A Gulf of Difference: Disputes over Gulf War-Related Illnesses

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The social discovery of Gulf War-related illnesses, like other occupational and environmental disease, is firmly rooted in ongoing disputes over causation. Pressure from veterans groups, as well as intra-governmental disputes, have driven innovative research directions and challenged the dominant epidemiological paradigm. This dominant epidemiological paradigm was originally a position that viewed stress as the primary causal factor. In the emerging dominant epidemiological paradigm, researchers view veterans' symptoms as similar to other multi-symptom diseases and conditions, but with a firmer respect for the reality of those symptoms. In addition, some researchers pursue interactions between stress and physical exposure. We examine the evolution of the DEP to demonstrate that in many disease disputes, an affected population challenges government and science decision-making, and even ways of knowing, in an attempt to negotiate a disease definition and etiology that results in better treatment and prevention. After considerable research effort, only limited evidence has been found for environmental causation, and even many researchers sympathetic to veterans are doubtful that much more will be found. We analyze the social discovery and ongoing contestation of these illnesses, and the conse-
Laypeople and scientists engage in contestation of an increasing number of diseases and conditions. Since the 1970s, citizens have maintained that environmental exposure has caused a variety of known diseases. Excess miscarriages at Love Canal, New York childhood leukemia at Woburn, Mass., thyroid disease at Hanford, WA, and innumerable lesser known sites have been the source of disputes between laypeople, scientists, and government officials, often becoming national issues. In addition to recognized diseases with a toxic-specific connection, we see an increasing array of mysterious multi-symptom diseases and conditions, such as multiple chemical sensitivity, chronic fatigue syndrome, and fibromyalgia that do not have a consensual recognition and that remain the source of much contention. We need to understand the process by which recognition takes place for these diseases and conditions. What parties play a role in identifying the problem, in pursuing research, in granting the recognition that enables medical and disability benefits, and in developing better epidemiology and medical science for treatment and prevention? Gulf War-related illnesses, which have been in the public spotlight and the subject of an extensive federally-funded research program, are a good example of contestation over unclear diseases and conditions. Many veterans have maintained that 1991 Persian Gulf War exposure to a variety of toxic substances caused numerous types of ailments, especially fatigue, joint pain, dermatitis, headaches, and memory loss. Approximately 70,000 have sought treatment for service-related illnesses, and an estimated 2.7 million people (veterans, family members, and civilians) are eligible for Veterans Administration benefits. Research has been plagued by poor data (see Gray et al. 1998; Reeves et al. 1999) and by disputes over how to study health effects (see National Institutes of Health Technology Assessment 1994; Institute of Medicine 1996, 1999). The Department of Veterans Affairs (VA) and Department of Defense (DOD) have significant differences on their lists of who served, who received immunizations and vaccinations, and even what dates constitute possible exposure. Veterans faced multiple potential sources of disease, including organophosphate pesticides, nerve gas, pyridostigmine bromide (nerve gas antidote), oil fire smoke, depleted uranium used in ordnance, toxic paints, and diesel exhaust (Institute of Medicine 2000; Clauw 1998). Federally-funded research on Gulf War-related illnesses has been extensive: $7.1 million in 1994, $17.3 million in 1995, $18.8 million in 1996, $34.2 million in 1997, and $37.9 million in 1998 (Persian Gulf Veterans Coordinating Board—Research Working Group 1999).

This paper examines Gulf War-related illnesses (GWRI) as a case of a “contested environmental illness,” as evidenced early on by conflicts over the widespread denial that such illnesses existed, and, subsequently, by arguments concerning various stress-related explanations. We first study identification, the basic social discovery of GWRI, then contestation, the ongoing controversies about these illnesses, and, finally, the effects of these disputes on health and public policy. We then develop a new approach that demonstrates how sufferers’ self-reported symptoms and exposures offer valuable data and more humane sensibilities to the medical community, policymakers, and health professionals, when recorded through lay-professional research collaboration. This model can be used for looking at health disputes in general, and environmentally-induced diseases and multi-symptom diseases and conditions in particular.

This paper stems from a larger project that also examines asthma and breast cancer as “contested illnesses.” Contested illnesses are diseases and conditions that engender major scientific disputes and extensive public debates over environmental causes. In our larger project we define environmental causes to be the effects of toxic substances (chemicals, air pollution particles, or radiation) in people’s immediate or proximate surroundings. However, in the case of Gulf War illnesses, “environmental” factors often includes treatments such as inoculations and antidotes, because it is hard to disentangle the iatrogenic effects of those treatments from other environ-
mental effects, and, indeed, some GWRIs research focuses on such combinations. It is useful to study GWRIs because, like other illnesses attributed to environmental factors, they illustrate the intersection of science, medicine, policy, and public values. Examining this intersection allows us to see more clearly how public attitudes toward disease, public policy, and regulatory action can affect funding, hypothesis formulation, research design, and interpretation. Additionally, the presence of social movements in these contestations demonstrates the intensity of the disputes, and these movements often play a major role in motivating research and government action, as well as changing public perception.

These disputes often bring to light an established belief system that we term the *dominant epidemiological paradigm*; we diagram this paradigm in Figure 1. The dominant epidemiological paradigm is the codification of beliefs.

**FIGURE 1. The Dominant Epidemiological Paradigm’s Process Disease Discovery, Definition, Etiology, Treatment, and Outcomes**
about disease and its causation by established institutions entrusted with the diagnosis, treatment, and care of disease sufferers. Upon beginning our research, we planned to develop a model for disease disputes. At that point we were unaware of the diversity of actors and perspectives on GWRIs, and it was only at the end of collecting data that we had a firm enough grasp upon the multiple factors within these processes to develop the dominant epidemiological paradigm. There are many structures and institutions that contribute to a generally accepted view of disease, but people don’t immediately see them. Furthermore, the dominant epidemiological paradigm is both a model and a process. It is a model in that it helps us understand the complexity of disease discovery. It is a process in that it delineates a variety of locations of action. Actors can enter the dominant epidemiological paradigm process at different locations, and take action on one or more of the components.

Our concept of the dominant epidemiological paradigm has roots in several literatures: social problems discussion of claimsmaking, actor-network theory, and medical sociology and environmental sociology approaches to popular epidemiology and toxic hazards disputes. Social problems’ discussion of claimsmaking (Spector and Kitsuse 1977) holds that social problems are the “activities of individuals or groups making assertions of grievances and claims with respect to some putative conditions” (p. 75). Since claimsmaking approaches are concerned with the social construction of the argument, rather than the verity of the problem, they emphasize specifying the actors involved and how their contrasting claims are formulated and disputed. Actor-network theory (Latour 1987) is useful in delineating how scientists engage in recruitment of other scientists, as well as extra-scientific actors, in order to solidify acceptance of a scientific discovery. This recruitment process enables the construction of a widely-accepted disease paradigm. Popular epidemiology (Brown and Mikkelsen 1990) examines how citizens initiate efforts to uncover evidence linking their symptoms to a particular cause. Amateur epidemiologists or lay disease sufferers typically seek answers from government and scientists who hesitate to acknowledge those lay findings. Much as scientists recruit other scientists and a variety of extra-scientific actors, lay advocates engage in such recruitment to enlist more parties in their perspective.

