Environmental Hazards and Veterans' Framing of Gulf War Illness

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Military personnel and other civilians were exposed to numerous environmental hazards during their service in the Persian Gulf Crisis. Nearly a decade later well over 100,000 veterans, spouses, and other civilians are claiming illnesses related to these exposures. The U.S. government denies a connection and refuses to sanction these claims of environmental illness. Analyzing data from in-depth interviews and various documents, the author examines the veterans' framing of Gulf War Illness and the government's response to this environmental illness frame.

Many scholars argue that modern society is characterized by the growing risks associated with environmental hazards (Beck 1992; Giddens 1990; Erikson 1996). Beck (1992) describes this modern era as the "risk society," and Erikson (1996) refers to a "new species of trouble" associated with modern environmental contamination. Furthermore, Erikson (1996, p. 209) argues that the environmental threats associated with the modern era transcend time and space as they involve toxins that "contaminate rather than merely damage." Increasingly, residents have discovered these environmental hazards in their communities and have complained of a collection of health symptoms commonly known as environmental illness, or multiple chemical sensitivities (e.g., Levine 1982; Brown and Mikkelsen 1990; Brown 1992). Despite growing evidence of environmental contamination and the increase of such claims, the medical establishment has refused to sanction environmental illness. The controversy surrounding and occurrence of environmental illness has not been limited to the general public, but has reached the military community. What has become known as "Gulf War Illness" represents one such occurrence.

In 1990 approximately 697,000 U.S. troops were deployed to the Persian Gulf to help liberate Kuwait. Massive media coverage of the seven-month war centered on the advanced technology of the military machinery and the precision of "surgical" bombings. According to official United States accounts, American war casualties totaled 376. For many Americans deployed to the Gulf, February 27, 1991, marked the end of the war but the beginning of a new struggle over health grievances. Some soldiers noted health difficulties while in the Gulf; others experienced symptoms after returning home. They complained of a variety of

problems, including memory loss, headaches, blurred vision, chronic fatigue, sleep problems, mood swings, skin rashes, aching joints, abdominal pain, and diarrhea. Some veterans' spouses noted similar health problems. Veterans also became aware of what appeared to be an unusual number of birth defects in babies born to Gulf War veteran parents.

Many Gulf War veterans and their spouses suspected a connection between their health problems and possible exposures in the Gulf to chemical and biological munitions. Troops were also given multiple vaccinations and drugs designed to protect and treat them in case of exposure to chemical and biological weapons. Some of these drugs, such as Pyridostigmine Bromide (PB) tablets, had not been fully approved by the FDA. In addition, the Department of Defense estimates that 150,000 U.S. troops were given at least one anthrax vaccination. Veterans were also likely exposed to depleted uranium munitions and smoke from oil well fires. Finally, large amounts of toxic insecticides such as DEET were used by the troops to repel sand fleas and other desert pests. Since the Gulf War ended, more than 100,000 veterans and spouses have experienced health problems they believe are related to exposures in the Persian Gulf. Despite their claims, the government denies these connections and refuses to sanction a medical diagnosis for Gulf War Illness.

The battle over the veracity of claims of "Gulf War Illness" is in essence a struggle over who has the power to define an illness as "real." Many sociologists have pointed to the precarious nature of constructing social reality (e.g., Berger and Luckman 1967; Spector and Kitsuse 1987; Gamson and Modigliani 1989; Best 1995; Clarke and Cochrane 1998; Loseke 1999), and some have focused specifically on the social construction of illness (Friedson 1970; Waitzkin 1989). As Fruend and McQuire (1991, p. 204) claim, social constructions of illness are "always open to the influence of social factors in their production, transmission, and development." These social factors include the mobilization of resources to shape definitions of what constitutes illness. Shriver, White, and Kebede (1998) argue that, while multiple frames of illness may exist, some groups will be more effective in making their definitions stick. They argue that dominant frames of illness are often supported by the mobilization of resources to discredit challenges from other perspectives. In this paper, I examine veterans' claims of Gulf War Illness and their reported treatment by the United States military establishment. This analysis may help explain, in part, why the environmental illness frame associated with Gulf War Illness has not been widely accepted.

Conceptual Framework

The constructionist perspective was first popularized by Berger and Luckman (1967) in their seminal work, *The Social Construction of Reality*. Since then this perspective has been utilized in a number of substantive areas

within sociology, most notably in the study of social problems (e.g., Spector and Kitsuse 1987; Gusfield 1981; Schneider 1985; Best 1987, 1993, 1995; Linders 1998; Clarke and Cochrane 1998). Social constructionists argue that problems become official "social problems" only when society defines them as such. Best (1995, p. 4) succinctly states, "Social problems are what people view as social problems," even in cases where conditions appear to be objective.

