is growing support for environmental causation. This, like all other policy outcomes, has been due to an extraordinarily large and successful social movement, perhaps one of the strongest in all areas of health. To the extent that support for environmental causation is growing, despite broad scientific skepticism, we see how the strength of the social movement trumps the science base in this case.

For Gulf War–related illnesses, there are several pieces of regulatory policy but none that directly affect sufferers. There has been extensive research funding and, despite initial government reticence, a growth in medical treatment and benefits. Citizen participation is relatively weak, both in mandate and practice. In looking at the factors responsible for these outcomes, we find a very weak science base and hardly any institutional support. High self-reported morbidity and extremely low mortality are matched by relatively weak public awareness. Although many activists support environmental causation, hardly any scientists do so. Social movement organizing is the weakest here of the three diseases, despite some articulate leaders. Any policy successes we see are more likely tied to congressional and public support for veterans as a class of people rather than the power of a social movement.

The centrality of scientific evidence to any HSM dealing with a disease believed to have environmental causes leads us to the diagram in Figure 2. Drawing from the three factors listed in Table 2, we demonstrate how the preexisting science base in support of an environmental causation hypothesis shapes the approaches and priorities on which HSMs rely. The diagram does not suggest that a strong science base is a necessary condition for policy. Indeed, we have shown that this is not the case in the many successes of the breast cancer movement. Rather, Figure 2 illustrates how the absence of a strong science base leads HSMs to mobilize whatever resources possible to generate scientific evidence that will justify future policies. In turn, their policy priorities begin with funding for further research and citizen participation. As these goals are achieved, or as the movement differentiates, compensation and treatment become priorities.
Eventually, as the scientific evidence warrants, the focus shifts to regulatory policies. When the science base is strong, HSMs mobilize public support by emphasizing the morbidity/mortality of their disease to increase public awareness and perception of the risk related to the disease. These efforts are toward the end of regulatory policies, compensation, and treatment. In the event that the existing science is challenged, further research and citizen participation may also become priorities.

Without the strain of having to identify environmental causes, HSMs dealing with infectious diseases will likely go through a different process. A comparison of the policy successes and the obstacles faced by AIDS activists would likely help to refine the list of factors we identified and the process we describe in Figure 2. For example, the stigma of AIDS as a gay disease clearly caused obstacles. On the other hand, once mobilized, science was able to make rapid advances in understanding (though not curing) the disease due to a strong base in the area of immunology.

We have argued that activists who face a weak science base will often attempt to create a stronger science base to legitimate their concerns. This requires some clarification. First, activists generally do not believe that science by itself is sufficient, and therefore they view it as one of several factors that help advance their efforts. Public support, political connections, media attention, and social movement organizing are crucial as well. In light of their importance, science alone is not as important as it was in the past. Second, when we examine activists’ search for scientific evidence, we
often see that they take innovative approaches that transcend normal science. For example, environmental breast cancer activists pursue the endocrine disrupter hypothesis, which is indeed a challenge to the bulk of breast cancer research. Gulf War veterans push for research on synergistic relationships of substances, in contrast to the common focus on single-source toxics. Environmental justice activists concerned with asthma put much energy on particulate emissions, which, while important to air quality researchers, is generally not dealt with much by asthma researchers and clinicians. And in all these cases, activists push for a strong community initiative in deciding what scientific issues to address and a community-academic partnership in pursuing those issues.

Hence, both in the type of scientific evidence and in the process of developing it, we see challenges to the traditional canons of science. Furthermore, we see that science alone is not the sine qua non for activists. They see science as not separate from moral values but rather as integrated with those values; societies and interest groups within those societies make science decisions based on what they want to know and to do, not on a completely value-free knowledge base.

By focusing on HSMs that deal with diseases believed to have environmental causes, we have illustrated how the strength of the science base, public awareness and perceptions of risk, and the sources of support for the environmental causation hypothesis shape the strategies and policy priorities of HSMs. We do not claim that comparing three diseases provides a sufficient base from which to make generalizations about all diseases in terms of policy outcomes. But there has been little or no research on this comparative approach. Our intent has been to make comparisons across three diseases so that we could begin to describe the dynamic relationship between HSMs and health policies. Other researchers should be able to add to our framework for understanding policy outcomes in HSMs by adding comparison cases, as we have hinted at with AIDS. In doing so, we believe the importance of citizen participation will become even more apparent, not just in policy making and agenda setting but also in the actual production of scientific knowledge. Furthermore, since citizen participation is tied to social movement activity, we expect that health activists will gain important credibility from these examples that can be applied elsewhere.

Note

1. Hereafter, we use the term "diseases" to include all three diseases/conditions. Although the widely used term "Gulf War-related illnesses" includes a variety of symptoms and conditions, rather than a discrete disease, we use "diseases" for stylistic purposes.

References