As we noted, the dominant epidemiological paradigm is an ongoing process. Continued challenges to the dominant epidemiological paradigm by lay advocates and by sympathetic professionals holding what we term a critical epidemiology approach, lead to shifts in the paradigm. In some cases, laypeople join with sympathetic scientists in a citizen-science alliance, but this has been undeveloped in GWRIs. With GWRIs, the dominant epidemiological paradigm originally reflected the view that stress was the primary causal factor. However, more recently the dominant epidemiological paradigm has been amended to reflect a view that veterans’ symptoms are similar to other multi-symptom diseases and conditions, but with a firmer belief in the reality of those symptoms. In addition, some researchers pursue interactions between stress and physical exposure.

One might expect that the presence and etiology of disease would be accepted through sufficient medical research, but this is only true when the disease and its putative cause are not controversial. A case in point is the failure of the powerful evidence linking tobacco and lung cancer to produce general social consensus about etiology. Tobacco companies confused the issue and created ambiguity by using their extensive financial resources to perform research on the mechanisms of cancer instead of the causes, focusing on individual characteristics that might have correlations to cancer, and funding advertising campaigns. Those efforts delayed full medical recognition for decades and stalled government action. Despite the strength of the scientific evidence, sufferers and their allies had to wage a political fight to further their claims (Brandt 1990; Proctor 1995).

We see similar problems with most environmental and occupational diseases. A broadly acceptable social definition, new expert consensus, and often a social movement are necessary to achieve a belief in the existence of the disease and its social and environmental causation (Rosner and Markowitz 1991; Brown et al. 2000). In Reich’s (1991) model of contaminated communities, toxic victims go through three stages: (1) making their issue into a public problem by identifying the disease and its social origin; (2) organizing collective action
to seek redress; and (3) mobilizing political allies since a victims' group alone cannot do all that is necessary.

As people and groups move through these stages, they engage in the type of popular epidemiology we described earlier. In that process people engage in cognitive and ideological "frame transformations," especially the development of an "injustice frame," where they revise normal assumptions and shift responsibility onto corporations and government (Gamson et al. 1982; Snow et al. 1986). In addition, laypeople seek ways to involve themselves in the ongoing scientific processes affecting the understanding of their condition. According to Beck (1995), lay participation in scientific endeavors is justified in what he terms the "risk society": "Why shouldn't laypeople—who are no longer what they used to be, namely, just laypeople, and who ultimately have to pay for all the benefits—ask questions that are forestalled by the false a priori of scientific theory, and in that way provide a critical supplement to the model of experimental testing?" (p. 55). Similarly, Wynne (1994) argues that the global environmental consequences of modern technological systems call for acknowledgement of indeterminacies and a precautionary approach to environmental health that would allow for a renegotiation of the epistemological assumptions of science. Such renegotiation is seen in the "expert knowledge" (Couch and Kroll-Smith 1998) approaches of citizens who employ science to research their environmental problems, but who do it in terms of a democratization of science and society (Irwin 1995; Couch and Kroll-Smith 1998). Lay participation in the scientific process through citizen-science alliances, and a greater acceptance of critical epidemiology and popular epidemiology approaches, may help direct science down previously unexplored avenues and produce greater public trust in science and government.

Yet whether citizens work independently to challenge the dominant epidemiological paradigm, or seek to do so from within the institutions of science, they face great resistance. In the case of uncontested illnesses, the dominant epidemiological paradigm produces an understanding of the disease that is satisfactory to the affected population. However, as we illustrate at the bottom of Figure 1, if people's needs for disease recognition and explanation are not met by the dominant epidemiological paradigm, then citizens, if they have adequate resources, may choose to work with scientists, the government, the private sector, or some combination of the three to push for an understanding of their condition that better meets their needs. With GWRI's, the dominant epidemiological paradigm originally attributed veterans' symptoms to war-related stress. Veterans and some of their scientific allies strongly opposed this version of the dominant epidemiological paradigm because they felt it blames the victim and discourages research on environmental causes. That opposition, in conjunction with the more sophisticated thinking of some researchers and the Institute of Medicine's (2000) recommendation for new research on stress-environmental interactions, has initiated a shift in the dominant epidemiological paradigm that views veterans' symptoms as similar to other multi-symptom diseases and conditions and has a firmer belief in the reality of those symptoms (e.g., Engel et al. 2000).

DATA AND METHODS

Methods include content analysis of government documents (Congressional hearings, Institute of Medicine reports, and reports from DOD, VA, and other federal agencies) and the scientific literature in medical and epidemiological journals; print media analysis; ethnographic observation of the last two federally-funded Persian Gulf Research Conferences (1999 and 2001) and (on 13 occasions) of the Boston Environmental Hazard Center (VA-based center for GWRI research, operated collaboratively by the VA Medical Center and the Boston University School of Public Health); 21 interviews with researchers, government officials, and veteran activists; and continuing discussions with a number of those interviewees.

The Boston Environmental Hazards Center provided access to their staff, activities, and meetings; facilitated our access to other VA programs; and aided in making contact with other Gulf War researchers and government officials. For interviews, we selected researchers on the basis of their involvement with the Boston Environmental Hazards Center, other specialized VA-university collab-
orations, or in related VA programs dealing with Gulf War veterans. We also selected them because of their recognition as leaders in the field, based on common knowledge and authorship of key studies. Officials were selected to include all major federal agencies involved in Gulf War research, treatment, and policy. This included the VA, DOD, Department of Health and Human Services (DHHS), Centers for Disease Control (CDC), and federal oversight panels. Veterans were selected on the basis of participation in the Boston Environmental Hazards Center's Community Advisory Board, referrals from those members to others, as well as some activists participating in the Gulf War Research Conferences.

After transcribing all of the interviews, we identified the central themes that had emerged during the interviewing process. These themes included, among others: the roles of science, activism, and the media; mention of disputes or conflicts among agencies, activists, and scientists; and mention of obstacles (both political and scientific) to further understanding of GWRIs. We coded the interviews for the themes we had identified while also developing new categories as we coded (see Appendix for coding scheme). Our analysis is based on the interpreted meanings of the frequencies of these themes in the interviews with scientists, agency officials, and veteran activists. Unreferenced quotations come from our interviews and observations.

Media analysis consisted of searching for articles (1991–1999) dealing with environmental causation of GWRIs in the New York Times, Washington Post, the three major newsweeklies (Time, Newsweek, U.S. News and World Reports), and general circulation science magazines (Science, Science Digest, Scientific American, Discover, and Popular Science). We found and analyzed a total of 362 articles dealing with environmental causation of GWRIs. These articles were coded for how they dealt with environmental causation, and we counted them to gauge the extent of public interest. Codes were developed based on issues we already identified from reading the scientific literature, government reports and documents, and print media. Additional codes were included after coding started. This article does not report in detail on the media analysis, but uses it as an adjunct to the other data.

IDENTIFICATION: THE SOCIAL DISCOVERY OF GULF WAR-RELATED ILLNESSES

Here we delineate the lay discovery process that initiated scientific investigation, and we discuss the complexity of the diseases and conditions and their potential causes. This helps us to trace the development of the stress-oriented dominant epidemiological paradigm.

Lay Discovery

As in most cases of occupational and environmental illness, sufferers were the first to identify their health problems. Soldiers were aware of the potential for exposures in the Gulf due to the military history of “Agent Orange,” media coverage of Iraq’s biological and chemical capabilities, chemical warfare in the 1980–1988 Iran-Iraq war, and military vaccinations and training drills with protective equipment and gas masks.