An early application of the constructionist perspective on social problems came from Gusfield (1981), who examined the process by which drunken driving came to be widely recognized and labeled an official "social problem." More recently, Linders (1998) traced the criminalization of abortion in the United States. Linders compares the United States to Sweden, where abortion failed to reach such notoriety. The constructionist perspective has been used to examine a wide range of issues topics including alcoholism (Appleton 1995), child abuse (Pfohl 1977), rape (Bourque 1989), and hate crimes (Jenness 1995). These analyses illustrate the various ways that issues become recognized and legitimated as social problems by the established order, as well as by the public. According to Clarke and Cochrane (1998, p. 19), the elevation of an issue to the position of social problem is a complicated process that includes political ideology as well as "common-sense knowledge."

The constructionist perspective has also been used by medical sociologists, who have adopted the framework for understanding illness. These analysts study the process by which certain illness frames become recognized and legitimated, while others fail to be acknowledged (Friedson 1970; Ehrenreich and English 1978; Latour and Woolgar 1979; Smith 1990; Anspach 1993; Fruend and McQuire 1991). They argue that illness is socially constructed and subject to various interpretations. Social constructionists in the field of medical sociology are not denying the objective basis for health claims. Rather, they are arguing that constructions of illness are influenced by a wide range of social, economic, and political forces (Latour and Woolgar 1979). According to Fruend and McQuire (1991, p. 3), "Medical systems involve concrete organizations that reflect the economic interests of such groups as doctors and other professionals, insurance companies, pharmaceutical industries, manufactures of medical equipment, hospitals, research organizations, government agencies, and medical schools." Thus, the definition of a state as an "illness" is the product of a system with potentially conflicting political and economic entities. The importance of these political economic factors is particularly critical to understanding illness frames associated with environmental hazards.

Since the 1980s the United States has witnessed an increased rate of discovery of contaminated communities and a growth in the number of people claiming environmental illness (Cable and Cable 1995; Levine 1982; Brown and Mikkelsen 1990; Brown 1992). The symptoms identified by these residents are varied, but include immune system deficiencies, chronic fatigue, rashes, memory loss, tremors, chemical sensitivity, night sweats, and depression. In some communities residents complain of excessive and unusual cancers, miscarriages, and birth defects believed to be associated with environmental hazards. Despite these complaints, residents have had a difficult time getting medical professionals to treat their complaints as a medical condition (Kroll-Smith and Floyd 1997; Rogers 1990; Shriver et al. 1998).

Shriver et al. (1998) document a community's attempt to establish an environmental illness frame in their study of residents living near the Oak Ridge Nuclear facility in East Tennessee. Environmental problems are well documented in Oak Ridge and the entire community has been an Environmental Protection Agency Superfund site since 1989. Residents complain of symptoms similar to those noted in other contaminated communities, including chronic fatigue, chemical sensitivity, arthritis, rashes, hair loss, and tremors. However, government officials, local elites, and the medical establishment successfully mobilized resources and suppressed the environmental illness frame.

Similar claims of environmental illness occurred in the U.S. military, where veterans have also struggled to establish a legitimate link between hazardous exposures with their health problems. These claims have been made by the Atomic Veterans and by Vietnam Veterans exposed to Agent Orange (Scott 1988, 1990, 1992, 1993). Scott (1993, p. 249) notes that, "veterans of all America's wars have encountered pitfalls in requesting medical treatment and compensation for service-connected injuries and disease." Scott (1993) argues that during periods of conflict the military often uses technological innovations that have unknown effects on its soldiers. As a result, for political purposes veterans' claims of illness often go undiagnosed or even ignored. In the current study I extend this growing body of research on environmental hazards and illness by examining Gulf War Veterans' attempts to establish an environmental illness frame.

Research Methods

Data sources for this research project include interviews, document analysis, and observation. The primary data for this paper came from in-depth interviews with 55 respondents. The interviews were conducted over a twelve-month period during 1999 and 2000. Initial contacts were made at a national planning conference on Gulf War Illness. This conference brought together Gulf War veterans and their supporters; government and private medical researchers and practitioners; and government officials involved in the controversy. After the initial in-depth interviews were conducted with contacts from the national planning conference, a snowball sampling technique was employed to identify the remainder of the participants. An interview schedule was used to prompt respon-

dents on their experiences. These semi-structured, in-depth interviews were conducted with those who served in the Gulf and their family members. The 55 indepth interviews ranged from one to four hours and were audiotaped. Additional data were obtained from newspaper coverage of Gulf War Illness, organizational newsletters and correspondence, and government documents such as transcripts from Congressional hearings on the issue.