Veterans returning from the Persian Gulf reported ailments not experienced prior to service. Media stories highlighted hardy people who found themselves debilitated to the point where they could not function at work or home, and who still faced problems getting the government to recognize and treat their illnesses. Veterans did not initially attribute their ailments to service in the Gulf. However, after learning of other veterans’ illnesses from media reports, they began to speculate that service in the Gulf might be a cause. All the veterans we interviewed spoke of informal social networks that shared strategies for getting treatment after VA physicians refused to treat them. One remembered:

Back in 1994 a lot of veterans were yelling in the newspapers. And every time something happened, the VA would get a workload. You know, they’d get this rush of complaints. If the U.S. government put out a list of possible complaints they could have had during duty in the Gulf War theater, I think that would have been a nicer way of doing it, not with all the veterans blurring up all over the United States.

Veterans organized themselves, relying on existing veteran service organizations such as Veterans of Foreign Wars, Disabled American Veterans, the American Legion, and AMVETS. Specific Gulf War groups, such as
the National Gulf War Resource Center and Operation Desert Shield/Storm Association, eventually formed, though without large national memberships. The Internet was a major resource for collaboration. Veteran activists regarded their action as crucial to the research enterprise, as did the Boston Environmental Hazards Center researchers we observed, as we see here in this quotation from an interview with one of the researchers:

That's really what got this thing up and running in the first place was the veterans groups and individual veterans with incredible stories to tell that became public news stories. I would say that without that you wouldn't be getting any of this, you know, the Gulf War related illness work. Wouldn't have done any of this and wouldn't still be doing it.

Complexity of the Issue

Research on Gulf War-related illnesses has been hampered by much complexity. GWRIs, more than many illnesses believed to have environmental causes, are ambiguous and lack a clear case definition. Some epidemiologists and physicians believe that the VA demand for a specific diagnosis has been too strict, and thus veterans were unable to legitimate their illness in the early period (Landrigan 1997). While most have abandoned the concept of a single Gulf War Syndrome, there is no consensus on how to delimit the range of symptoms and illnesses. This is due primarily to the multiplicity of exposures and diffuse nature of complaints. Epidemiological studies have identified different clusters of symptoms but without a conclusive connection to specific exposures. Some symptoms resemble chronic fatigue syndrome, fibromyalgia, or multiple chemical sensitivity, all of which are poorly understood and subject to much dispute (Davis 2000; NIH 1994). The uncertainty further confounds the process of research, as there is no consensus on which of the many potential approaches, methods, and hypotheses to pursue. An epidemiologist pointed out:

I think it's very difficult for researchers. Even though we say we're totally objective, we state hypotheses, we develop a questionnaire where we, you know, do you permit five questions or fifty questions about something? An infectious disease scientist is going to look for infectious mechanisms. A neurotoxicologist is going to look [for other things]. So the scientists kind of design their studies in a way that they hope to find things that are in their field, what they'd like to find.

The Current Research Base for Gulf War Illnesses

Despite the complexity of the issue and early resistance to disease recognition, the identification process has moved forward from initial lay discovery, and then government and scientific discovery, to produce a body of literature addressing the prevalence and possible causes of veterans' illnesses. In this section we
demonstrate how the initial stress-based dominant epidemiological paradigm was formed, the science that emerged in support of it, and the political struggles that took place in an attempt to counter it.

Though we emphasize lay discovery, in the case of GWRIs there is anecdotal evidence that DOD officials anticipated exposures, since most troops were administered vaccinations against anthrax and received pyridostigmine bromide to protect against nerve gases such as sarin. The military received special permission to bypass Food and Drug Administration regulations for these drugs (Rettig 1999). Pentagon officials were also concerned about the health effects of oil well fires and sent a research team from the Army’s Environmental Hygiene Agency to the Middle East immediately after the ground conflict to begin monitoring the pollution, even though the team’s report concluded negative health effects were unlikely (U.S. Army, Environmental Hygiene Agency 1994). In addition, the military expected many of the stressors that were present during the war to cause some troops to experience post-traumatic stress disorder, as had been the case with Vietnam veterans. Thus, the military set up centers at several bases through which deployed troops were processed upon return, designed to detect psychological stress in returning troops. The fact that many of the DOD’s medical personnel were primed to treat psychological symptoms may have caused them to jump too quickly to attribute physical symptoms to psychological stress, even though there were very few returning soldiers exhibiting classic post-traumatic stress disorder symptoms (Wolfe et al. 1999).

Yet when DOD medical professionals were sent to study reserve units in Indiana and Louisiana, the reports concluded that psychological stress was the cause of self-reported physical symptoms. By 1994 when the NIH Technology Assessment Workshop took place, most experts who testified before the panel had been involved in the early psychological stress diagnoses in Indiana and Louisiana. This may explain the panel’s conclusions (NIH 1994) which stated that “it is possible that the expression of post-traumatic distress may be distinct in the Persian Gulf experience, and may take the form of somatic and multisystem symptoms rather than classic post-traumatic stress disorder numbness and flashbacks” (p. 12). While the panel’s report went on to emphasize that they did not mean to suggest “that there is no physical basis for the reported symptoms,” the panel nevertheless added that “expression of the reported post-traumatic stress disorder symptoms represents a psychophysiological response that needs to be evaluated.” The culmination of the stress-based dominant epidemiological paradigm was the Presidential Advisory Committee’s 1997 report that attributed veterans’ illnesses to stress.

During this mid-1990s period, however, James J. Tuite III, a staff member of the Senate Committee on Banking, Housing, and Urban Affairs, had been assigned by the Committee Chairman, Senator Donald Riegle to investigate possible U.S. exports to Iraq of biological materials used to manufacture warfare agents. In response to Tuite’s confirmation of Iraq’s biological weapons capability and the testimony of veterans who believed they had been exposed to chemical warfare agents, Congress allocated money for VA investigations. The VA’s research agenda was weighted heavily towards projects examining toxic exposures and their physiological and neurological effects (PGVCB-RWG 1999).

At the same time, VA research examined whether there was a higher prevalence of symptoms in veterans, and explored links to particular exposures that might be the cause. This work was hampered by unresolved debates over the case definition for GWRIs, and whether GWRIs represent a unique syndrome or a series of unrelated symptoms. Even though most researchers no longer believe that GWRIs represent a unique syndrome, some veterans groups do, so the debate continues.

The 2001 conference on federally-funded Gulf War illness research featured a plenary session entitled, “Is There a Gulf War Syndrome?,” and included Dr. Robert Haley on the panel, one of the only researchers currently arguing for the syndrome definition (Haley et al. 1997).

Significant findings about Gulf War illnesses

Relying on DOD and VA registries, researchers have found excess mortality among Gulf War veterans only for motor vehicle accidents (Kang and Bullman 1996). Gray et al. (1996) concluded that there were no excess hospitalizations and no excess birth defects. Veterans countered these findings,
noting that while many symptoms do not require hospitalization, they affect the daily quality of life and impede the ability to work. Eula Bingham, head of the VA’s Persian Gulf Expert Scientific Committee, criticized the Presidential Advisory Committee for its failure to understand this point (Shenon 1996c). Critics also point to the fact that only inpatient admissions to military hospitals were included, and that the study period only extended 25 months after the end of the war (Kolata 1996).

It is possible that excess hospitalizations could have occurred in non-military hospitals since veterans had already experienced military reluctance to treat them. Additionally, veterans covered by their spouse’s health insurance might choose private care.