The Struggle for Medical Recognition: Environmental Hazards and the Framing of Gulf War Illness

This section examines the respondents' experiences with Veterans Affairs (VA) and the military medical establishment in their attempts to validate claims of Gulf War Illness. I pay particular attention to measures used to debunk the environmental illness frame and also medical practitioners who validate Gulf War Illness. I begin by discussing the Veterans Affairs policy and practice regarding claims of Gulf War Illness. I then discuss how the lack of information has hampered the establishment of this environmental Illness frame. Finally, I discuss how the struggle for recognition of Gulf War Illness may have affected Veterans' medical treatment.

Veterans Affairs Reactions to the Gulf War Illness Frame

The Gulf War Illness frame has largely been denied through policies that come directly through Veterans Affairs (VA). As a result, many veterans and spouses describe their problems associated with getting treatment and/or compensation as directly related to the VA's refusal to sanction Gulf War Illness. A veteran and his spouse discuss the VA's framing of Gulf War Illness:

The first day we go to the VA for the Gulf War exam everybody we see, including the nurses, tells us that Gulf War veterans aren't sick. They say that they've been to all this training at all these places and there is nothing to it. "There is no Gulf War Syndrome." This includes the doctor that does the Gulf War review!

A veteran and long-time Gulf War Illness activist states,

As late as two or three months ago doctors are standing there telling veterans there is no such thing as Gulf War Illness. "Wait a minute here!" I understand the difference between medical professional opinion and laymen's. But to stand up there and say there is no Gulf War Illness!

He continues by discussing his frustration towards the VA surrounding the inconsistency in its response to claims of Gulf War Illness:

Common sense tells you that if we were in Atlanta for that conference which was to try and decide how to disperse sixty-four million dollars for medical research [on Gulf War Illness], it doesn't jive that a doctor tells me there is no Gulf War Illness. If there is no Gulf War Illness, why are we spending sixty-four million dollars? That doesn't jive!

Another veteran discusses similar frustration:

As far as the VA is concerned, they have done nothing but fight us. I understand where the VA is coming from. My biggest problem with the VA is, knowing what happens here in the field, and going to Washington and listening to what the VA representatives in Washington tell the congressmen and senators. It is not what is happening in the field.

Most veterans and spouses believe that the VA's reaction to the Gulf War Illness frame comes from higher up in the system. As one states, "It's got to be at the top because we're hearing similar stories from VA facilities all over the country." Another respondent points to senior VA officials:

You have two individuals like that [senior VA officials responsible for VA policy towards Gulf War veterans and Gulf War Illness] who have repeatedly stated that there is no evidence these toxic exposures are responsible for these illnesses. That sends, I think, a very clear message to the rank and file medical staff throughout the VA that this issue is not to be taken seriously. You have senior officials at the VA who have really set this policy in place and it has been communicated down to the rank and file.

Thus, veterans and their spouses believe the policy regarding Gulf War Illness is set from above and filtered down to the local level. A veteran talks about how local VA hospital administrators were controlled by these policies from above: "The hospital administrator [at the VA] is the person that provides the funding for whatever they are trying to do. They are told, 'You will not address this, you will address that.' There are guidelines that come down from Washington."

Respondents' criticism of VA policies on Gulf War Illness has been consistent throughout the country. Veterans tell similar stories of their poor treatment by VA medical staff after mentioning Gulf War Illness. Since official VA policy does not recognize the diagnosis of Gulf War Illness, veterans and their spouses express similar frustrations at being unable to receive a diagnosis for their problems. One spouse exclaims, "Nobody has a diagnosis! It's all undiagnosed!" A veteran adds, "They [VA doctors] come up with anything they can to keep from admitting that it is connected to Persian Gulf. They've gotten quite good at it." Without an official diagnosis for Gulf War Illness, most veterans have been unsuccessful in their attempts to get any compensation for their health problems. A veteran explains, "Gulf War Illness does not exist. You cannot get disability with the code of Gulf War Illness. They are given disability for different symptomology but it is not labeled Gulf War Illness."

While to date no one has received a diagnosis of Gulf War Illness from the VA, many have received a diagnosis for Post Traumatic Stress Disorder (PTSD). After the Vietnam War, Veterans had to fight with the VA to receive a PTSD diagnosis. It took a long time for the medical bureaucracy to respond to the vet-

erans' claims with a medical diagnosis. Over time, PTSD shifted from unacknowledged veterans' claims to a legitimate VA diagnosis (Scott 1990). Today some veterans now feel the diagnosis of PTSD is being over-used. According to one activist:

Now it [PTSD] has almost become the VA's Holy Grail. Anything that they can't medically explain, tie to a virus, tie to a bacteria, tie to something within conventional medical science, they'll try to hang a PTSD label on it. So the pendulum has swung entirely too far in the direction of trying to ascribe PTSD or other psychosomatic type diagnosis where there is in fact no clinical evidence to support it.

A veteran discusses his frustration with the PTSD label, stating, "They can sit there and write so many issues off, like headaches, even memory defects. They can write them off with PTSD. They can say that depression can cause you to have aches and pains." Another veteran discusses being sent to a program specially designed for PTSD: "I've gone to a 30-day program that they said I needed to go to for PTSD and the only diagnosis from that program was PTSD."

Other veterans are frustrated with the VA for connecting all of their health problems to psychological factors. A former scout sniper states, "They [VA] basically threw the psychological problem thing at me and it was about all I could do to keep from choking this little piss ant. I've refused to go back there ever since." The spouse of a veteran who also suffers from severe health problems states, "If you even mention the word Gulf War Illness, the staff is like, 'Yeah, here is another one of these flaky puffs." Another angry veteran exclaims, "The VA says my neurological problems are from the psychological problems. To me that's putting the cart in front of the horse!"

This treatment has forced many veterans to avoid mentioning Gulf War Illness at the VA. They believe that this language choice increases their chances of getting better treatment. According to one veteran, "If you say its Gulf War Illness then they have all of this propaganda out that it's all in our heads. They won't take your symptoms seriously." Another veteran concurs, stating, "It's better not to press on Gulf War Illness. In order to get any treatment, they [veterans] accept the diagnosis they are given." She goes on to state, "Lots of people get into lots of problems when they start trying to press the issue. Its easier to just say, 'Oh, I have this illness' and stop the conversation at that." These comments illustrate the importance of socially constructed illness frames. The veterans support the Gulf War Illness frame within the veterans' community and among the general public, but have chosen not to address it within the Veterans Affairs medical establishment in order to receive needed medical attention.

Some veterans have simply given up on the VA altogether. One veteran states, "I don't even go to the VA anymore; I got so fed up with them." Another says that this trend is widespread: "There are a lot of veterans that won't even mess with the VA." Yet another states, "Down here where I'm at this VA we've got has run everyone off." Finally, one particularly angry veteran characterizes the VA by saying, "My personal opinion is the VA makes Nazis look good."

One way the VA has controlled official response to veterans' claims of Gulf War Illness is its handling of compensation claims. Veterans who have disabilities including health problems that they believe are connected to their military service are eligible for service-connected compensation. In order to receive these benefits, however, veterans must have their claims legitimated by the VA. A veteran explains how the review process works:

The first thing you've got to do is fill out your VA paperwork. You're basically saying what documentation you have and when it was diagnosed. Then they schedule you months down the road at a local VA. Then they do a physical, if you want to call it that. Most of the doctors never even touched me. What they write up there goes to the review board at your regional office. Then they assign a percentage. They are putting how much our bodies are worth.

The handling of these claims is extremely inconsistent. One couple suggests that it is largely the "luck of the draw" that determines the review and its outcome. They state, "It's all up to someone in that rating board." Another respondent adds, "It depends on who you talk to. Some of them are real nice. Most of them feel like you are taking money out their pocket." Other respondents concurred with these sentiments. According to one veteran, "I talk to vets that have the same things wrong with them and they were rated at 20%. I was rated at 80% but I had good documentation and I had my congressman involved and everybody else." Another veteran argues that the VA purposefully kept his rating 1% lower to avoid giving him a better compensation package. He states, "So I am only really 44% (service-connected disability) because if I was 45%, just one more percent, they could never take my disability away. You'd think it would be 50%, 30% and 20%. But it's 44% in their eyes."

Veterans and spouses tell numerous stories of their struggles with the VA. The widow of a Gulf War veteran relates her story:

[Husband] went to his grave knowing that his country did not back him up. He got his first denial [of a VA claim] in July and he died in August. I can't think of a more horrible way to die. You are told when you go into the military that if something happens to you we will take care of you and these military people believe that. They are told that and they believe it to be sincere. And to be dying, knowing you are leaving two babies and a wife, and the government isn't going to do what they said they'd do. I can't imagine what he went through.