Veterans’ claims are supported by studies that show an excess of self-reported symptoms among deployed versus non-deployed troops, including chronic diarrhea, other gastrointestinal symptoms, memory loss, concentration difficulty, trouble finding words, fatigue, depression, post-traumatic stress disorder, bronchitis, asthma, alcohol abuse, sexual discomfort, and anxiety (Iowa Persian Gulf Study Group 1997; Fukuda et al. 1998; Proctor et al. 1998). The validity of self-reported symptoms has been repeatedly questioned since physical examinations in major studies failed to find medical conditions. Proctor et al. (1998) found increased symptoms in many organ systems in two Persian Gulf cohorts, as compared to soldiers in Germany. When veterans diagnosed with post-traumatic stress disorder were removed from the analysis, virtually no changes were noted. This finding supports the contention that stress alone is not the cause of veterans’ complaints. A further contribution of this study is that the researchers found positive correlations between several exposures and symptom reporting for the specific organ systems where the effects would be expected. Some epidemiologists consider this work on self reported symptoms and exposures is central to a new perspective on how to conduct research on environmental health.

Other research has investigated the possible effects of pyridostigmine bromide, a widely administered nerve gas antidote, depleted uranium, and oil well fires. The DOD-sponsored RAND summary and the Institute of Medicine’s summary of the knowledge base concerning these and other exposures both conclude that there is no concrete evidence in support for the notion that any of these exposures cause GWRIs. Both reports note, however, that dose-response effects at chronic low exposure levels are not understood well enough to completely rule them out. They note poor record keeping as a major obstacle. Since these reports determined that there was not sufficient evidence to decide whether there were toxic health effects, some might interpret this to mean that the door is still open to conduct environmental health research.

Researchers continue to identify biological markers that might provide evidence of exposure. Researchers we interviewed at the Boston Environmental Hazards Center believe that studies of neurophysiological and neuropsychological symptoms are going in a promising direction and have found subtle changes in nerve conduction, cold sensation, finger dexterity, and executive functioning. There are also alterations in eyeball movement, weakness of lower extremities, indices of neuropsychological dysfunction, and some auditory functions. Researchers, however, are uncertain about whether some of these changes are markers for diseases, or merely non-functional differences.

The research base includes studies from allied nations. A United Kingdom study (Wessely 2000) compared a random sample of British veterans with two control groups: non-deployed personnel and troops returning from Bosnia. Deployed veterans had higher rates of unusual self-reported symptoms but no increase in mortality. Likewise, a Canadian study (Gulf War Illness Advisory Committee 1998) found an increase of self-reported symptoms but no increase in mortality. Other European studies report similar findings. France alone reports no increase in mysterious symptoms among their returning veterans. Interestingly, the French generally also generally report little chronic fatigue syndrome or multiple chemical sensitivity (Wessely 2001).
tion, and secrecy; (2) distrust, disputes, and fragmentation; and (3) issues of legitimacy.

**Missing Information, Misinformation, and Secrecy**

Research on GWRIs is plagued with insufficient or incorrect information, especially the lack of pre-deployment health assessments and exposure records. Researchers must contend with the difficulties of retrospectively determining pre-deployment health status. In lieu of those data, scientists must rely on self-reported pre-deployment health, an approach that is typically criticized for its lack of reliability and validity (NIH 1994). Government realization of the lack of pre-deployment health data has led to numerous proposals for improved data in the future, including improvements in the monitoring and recording of possible exposures (IOM 1999).

Veterans and researchers we spoke with all identified the denials and disputes over exposures as major barriers. One veteran remarked, “From a political standpoint, the biggest job for us is getting the government to recognize the findings that they don’t want to hear about.” A VA researcher commented:

> The government hasn’t been real forthcoming with releasing information, and that’s causing problems with the research. Right now we have a grant [from] the Department of Defense, looking at some people who were actually around where the detonation of chemical warfare agents occurred. And getting the information from them is extremely difficult. You feel like you’re trying to do research with your arm tied around your back . . . So I have to go scrap around and beg and go through all the channels to see if I can get this released even though the Department of Defense has funded this study. Because I’m not in the Department of Defense, I constantly get the feeling that I just get the information they want me to have.

Until public disclosure about the presence of nerve gas at Khamisiyah, the DOD maintained that no exposures occurred, thereby denying vital information to veterans and researchers. When the President’s Advisory Committee asked the DOD to turn over the extensive logs of exposure data from the Gulf, the Defense Department was only able to locate 36 of an estimated 200 pages (Shenon 1997a). Whether or not the DOD hid the missing logs, as some claim (Tukey 1997), the lost information is a serious impediment to research (NIH 1994).

Despite the fact that chemical alarms sounded daily, and soldiers were trained to don gas masks upon hearing them, military commanders later told Congress that the Defense Intelligence Agency and Central Intelligence Agency said that many were false alarms, yet they had not communicated that information down the chain of command. Thus, soldiers believed they were being exposed to chemicals when they were not. As the 1994 NIH Panel observed, “Although warfare has always been stressful and fear-inducing, the Persian Gulf War was the first combat experience in which the real threat of chemical and biological warfare was known to troops before entering the combat area” (NIH 1994).

According to many researchers we interviewed, there is no serious dialogue between the researchers performing studies on GWRIs and the physicians who are treating the veterans. As one epidemiologist noted:

> I know in the veterans’ eyes it’s a real issue. They have a lot of complaints about their medical treatment and their clinical care that they come and voice to us. But as a resource center we’re not directly responsible for taking care of them clinically and so we, I tried to help and direct them into proper channels within the clinical care side of it, people that I know here. But there is a division or separation and so we could spend our whole life trying to clinically get them treated.

Consequently, researchers told us, uninformed clinicians are not asking their patients questions that might provide clues to etiology. Thus, patients may not receive the best possible care, and valuable research data are not gathered. Also, the VA funded several research centers to do dedicated work on GWRIs, yet did not provide ongoing channels of collaboration.

**Distrust, Disputes and Fragmentation**

Many veterans whom we interviewed distrust government research on toxics, due to past practices. For decades, the government denied the existence of diseases among “Atomic Veterans” and civilian workers in nuclear weapons production (Caufield 1990). For Vietnam veterans, The Agent Orange Act
that specified compensation for Agent Orange-related illness was not passed until January 30, 1991. The Institute of Medicine (1994) didn’t link Agent Orange exposure to Hodgkin’s Disease, Non-Hodgkin’s lymphoma, soft-tissue sarcoma, chloracne, and spina bifida until 1994, 16 years after the first Congressional hearings and 24 years after the spraying. The government did not validate Agent Orange connections to diabetes, and to Vietnamese birth defects until 2000 (Aldinger 2000). As the director of a veteran’s group noted:

How long did it take those exposed to the atomic bomb . . . they actually had people and they wanted to find out what effect this stuff had on them. They tested it out—radiation . . . So there’s a pattern, it looks like to me, that, Hey if we wait long enough, those of you who are sickest are going to die off and we don’t have to spend all this money to give you the benefits.