One veteran emphasizes the "battle" he has had with the VA: "It's been a continual struggle. I've been through three appeals with the VA over five years. I've been denied countless times." Another adds, "They denied everything. He

[the VA doctor] listed all of these diagnoses but he stated that it is unlikely he can explain how I got them."

Another veteran notes that government denial illustrates that the burden of proof regarding the Gulf War Illness frame remains with veterans:

If you look into what the Department of Defense is investigating, they are not investigating whether the issue happened. They're investigating whether an individual can prove it. What they are looking at on all of these issues is a courtroom standard of proof to prove that we were exposed to it. So they are putting the burden of proof directly on the veterans rather than the government, where it belongs.

Those who have received favorable compensation claims from the VA sometimes utilized experts and politicians. Lowney and Best (1997, p. 50) refer to these as "organizational resources" and emphasize their importance in promoting and legitimating claims. According to one veteran, "I was denied four times and I finally went before the VA Board of Appeals with one of the leading toxicologists from the EPA. They finally overturned it." One of the few veterans interviewed who had received full, 100 percent service-connected disability explains her strategy:

I literally badgered the VA. I was relentless on them. I was on them all the time. My mother and father sent letters to President Clinton and to my Congressman. I had a lot of letter writing going on. I also contacted my Congressman. Every Congress office has a VA liaison in it. The troops aren't aware of it. I contacted mine and he went to work at the VA saying, "Why aren't you treating this woman and why isn't she being compensated?"

She essentially argues that it was a war of attrition, continuing: "I think basically in my case [the outcome] was that I wore them down. They thought, 'Let's give her the compensation and shut her up and she'll go away.' But they were mistaken. I didn't go away." Another veteran summarizes the VA's treatment of Gulf War veterans' compensation claims in this way: "The VA is throwing us to the dogs. You are a hard worker and a harder charger and you feel kicked to the curb. You really do. You feel cast aside."

Veterans and their spouses are largely dependent on the VA medical establishment for the diagnosis and treatment of their health problems. Some veterans have the resources to seek medical care outside the VA. For others, especially those too sick to work, the VA is the only available source of medical care. Not only do VA policies influence medial treatment, but they also impact public perception. The VA's handling of diagnosis and compensation claims has made it difficult for veterans to receive acknowledgement from the medical community but also from the general public. In addition, control of information has made it difficult for veterans to elevate Gulf War Illness to the status of a socially recognized medical problem.

Lack of Information and the Struggle to Establish the Gulf War Illness Frame

Veterans believe that the government has purposely withheld important medical information regarding the Gulf War Illness frame to protect its own interests. According to one veteran,

The DoD, along with the Office of Special Assistance for Gulf War Illness, has attempted to keep everything separated, segregated, and keep individuals from tying it all together. Because once you've tied it all together it's just so obvious it's unbelievable. It's like a light bulb comes on.

Another veteran adds, "They just kind of give you a recipe and want you to follow it. But they don't give you enough education and training." He believes that the lack of information regarding Gulf War Illness is purposeful and designed to control health grievances. He adds, "They give you only what you need to be a monkey so you won't question it."

Some veterans have sought to gain control over the circulation of information. A great deal of material regarding Gulf War Illness is exchanged on the Internet. When individuals and groups acquire documents related to the Gulf War Illness frame they often disseminate them to others via the World Wide Web. Several respondents note that there have been attempts to reclassify government documents or simply re-release the documents with certain sections deleted. One veteran states, "When they first started putting this stuff out on the net they put out a bunch of stuff that was classified. And then the government pulled it back off and re-posted it with a lot of the stuff taken out of it." Another veteran concurs, saying, "I've seen plenty of that, including the attempt to reclassify hundreds of documents that had previously been released."

At various public meetings sponsored by government agencies veterans have been given the chance to give personal testimonies regarding their health. Veterans share their stories and present their claims of illness to the audience. Veterans discuss the difficulty they have trying to communicate with medical researchers and other scientists. A respondent tells the following story of how she attempted to present findings from a research project on common symptoms found among Gulf War veterans:

Even for the Presidential Advisory Committee when the government sent out their little panel I was given five minutes to testify. Instead of giving my own story I presented [veteran's name] survey which he did of 10,000 veterans because I thought it would have more impact. And basically they shut me up. They cut me off and said it wasn't a valid survey.

These experiences are similar to those of other activists groups that have conducted their own epidemiological research. Citizens from various contaminated communities, for example, have also struggled to convince medical experts of the medical veracity of environmental illness. These cases have been well docu-

mented (Levine 1982; Brown and Mikkelsen 1990; Brown 1990; Brown 1992; Kroll-Smith and Floyd 1997; Shriver et al. 1998). In the case of Gulf War Illness, too, the control of information has made it difficult for veterans to define their health problems as a legitimate illness among the general public.

Veterans suggest that the control of information includes the loss of medical files. As one Gulf War veteran and activist explains, "That is a major constant that we have, the fact that these medical records are missing. The VA says, 'We have no medical records." Similarly, a veteran's spouse explains her husband's first visit to the VA hospital:

They asked him questions about his health and then they turned around and asked for your financial status and hospitalization and things like that. Then they said, "OK, we've got your claim filed." We had never done this before. They told us we had filed a claim and she [a nurse] signed a piece of paper. She [the nurse] gave him a copy of it, which is the only record now of him ever being in the VA in 1992. Everything else disappeared. If we didn't have this signed by this nurse we couldn't prove that he was in there.

Some veterans explain that they have had to start new files at the VA after their originals were either lost or tampered with. According to one veteran, "I was at the VA yesterday and two-thirds of my records are missing." Others believe that incorrect information is included in their files. According to one veteran, "There is a lot of incorrect information in there that I'm having to completely change." Another veteran who had both missing and incorrect information in his file relates that he was told by the VA staff to start a new file: "So the people there, the staff, have agreed that I need to just start from scratch."

Some veterans have asked politicians to intervene on their behalf to force the VA to locate their missing files. A veteran explains the problems she had with her file after she was awarded a compensation claim:

When my claim was adjudicated and I received my 100 percent I was told that my chart was lost. My file was lost! It had been sent to Arizona and back to Oakland and they didn't know where it was. I called my congressman and I said, "Look!" At that point we were going to go bankrupt and we were losing our house. My congressman stepped in and all of the sudden my file reappeared at the regional office in Oakland.

The VA located one veteran's file after his spouse threatened to contact her congressman and go public. "We went there and I said I want to see his file. They told me they didn't think they could find it. I said, 'You've got five minutes to find it before I go to my congressman and call the newspapers.' Well, they found it." She explains that it was returned, but all of the information was missing: "We opened it and everything was gone, all the medical records, everything."

In addition to having files lost, many veterans believe their medical records have been sanitized. According to veterans, this includes not having certain medical procedures such as vaccinations and other medications documented in their medical files. In addition, many veterans believe their medical records have actually been altered. There has been great controversy surrounding the use of vaccinations and experimental drugs on Gulf War soldiers. Some of this controversy surrounds the anthrax vaccination used on many veterans. The government initially denied the use of anthrax, but later acknowledged that it had been used on at least 150,000 people. Many veterans believe their health problems are related to these experimental vaccinations at least in part. But most have no documentation of these vaccinations in their medical records. A Gulf War nurse describes how she had to battle with a medic in the Persian Gulf to force him to document the vaccinations in her medical file.

I said, "What is this you are giving me?" and he said, "I can't tell you." I said, "Well I'm not taking it. I'm not taking something that I don't know what it is. I'm already sick and I was so tired so I knew my immune system was down." And he said, "I will tell you that it is anthrax but you are not supposed to know that." I said, "Well, I don't get it." He said, "I'm not going to document it in your shot record." He said, "We are under orders that if you do not take it you will be court marshaled." At that point I was still military minded enough to know that was disastrous for a career. I asked why he wouldn't document it in my shot record and the response was that they couldn't put it in our shot records because if Saddam ever got a hold of our shot records he would know that we were being immunized against his biological weapons. I said, "Please, like Saddam Hussein wants my shot records."

She continued to push the medic and eventually forced him to write something in her record. She explains, "I got really kind of nasty. The kid giving it was an enlisted medic and he was trying to do his job. I said, 'Don't mess with me—you will put something in my record.' So what he put in my shot record was 'Vaccine A.'"

This veteran had a medical background and pushed hard to get some documentation of the vaccination. Other veterans interviewed had no records of vaccinations in their files after returning from the Gulf. One respondent describes his medical file, "When I was discharged from the Marine Corps, I looked through my medical records and every shot and pill, everything that I had received when I was in Desert Storm was not on my medical record." He adds that this was a typical scenario: "That happened to all of my buddies that were over there. There was no medical documentation on any of the vaccinations or pills that they have given."