After the Gulf War, sick veterans complained that officials offered only a psychiatric explanation and wouldn’t take seriously reports of toxic exposures. One remarked:

When . . . Gulf War veterans went to clinics and hospitals run by the Department of Defense and Veterans Affairs, they weren’t met with open arms by many doctors. Many doctors thought that they understood readily what was occurring with these veterans. It was a short war; this must be mental illness or post-traumatic stress disorder . . . And then, when veterans complained about being exposed to chemical weapons in the Gulf—seeing them, the alarms going off, reporting symptoms consistent with exposure to chemical weapons—these claims were not investigated seriously or with any sort of vigor at all by the Department of Defense . . . When, after all that, these agencies now are tasked with investigating Gulf War Syndrome, do you think veterans are gonna believe the kinds of conclusions they come up with? Absolutely not.

Similarly, Dr. Michael Hodgson, then an American Legion medical advisor but now working for the VA, remarked, “It is hard for me to believe that you can announce every other week that yet another 10 or 15 thousand may have been exposed to nerve gas and then convincingly tell veterans they don’t have nerve gas disease” (Kolata 1996).

There are also disputes between government bodies: the DOD, the VA, the CIA, the Presidential Advisory Committee, Congressional committees, the NIH Panel, the Institute of Medicine committee, and the Department of Health and Human Services. At the center of these disputes is the DOD, accused by veterans groups of concealing exposure information and strongly criticized by the Presidential Advisory Committee for mishandling the issue (often in surprisingly strong terms, such as: “DOD’s slow and erratic efforts to release information to the public have further served to erode the public’s trust”) (Shenon 1996a). Further, the Presidential Advisory Committee tried to censor information. One of its researchers, Jonathan Tucker, claims he was fired for gathering information from veterans and whistleblowers, as he sought to show that Presidential Advisory Committee overemphasized the stress paradigm, at the expense of research into chemical exposure (Shenon 1996d). Another government panel, the VA’s Persian Gulf Expert Scientific Committee of the Department of Veterans Affairs, headed by former Occupational Safety and Health Administration head Eula Bingham, was very critical of the Presidential Advisory Committee’s support of the stress perspective (Shenon 1996c). There were also significant disputes among Presidential Advisory Committee members (Shenon 1997b).

Congress responded to DOD and the VA shortcomings. Congressional Representative Christopher Shays (R-CT) requested that the General Accounting Office investigate why federal studies failed to confirm the existence of Gulf War illnesses or their potential environmental causes, and the resulting report was quite critical. Shays chaired a House committee that severely chastised the Pentagon and VA for poor work, and asked that they be removed from further oversight of GWRI research (Shenon 1997c). Dissatisfied with VA research and treatment, Representative Lane Evans introduced a bill in 1998 to have the IOM compare Gulf War veterans with other veterans; any conditions found to be different would lead to a presumption of disease, treatment, and compensation, without concern over cause.

Because they view the government as the cause of the problem, veterans question the government’s ability to perform objective science. A similar situation would be seen as a conflict in other areas of health, if, for instance, corporations were responsible for
researching occupational health. A 2001 report by the National Gulf War Resource Center, one of the more vocal veteran organizations, recommended that “Congress should reprogram funds allocated to GWS [Gulf War Syndrome] research away from . . . DOD-DVA medical research programs (including all examining stress) into private sector or state-run medical research initiatives (overseen by an independent body, including veterans service organizations).” Even though veterans are invited to be part of panels and conferences, they continue to feel slighted. This was apparent at the 1999 conference of federally funded Gulf War researchers. Even though the conveners dedicated a panel to veterans’ concerns, with veterans as speakers and DOD officials present to answer questions, poor attendance by researchers and officials suggests a lack of interest in veterans’ perspectives. At the 2001 conference’s “Public Availability” session, at which veterans’ concerns might have been made to a large audience, the conference organizers arranged the format as a series of informal roundtables. Veterans in attendance told us they felt this was an attempt to fragment and silence them.

Struggles for Legitimacy and the Role of Stress in the Dominant Epidemiological Paradigm

The struggle to legitimate both the study of Gulf War-related illnesses and the illnesses themselves creates tension and conflict for both veterans and scientists. Veterans want the government to recognize their illnesses as legitimate and to ensure eligibility for treatment and disability benefits. They also want a sign of official belief that they are not mentally ill—which has real psychological value to ailing soldiers. For many veterans, the reliance on a stress model, with the VA’s accompanying cognitive behavioral treatment trial, is a form of delegitimation.

Though our data suggest a shift in the dominant epidemiological paradigm from a “primary stress perspective” (stress as the primary causal factor) to what we term the “contextual stress perspective” (stress as one part of a complex equation of factors), many veterans feel their illnesses are not legitimate as long as researchers claim that stress plays any role. It is understandable that veterans would oppose the primary stress perspective, which is often framed around the idea that all wars are stressful and that soldiers have always returned with some stress-related illness (Hyams 1998). That approach focuses on individual psychopathology and minimizes the effects of toxic substances and other environmental conditions. It also taps public stigma concerning stress as a cause of physical health problems, as noted by Senator John D. Rockefeller IV (D-WV):

When you say “stress” to the American people, when it’s diffused through the media, they think it’s something psychological, it’s something of the mind, when in fact these people—maybe 50,000 or more of them—who went over there completely healthy and came back who are now very, very sick, and it’s not just a stress syndrome (Schmitt 1997).

This resistance to stress explanations is captured by Congressperson Bernard Sanders’ (I-VT) reaction to the Presidential Advisory Committee’s conclusion that GWRIs were primarily stress-related. Sanders drafted a letter demanding that the committee chair re-write the conclusions.

Nevertheless, some might think that a primary stress model would be beneficial. After the Vietnam War, veterans stricken by nightmares and intrusive memories, and some sympathetic mental health professionals, lobbied for the inclusion of a combat-related disorder in third edition the American Psychiatric Association’s Diagnostic and Statistical Manual. The claimsmakers were successful and post-traumatic stress disorder was the result (Scott 1988). However, while the creation of post-traumatic stress disorder validated the suffering of Vietnam veterans, many mental health professionals have concluded that Gulf War veterans do not meet the clinical criteria for post-traumatic stress disorder (NIH 1994).

Whether they meet the criteria or not, the fundamental difference between the experience of Vietnam and Gulf War veterans is the attribution of responsibility. Vietnam veterans accepted post-traumatic stress disorder diagnoses because it meant they could get treatment and that the government was actually attributing their condition to their experiences during the war. The government has not taken responsibility for Gulf War veterans’ illnesses in the same manner. Gulf War veterans view a post-traumatic stress disorder diagnosis or
other stress-related explanation as the government's attempt to place responsibility on the veterans for their problems.

Because of the valence of the primary stress explanation, many veterans still oppose the contextual stress perspective, even though it acknowledges an interaction between stress and possible toxic exposures. One veteran formulated the problem this way:

Many of the vets, in the early 90s after the war, were either diagnosed with major depression or post-traumatic stress disorder, or anxiety disorders and things like that, and they reacted ferociously, many, to these diagnoses, and suspected that physicians, especially physicians who worked for the government either in the military or VA, were trying to deny the legitimacy of their symptoms by suggesting that they were psychological in nature. So after a couple years, you couldn’t say stress, and you couldn’t say mental illness in a room of Gulf War veterans without really risking your health, and so the debate was hampered by that, because, you know, being exposed to oil well fires I'm sure isn't good for you, being in a deep funk and being exposed to oil well fires is probably worse for you.