Some veterans believe the sanitation of medical records goes beyond simply refusing to document vaccinations and medications. Some believe that their medical records have been altered. A veteran and his wife describe an incident involving his medical file at the VA hospital:

We actually had his medical chart one day sitting at the VA waiting to go from one clinic to another and we took it out of the hospital and copied it. You could see where a doctor put one thing, then scratched it out and put another thing. And they do that all the time. They don't document anything that would make them look bad.

Another veteran describes an incident in which a nurse practitioner at the VA hospital diagnosed Gulf War Illness in his file, but later changed that diagnosis. He explains,

I went to a nurse practitioner and she was the first one to write down Gulf War Illness in my medical records. After she got done she said she'd have to go talk to her supervisor and get his evaluation. They were gone for probably an hour before they came back. When they came back he said that she had made a mistake and that there was no such thing as Gulf War Illness.

The Struggle for Recognition and Treatment of Gulf War Illness

Veterans believe that the difficulty they have had receiving diagnosis and treatment for Gulf War Illness stems, in part, from the fear and/or control medical doctors perceive and/or experience in the military and in the VA. Veterans believe that physicians fear harassment, even job loss and, as a result of such fears, they refuse to treat and/or conduct research on Gulf War Illness.

Veterans narrate numerous stories of their experiences with VA physicians reluctant to treat Gulf War Illness. According to one veteran:

My own doctor told me three or four years ago, "I think I understand this. I think you guys were exposed and I think I know to what." At that time he was thinking nerve gas. We didn't know for a fact because we didn't have the logs at that time. I said, "Well that is wonderful, you have to take it on up and expose this." He said, "The problem is, although I believe you guys were exposed, I told my boss about it and he told me that if I didn't keep my mouth shut they would find me washed up on a shore some place." Those were his exact words. So he never went forward with it.

Another veteran and his wife probed their VA doctor:

We asked him [VA doctor], "Do you see a lot of sick Gulf War vets coming through?" And he looked at us with a weird look and he said, "NO!" And he put his head down. In five minutes he put his pen down and he turned to us and said, "You know what? I've got six years to retirement. I really can't say anything about Gulf War."

The spouse continued, "To hear that doctor say that, and being a registered nurse. I would lose my job before that, you know. We did take an oath, all of us in the medical field, to be a patient advocate first." Despite her frustration, she does acknowledge the difficult position VA doctors are in regarding the Gulf War Illness frame.

You have to understand a little bit. I think he has something like 26 years in, a very large number of years in. So you can understand his concern. This is his life. Probably he will come forward when he is done, but that doesn't help the people that are dying right now.

Other veterans offer similar sentiments regarding the predicament facing VA doctors. One states,

The bottom line is that I think there are some very very good doctors in the VA but when they try to step outside those boundaries they are absolutely done in. Look at [Doctor's name]. The VA did him in. They got rid of him.

Another veteran puts it bluntly, "Yeah. I think VA doctors are open and honest as far as they can be. They are not going to put their careers on the line."

Another veteran tells of being warned by his VA doctor off-the-record. He states, "[the VA doctor] tells me, 'You are very sick and you have a lot of health problems. Whatever you do, don't let this VA shut the door on you." A veteran and long-time activist on the issue offers this assessment, "And you have a handful of doctors within the VA system who have basically stood up and said, 'This is bullshit.' Most of them have been forced out. Most of the ones who have spoken up vigorously have in fact been forced out." Another adds,

Every doctor that has challenged the protocol in different VA systems has been fired. And every doctor that has ever found a correlation between the stuff that we were using and our symptoms of illness have been denounced. They say their research procedures are flawed—every single one!

Several veterans interviewed discussed the case of a research physician who was denounced by the VA after his research findings drew a connection between veterans' symptoms and exposure to depleted uranium. The physician's research assistant explains, "He got involved with them [those potentially exposed to depleted uranium in the Gulf] and started testing to see if there had been exposure. Suddenly, things became very difficult. Ultimately, what happened was that the samples were lost." She goes on to say, "The people involved got reassigned or fired. The urine samples were lost. He was actually accused of stealing them. He was quote/unquote rifted from the VA. Ultimately, all those activities related to it were brought a halt immediately." When asked if he was officially fired she responds, "They called it a reduction of force." She continues by offering an explanation of why the treatment of the doctor has been so harsh.

I think that the administrators were not supportive because they wanted him to stop. They were getting word in the VA system for him to stop all the controversy. He was one of the only people in the VA system that could, with credibility, say what was going on. So they weren't happy and harassed him.