The contextual stress perspective establishes the link between psychological stress and poor health, seeking to understand how stress impacts the body physically. If this framework is applied, the reality of veterans' illnesses is not denied, but because of the earlier use of the primary stress perspective, veterans are equally resistant to the contextual stress perspective. As we already discussed, the National Gulf War Resource Center has called for the transfer of funds away from all DOD and VA-funded studies examining stress. If sick veterans were thought to be manipulating the system to get compensation and benefits, we might expect them to accept a stress explanation, since it could justify benefits as it did with post-traumatic stress disorder in Vietnam veterans. That veterans continue to challenge even the emerging dominant epidemiological paradigm which addresses the interaction of stress with environmental exposures illustrates their deeply held belief that their symptoms are attributable largely to environmental exposures.

While veterans have struggled with legitimacy in terms of defining their illnesses, scientists have also dealt with threats to legitimacy, especially those who pursue alternative hypotheses or work with lay people as co-participants in the research process. Many scientists assume that involving lay people means lowering one's standards of proof and compromising the practice of good science. Consequently, researchers who embrace community action models are subjected to greater scrutiny. One lay advocate even suggested that funding may have been withdrawn from some studies due to lay involvement. GWRIs are not included in medical and public health curriculum, thus leaving it unfamiliar to potential researchers. Other researchers may have decided against investigating GWRIs, after seeing how long Agent Orange research and compensation took. Researchers' institutional requirements, such as tenure and the need to provide part of their salary through grants, may also influence their willingness to study such a controversial and difficult topic.

THE DOMINANT EPIDEMIOLOGICAL PARADIGM AND LAY CHALLENGES

As we noted earlier, the dominant epidemiological paradigm is a broadly accepted explanation for a disease and condition. Because the dominant epidemiological paradigm is so well-entrenched, challenges to that dominant belief system by lay involvement and social movements are necessary components of medical-scientific progress (Legator and Strawn 1993). The contestation over Gulf War-related illnesses has resulted in some alliances between veterans and sympathetic professionals, even though these are less well-developed than in areas such as breast cancer and asthma.

Formation of the Dominant Epidemiological Paradigm

Although discovery may be attributed to government, researchers, or other actors, efforts to address the diseases and condition are usually drawn from lay initiative. For example, while most states collect cancer data, few if any take action when excess cancer rates are discovered (Greenberg and Wartenberg 1991). Activists or others must discover the data and press the issue. In other instances, scientists encounter a disease first, only to have a disease group or the government latch onto the
findings in order to support their causes. Early efforts to link tobacco and lung cancer were spearheaded by medical and public health experts, even though later efforts to tighten regulations were headed by lay activists (Proctor 1995). Such professional-initiated discoveries underscore the need to expand the popular epidemiology explanation, which relies on lay discovery. In yet other cases, investigative journalism might uncover patterns of illness previously undetected.

In all cases, however, the discovery process leads to a dominant explanation for the disease. This need not be a regressive explanation: The dominant explanation of many diseases is generally acceptable and not the subject of dissent. However, the explanation put forth by the dominant epidemiological paradigm often fails to make links to a contaminant, an iatrogenic treatment, or another problem of human action. That failure may result in incomplete recognition, treatment, and prevention. With cancer, for example, the dominant epidemiological paradigm’s explanation for local excesses utilizes probability theory to dispute the existence of clusters, claiming that these are random alterations in the normal distribution. This explanation precludes the possibility of searching for a source of environmental causation (Steingraber 1997). In such a case, disease victims’ needs are not met by the dominant epidemiological paradigm’s conceptualization of their illness, and opposition to the dominant epidemiological paradigm grows. Following debates in government, science, and private sector organizations, a new version of the disease may emerge. Ideally, this version’s conceptualization of the discovery, definition, etiology, and treatment of the disease leads to greater scientific knowledge, new policies, and greater public understanding, as indicated in the lower section of Figure 1. However, because of the dominant epidemiological paradigm’s nature as a paradigm, challenging it is very difficult. Embedded institutional practices, cultural belief systems, social norms, routinely accepted ways of knowing, and vested interests serve to perpetuate the existing understanding of the disease. The dominant epidemiological paradigm persists through the privileged position of those who define it and subscribe to it, and by subsuming or defeating any counter-explanation offered by those who oppose it. As shown in Figure 1, the dominant epidemiological paradigm consists of multiple locations of science, government, academia, and media, all of which contribute to the status quo of disease identification and causation. Hence, challenges to the dominant epidemiological paradigm must take on many different actors in order to put forth a new model.

The dominant epidemiological paradigm is not the result of conspiratorial practice. Indeed, the fact that there are so many components of the dominant epidemiological paradigm suggests these many parties must have considerable agreement. This agreement is not the result of a consensus meeting, but of an affinity of perspectives among diverse actors. The formulation and maintenance of the dominant epidemiological paradigm may include some calculated efforts to withhold information and shape research directions, but mainly an institutional logic of ordinary practices places routine barriers to challenges that argue for environmental or other controversial causation.

One key barrier is the determination of what counts as evidence. For veterans, self-reported symptoms and self-reported exposures are both important pieces of evidence. For the military and for most researchers, self-reported symptoms have marginally acceptability, and self-reported exposures are virtually never acceptable. Gulf War veterans give much credence to personal narratives of healthy people who returned from the war with illness, while the military and researchers see these narratives as merely anecdotal material that is contradicted by large epidemiological studies. When veterans uncover examples of military secrecy, such as the reluctance to admit that the U.S. blew up the chemical weapons depot at Khamisiyah, they take this as evidence that some toxic health effects must have occurred. On the other hand, the military relies on its data that show no difference in health status regardless of proximity to the depot. In addition to these differences, which might be explained as expressions of lay explanatory models, veterans also focus on the few scientific studies that report positive findings on toxics and health effects. Despite widespread methodological criticism of those studies among scientists, veterans hold those studies as key evidence of toxic damage.

The case of GWIRs illustrates how external pressure, as well as internal efforts, can lead to a change in the dominant epidemiological paradigm. For example, a former VA employee
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reported that over a five year period, he saw the VA “moving from a defensive posture and a posture of denial to a posture of addressing veterans problems, and acknowledging that this isn’t a matter of blame, that this is a matter of, ‘we have a duty to help them get better.’” He explained this change:

I think it was a combination of things. I think the average veteran was just saying “Would you please acknowledge there is something wrong with me and don’t tell me it’s in my head.” The other is . . . despite the fact that we were being beaten up by certain corners of the community, particularly Congress, scientific panels were providing confirmation of what our findings had been up to that date, and I think that, even though there were criticisms by those groups too, it allowed us to be a little more bold, and also those committees taught us really good lessons. The Presidential Advisory Committee . . . was one because . . . they took to task VA and DOD for not doing the best job to reach out and take care of veterans and also the failure to communicate effectively.

In challenging the initial stress-based dominant epidemiological paradigm, veterans began by seeking assistance from their Representatives. Some veterans felt Congress has not been as great an ally as it was to veterans of other wars, due to the absence of any Gulf War veterans in Congress. Still, they maintained that veteran pressure on Congress has led to many beneficial outcomes: the 1992 legislation requiring VA and DOD to create health registries, 1994 legislation permitting VA to provide benefits to veterans with unexplained symptoms, allocation of the $150 million spent on research, and 1998 legislation guaranteeing presumption of exposure similar to Agent Orange legislation. Veteran activists report much less success with other areas of the government, as evidenced by the ongoing tension with the VA and DOD, and veterans have had only, minimal success within the scientific community. Though veterans’ interests in studying depleted uranium and other exposures have resulted in concerted efforts by VA to fund research addressing their concerns, this research has failed to show health effects. Veterans have also had mixed success with the media. At first, sick veterans were media heroes. Even into 1996, coverage of GWRIs was prominent, with a shift from the human-interest story of sick veterans to a potential Pentagon cover-up. More recently, according to our content analysis and the veterans we interviewed, the media has shown little interest in GWRIs.

At present, there has been a shift in the dominant epidemiological paradigm, from a primary stress approach to a contextual stress approach. This is still a paradigm-in-formation, without the firm consensus that would make it generally applicable. In place of the primary stress model, where complaints were seen as psychological symptoms, the new approach sees symptoms as real, even if unexplainable. In a contextual stress approach, researchers understand the stress of potentially real exposures, for instance, the stress of experiencing chemical alarms in the face of known and threatened chemical exposures. While there is not much research yet, more scientists are calling for studies of the interaction of actual exposures and stress reactions. Researchers also take seriously the stress experienced by veterans over the inability to find explanations for their mysterious symptoms. There is no major research program to confirm this dominant epidemiological paradigm-in-process. Indeed, the transition is more apparent in the clinical sphere. One clear implication is that clinicians should not immediately resort to psychiatric consultations as a chief form of care. Instead, a more multifaceted treatment program is necessary (Engel 2000). This developing dominant epidemiological paradigm also has a strong policy component. One part is the pressure for predeployment health data in future engagements. Another part is realizing the political and clinical costs of denying health problems in the first place. So, in response to both internal shifts and veteran pressure, this new dominant epidemiological paradigm is moving forward, especially in terms of clinical and policy developments, without the scientific evidence to justify it.

Despite obstacles to obtaining adequate data, most researchers looking at GWRIs are seriously trying to understand this mystery. Many have tried to find relationships between symptoms and a variety of exposures, and in the absence of support for those associations, they have attempted to find respectful explanations for veterans’ problems. In this process of learning to better understand the unexplained symptoms, we witness an ongoing negotiation of the meaning of illness. Veterans are trying to transform their ambiguous suffering into an
understandable phenomenon. This is an example of the medical sociological perspective that speaks of “organizing” the “unorganized” illness through clinical interaction and negotiation (Balint 1957). In the initial formulation by Balint, organizing is typically done in doctor-patient interaction, but in this case it is done through a larger series of interactions that extend beyond the doctor-patient relationship. The negotiation is on a large scale, questioning the meaning of mysterious symptom complexes in the absence of tangible etiology (Aronowitz 1998; Morris 1998). As the case of GWRIs illustrates, negotiation of meaning becomes more and more complex as the illnesses themselves grow in complexity and as the number of interests competing for acceptance of their definition grows.

A MODEL FOR STUDYING CONTESTED ILLNESSES

As we discussed at the outset, contested illnesses are diseases and conditions that involve scientific disputes and public debates over environmental factors. Looking at the contested illnesses with which this larger project is concerned, it makes sense to view contested illnesses as being of two major types. One type, known diseases, includes diseases for which there are varying degrees of belief in the disease's existence. With breast cancer, there is extremely clear agreement as to the presence of the disease; with asthma, there is very clear agreement, though with some concern over lack of specificity in diagnosis. The second type, presumptive diseases, includes Gulf War illnesses. Here, there is basic dispute over whether any syndromes or diseases actually exist.

In both known and presumptive illness, there may be disputes over the role of environmental factors, but with the presumptive illness the dispute over the actual existence of the disease precedes any discussion of cause. In terms of generalizing from the experience of Gulf War-related illnesses, it makes sense to focus on a general model for sociological understanding of the presumptive form of contested illnesses. Such a model can be helpful, since other contested illnesses have gone through the process of identification and social recognition. If we look at the history of various occupational diseases (such as silicosis) or toxic-induced diseases (such as lead poisoning), we see how economic and political factors affect government and corporate resistance to recognition.

Our model of the dominant epidemiological paradigm attempts to advance our understanding beyond isolated emphases on political or economic factors in the disease recognition process. We suggest that these factors, when integrated with scientific ones, combine to form a dominant epidemiological paradigm. By examining this paradigm and its components, our model can help sociologists examine future occurrences of unexplained, mysterious diseases where there are disputes over environmental factors by illustrating the process in which an affected population mobilizes to challenge the dominant epidemiological paradigm. The dominant epidemiological paradigm model suggests five successive stages. The first is a prerequisite for the later ones, though later stages can come in varying order, and do not always all occur.

The first stage is identification. This can be done by scientists, clinicians, or affected people. It almost always done by sufferers, who typically identify a set of as-yet-unconnected symptoms. Based on pre-existing scientific knowledge, policies, and public awareness, people respond to the newly identified symptoms. One common reaction is to dismiss the symptoms as the expression of another disease. For example, many researchers and clinicians argued that Gulf War veterans were manifesting mental illnesses.

Almost as soon as individuals identify problems, they share them with others, leading to a second stage of shared experience and collective engagement. This stage is hastened when a dominant epidemiological paradigm inadequate to the affected population’s needs compels individuals to share not just their disease experience, but also their experience in the medical system. In this stage local and national groups form to advocate for the sufferers. Advocates can choose to focus their energy on the science, policy, or public awareness that they feel is necessary to get the response they need.

No matter where they focus their energy, advocates ultimately are engaged in a search for treatment and/or causation and/or prevention, which is the third stage. Both sufferers and the scientists and government whom they ask for help face an unnamed, unclear etiology
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and the lack of an acceptable diagnosis. Sufferers look toward environmental causation, especially when they are aware of the widespread exposure to many hazards. The search for causation is important not just in terms of leading to treatment and prevention, but also in terms of attributing responsibility, the fourth stage. For some parties, especially the government, searching for causation is not a worthwhile endeavor, since they don’t want to be held responsible. Even if causation cannot be determined, sufferers may focus on one or more purported causes in an attempt to attribute responsibility to other parties that may have been involved in the events related to the problem.

The fifth stage is political determination. In this stage, the sum total of the activity in previous stages combines to yield an overall social construction of the problem and a policy perspective from military, government, and other entities that hold political power. This last stage may be the most difficult, and may not happen, and if it does happen it may be incomplete. In a successful case, a presumptive disease gets recognized as an entity, even if the cause is not ascertained.

As mentioned above, the first stage is a prerequisite for the later ones, though later ones can come in different order. When advocates are effective, these stages result in new scientific understanding, new government policies, and new public awareness. When advocates lack the resources to push through the stages of the dominant epidemiological paradigm process, the dominant epidemiological paradigm remains relatively unchanged.

DISCUSSION AND CONCLUSIONS

It is striking how the contestation over Gulf War ailments, like a growing number of other medical concerns, has become a public dispute, with citizens playing a central role. In fact, Sheldon Krimsky (2000), in writing about lay and media action concerning the endocrine disrupter hypothesis, writes of a “public hypothesis,” in which many actors outside the usual scientific realms, especially laypeople, play major roles. Disputes concerning GWRIs have led researchers to utilize less established methods (e.g., the use of self-reported symptoms and self-reported exposures), and have pressed clinicians and researchers to take seriously the symptoms experienced by veterans. We see another significant example of this process in the case of AIDS activists who influence the formulation and implementation of treatment trials (Epstein 1996).