According to those interviewed, private physicians are also reluctant to sanction the Gulf War Illness frame. Several veterans tell stories of the difficulties they have had with private physicians. One spouse states, "Part of them are scared. I've had a heck of a time getting a doctor that would treat my husband. As soon as you say Gulf War they say, 'No, don't want to touch him." Another veteran tells the story of providing her private doctor with information on Gulf War Illness in an effort to get help: "I gave him [the doctor] all of the literature and he said, 'I'll help you but you never tell who it was that helped you.' He said, 'You never tell nobody I helped you,' because he said, 'I could get in a lot of trouble for this."

As a result of this perceived fear and control, veterans believe that they are being refused treatment for their health problems. A spouse tells the story of trying to get her sick husband into the VA hospital shortly after he returned from the Persian Gulf.

Within a month of him coming home I caught him lying on the bed holding his head and he was rolling back and forth and crying, "God, do something." He was saying, "My head is going to explode—you have to do something." He told me to call the VA and I was like, "Yeah, that's right, that's what you do, you call the VA for veterans." I called and explained to the guy on the phone what was going on. He said, "Let me make an appointment. I can get him in six months." I'm like, "You don't understand," and he said, "Ma'am, I'm sorry, that is the best I can do." I knew we were pretty much in trouble.

The mother of a veteran relates her son's neglect by a VA doctor. She explains:

Every time you turn around he's going up to the emergency room, either bleeding out of the rectum, throwing up blood, or breaking out in shingles. Every time I see him there is something wrong. I tell him, "This isn't right, something is wrong." [The VA doctor] told [my son], "You are a well-conditioned athlete and there was nothing to worry about. We will see you again in a year."

A frustrated veteran explains his diagnosis and treatment plan from his VA doctor.

A doctor in [location] at a VA hospital told me the best thing I could do for my own health would be to stop taking my medication and go to the library and find me a good book to read. And that would make me all better. Just find a good book to read and that would take care of all my problems.

Discussion and Conclusion

Nearly 700,000 U.S. troops were deployed to the Persian Gulf and several hundred thousand were given multiple vaccinations and experimental drugs such as Pyridostigmine Bromide (PB). Personnel were potentially exposed to chemical and biological weapons, as well as to environmental hazards such as burning oil well fires. In addition, many veterans used large amounts of insect repellents, such as DEET. Despite the evidence of exposure to multiple environmental contaminants and the claims of illness from over 100,000 veterans and spouses, the United States government still refuses to sanction Gulf War Illness as a legitimate medical condition.

This study merges social constructionist perspectives of illness with the study of environmental problems. Definitions of illness are socially constructed and those with the greatest power and organizational resources are the primary guardians of widely accepted definitions. Gulf War Veterans are fighting for an official recognition of Gulf War Illness. The government, however, controls VA policy on claims of Gulf War Illness and has the most power to shape public perception. The struggle to legitimate Gulf War Illness indicates that the mobilization of organizational resources is important not only among claimsmakers, but also among organized opposition (see also Lowney and Best 1997).

This research suggests that, as in the case of Agent Orange, the government utilized a number of organizational resources, including control of the medical establishment, to deny the environmental illness frame associated with Gulf War Illness. Veterans are most vocal about the government's reluctance to accept medically based claims for disability compensation, and they note difficulties in accessing the necessary medical information needed to make such claims effectively. The veterans interviewed in this research believe that the government's refusal to sanction Gulf War Illness is based, in part, on its unwillingness to treat and compensate those affected. If Gulf War Illness is sanctioned the government would potentially be forced to compensate tens of thousands of veterans, spouses, and children.

Additionally, validating the authenticity of Gulf War Illness would pose additional threats to the government's legitimacy. The government is charged with protecting the public from harmful environmental hazards. If the government acknowledges that military personnel, or the general public, have been exposed to chemical and other harmful pollutants that make them sick, public confidence in the role of the government in safeguarding health will be negatively effected. The case of Gulf War Illness, as well as environmental illness in general, shows that the state has a stake in denying certain environmental illness frames, even at incipient stages of their development, to protect its interests. Moreover, the state holds the power of definition through its vast organizational resources.

Environmental illness deserves much more sociological analysis. Military personnel, as well as the general public, face increasing hazards associated with high-risk technologies. The social constructionist approach provides an excellent framework for examining the conditions under which environmental problems and illness claims become validated and/or suppressed. This analysis of efforts to establish a Gulf War Illness frame suggest that social control agents are critical to our understanding of environmental illness and the factors that shape its diagnosis and treatment.

ENDNOTE

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