At present there is little evidence that environmental exposures affected soldiers’ health. Meanwhile, researchers have had to face declining funding. For instance, the Boston Environmental Hazards Center finally lost its special financial support in early 2000 when the VA changed its mandate from a unit dedicated to Gulf War research to one studying general environmental health. Several research projects were simply terminated.

Some researchers and many veteran activists want lessons from the Gulf to inform future military involvements so that caution is taken with inoculations, antidotes, and toxic exposures. Indeed, there has already been post-Gulf War resistance to anthrax inoculations, as well as large-scale departures from the reserves due to compulsory vaccination (Ricks 2000). Many sick veterans and some researchers believe there are environmental causes for Gulf War ailments and intend to keep alive their quest for confirmation.

In addition to describing and analyzing this particular case, our examination of disputes over Gulf War-related illnesses can contribute to a general approach toward disputes over disease discovery, responsibility, and treatment. Our concept of the dominant epidemiological paradigm demonstrates the power of the status quo and the difficulties in overturning it. Lay action around contested illnesses can involve pressure on government to conduct research, and in this arena veterans have succeeded, even if the results are not what they hoped for. Lay action also can involve direct participation, through citizen-science alliances. Gulf War veterans have not successfully forged the strong citizen-science alliance we see in other contestations over environmental and occupational exposures. Lay involvement at our research site, the Boston Environmental Hazards Center, showed an atypical level of participation, with veterans helping develop questionnaires, pressing for study of certain exposures, and helping boost response rates. The weakness of the citizen-science alliance is partly attributable to the military’s and VA’s tight control of data and research, as well as the veterans’ patriotism and military culture.
that discourage attacks against the government.

Professional allies are needed for a citizen-science alliance, and these are most often found among what we term critical epidemiologists. A primary objective for critical epidemiology is to "see" how epidemiology is an organized system of human endeavor to construct knowledge about the distributions and determinants of population health. Critical epidemiology examines how the historical context of epidemiologic investigations, particularly the dominant political ideology, influences what we know and don't know about disease etiology, health services, and prevention strategies (Zierler 2000). Critical epidemiology tries to apply the discipline's epistemology to achieve social justice. This includes taking a social-structural and health inequalities approach to epidemiology, and working with laypeople, or seeing themselves as tied to social movements (Wing 1994). One example of critical epidemiology working with a citizen-science alliance is scientists working with community groups to search for potential environmental causation of diseases, especially when traditional funding sources and regulatory and public health bodies strongly oppose such connections. This can be seen in the work of scientists at Woburn, Love Canal, Hanford, and other contaminated communities (Brown et al. 2000). Another example of critical epidemiology is how epidemiologists teach lay activists enough science so that they can engage with scientists and officials; the National Breast Cancer Coalition's Project LEAD is one such effort, where epidemiologists provide breast cancer activists with sufficient scientific capacity to serve on federal review panels. In a few special applied settings, entire research organizations, such as Silent Spring Institute (funded by the Massachusetts legislature to research environmental factors in breast cancer), merge their scientific inquiry with direct participation in social action. We also see critical epidemiology at work in academic settings, challenging risk-factor epidemiology with a social-structural perspective that emphasizes the role of "fundamental causes" such as race, class, and sex (Link and Phelan 1995). Critical epidemiology also involves critiques of mainstream approaches, eschewing the emphasis on the most modern mathematical models and returning to the "shoe-leather" epidemiology and commitment to social justice that initiated the field of epidemiology (Wing 1994).

Through examining critical epidemiology and citizen-science alliances we can understand how lay-professional collaboration functions in the discovery of, and action on, environmentally induced diseases and multi-symptom diseases and conditions. Finally, our model of how to study disease discovery and contestation, based on this project, offers a general approach for sufferers of other environmentally-related diseases and conditions who are forced to challenge the dominant epidemiological perspective in order to get their needs met.

NOTES

1. We recognize that there is a substantial body of literature on the distinction between physiological disease and personal experience of illness; we do not intend this terminology to reflect that literature. The term "contested illnesses" makes sense since there is no single defined disease for Gulf War veterans and it is their experience of illness that is central.

2. We use the term "conditions" to refer to symptoms and symptom groupings that are not specifically defined as diseases or syndromes. Most researchers and clinicians view Gulf War veterans' complaints as "conditions."

Appendix

Gulf War Illnesses—Interview Codes

In the interest of space, this coding sheet does not provide all response categories. For example, under "self-report of exposure," we actually coded for the following response categories: acceptance, disagreement on, distrust of, value in research, veterans' belief in.

Actors
activism
government—US
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government—foreign
media
medical schools
public
public health schools
scientists
social movements
universities
veterans
veterans organizations

Agencies and organizations
Centers for Disease Control
Congress, including Congressional committees
Department of Defense
Department of Health and Human Services
General Accounting Office
Institute of Medicine
National Institutes of Health
Office of Special Assistant for Gulf War Illnesses
Persian Gulf Veterans Coordinating Board—Research Working Group
Presidential Advisory Committee
RAND
Department of Veterans Affairs

Data and methodological issues
alarms
exposures
Khamisiyah
morbidity
mortality
pre-deployment health
record-keeping
reliability of data
secrecy
self-report of exposure
self-report of symptoms

Disease definitions and attributions of causality
case definition
causation
Chronic Fatigue Syndrome
definition
discovery
environment
fibromyalgia
mental health
medically explained physical symptoms (MUPS)
multiple chemical sensitivity
post-traumatic stress disorder
stress
symptom clusters
symptoms
syndrome

Policy
Agent Orange
benefits
future wars
inclusion of conditions
inoculations
legitimacy
pre-deployment health
recognition
treatment
Vietnam War

Research issues
alarmism
barriers
collaboration
communication
conspiracy
data access
disputes
funding
“good science”
important studies
information
knowledge base
lay involvement
obstacles
researchers, significant
researchers, maverick
responsibility
secrecy
surveillance
trust

Specific environmental factors
air particles
antidotes
chemical weapons
depleted uranium
diesel exhaust
inocculations
oil well fires
nerve gas
particulates
pesticides
pyridostigmine bromide
radiation
sarin
toxic chemicals
vaccinations

Analytic Methods for Interviews and Observations

Our research began with the content analysis of media coverage of Gulf War-related illnesses. Through the process of developing coding categories for the media analysis, we were able to develop an interview schedule to guide our interviews with scientists, veterans and public officials. The media analysis also brought to our attention the themes and issues that would be most relevant to explore in our analysis of official reports, public documents, and other related material. In analyzing our interviews, we used the interview questions as the initial categories. As we conducted the interviews and transcribed them, additional issues and themes relevant to our analysis emerged. The end result was a list of coding categories, the most prevalent of which we used to organize our analysis. Codes were called up in the NVivo software to locate all occurrences. In addition, interviews were continually re-read and discussed in the research group, in order to assure that there was agreement on the meaning and context of codes, and to determine which extracts best conveyed the findings.
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Phil Brown is Professor of Sociology and Environmental Studies at Brown University. He has written No Safe Place: Toxic Waste, Leukemia, and Community Action and co-edited Illness and the Environment: A Reader in Contested Medicine. His research interests are in disputes over environmental factors in asthma, breast cancer, and Gulf War illnesses; community responses to toxic wastes, race and class biases in the burden of environmental hazards, and theoretical models of the social construction of health and illness.

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Sabrina McCormick is a graduate student in Sociology at Brown University. Her research interests include environmental causation of illnesses and responses to them, the role of gender and race in the construction and contestation of illness paradigms, and epistemology.

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