Environmental Illness as a Practical Epistemology and a Source of Professional Confusion

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“Listen to the patient, he will tell you the source of his disease. Listen more closely and he will likely tell you how to cure him.” I heard something like that once in medical school.

(The first author’s family physician)

The confusing nature of MCS is reflected in the number of terms enlisted to describe it: environmental illness, chemical sensitivity, cerebral allergy, chemically induced immune dysregulation, total allergy syndrome, universal reactor syndrome, ecologic illness, chemical hypersensitivity syndrome, universal allergy, and, more alarming, chemical AIDS and twentieth-century disease. To simplify discussion we will use the terms multiple chemical sensitivity, or MCS, and environmental illness, or EI, to refer to the disease and the terms chemically reactive and environmentally ill to refer to the people living with the disease.

While the terms describing this medical condition vary, they converge on a number of common premises that together describe a nascent theory of the body and its relationships to the materials of modern life: office buildings, houses, shopping malls, yards and gar-
dens, common consumer products, and so on. Importantly, what medical science knows about the etiology, pathophysiology, and treatment of EI is derived from the stories the environmentally ill tell about their bodies. Stories are all we have at the moment because there are no agreed-upon criteria for defining EI as an official medical condition and, consequently, there is no consensus regarding appropriate diagnostic protocols or treatment regimens (Ashford and Miller 1991; Bascom 1989). On the second page of their recent collaborative report, the U.S. Department of Health and the Agency for Toxic Substances and Disease Registry (ATSDR) reported that the natural history of EI describes “diverse pathogenic mechanisms . . . but experimental models for testing them have not been established (Mitchell 1995, 2).

Thus, medical researchers and physicians who accept the possibility that MCS may be a legitimate physical disorder must listen closely to their patients’ efforts to explain what is wrong with their bodies. Attending to the stories of people in pain recalls the typical eighteenth-century dialogue between patient and doctor, which typically began with the question “What is wrong with you?” Today, however, as most of us know, a physician is more likely to ask “Where does it hurt?” reflecting her greater faith in sophisticated technology than in the commonsense reasoning of her patients (Foucault 1973, xviii).

But the symbols of medical technology are silent on the issue of EI. It is, rather, the phenomenology of MCS, the experiences and accounts of those living with the malady that are the primary source of knowledge about this nascent physical disorder.¹ A remarkable feature of the accounts collected for this book are their similarities, in spite of the fact that with a few exceptions the people interviewed do not know one another. Interviews with plumbers, accountants, pharmacists, postal workers, homemakers, marine captains, insurance salespeople, sugarcane workers, college professors, and others from all fifty states, with little more in common than that they all happen to be alive at the same time, consistently reveal common patterns. Discrete people, without recruitment ideologies typical of social
movements, are thinking about their troubles in an essentially similar manner.

One explanation for this uncoordinated convergence in the style and product of thinking about illness is the possibility that common changes in people’s bodies are shaping common thought processes. Other, arguably less sympathetic, accounts of this unorganized collective pattern are found in several academic discussions of the MCS phenomenon, including arguments that it is a form of hysterical contagion (Brodsky 1984) or chemophobia (Brown and Lees-Haley 1992). Complementing these psychosocial constructions is the unsettling idea that MCS is a pandemic outbreak of one of a number of faulty thinking disorders, including conditioned responses, symptom amplification, or displacement/avoidance activities (Simon 1995, 45; Simon, Katon, and Sparks 1990; Terr 1987).

The environmentally ill talk about a polysymptomatic disorder that starts with an acute or chronic exposure to chemical agents. Many of these agents are found in ordinary household and work environments in amounts well below recognized thresholds for toxicity. Following the initial sensitization experience(s) to a single chemical irritant, the body begins to express intolerance to an increasing array of unrelated irritants. A person with EI, for example, can react to volatile organic compounds emitted from gas stoves, dry-cleaned clothing, ammonia found in paper products, boron in cosmetics, phenol in air fresheners, and ethyl chloride in plastics, at doses that are magnitudes below those known to be dangerous. Ann became ill when she was exposed to formaldehyde in the new carpet in her office. A few days after the onset of her initial symptoms, she noticed that her body reacted adversely to her husband’s colognes, her housekeeper’s cleaning solvents, the painted wooden baskets hanging in her den, her laundry soap, and so on.2

The body’s increasing intolerance to ordinary, putatively benign places and mundane consumer products is a key feature of this illness and one that baffles most physicians. “We don’t dismiss these people, they are truly ill,” admits a prominent allergist and medical researcher

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who speaks for the majority of practicing physicians, “but batteries of chemical tests can’t pinpoint any specific sensitivity. Some are definitely allergic and we all agree that they are suffering, but we simply don’t understand the cause of the disease as determined by medical diagnosis” (Selner 1991, 2–3). Another sympathetic but discouraging assessment concludes that “there is no laboratory test that can diagnose MCS, no fixed constellation of signs and symptoms, and no single pathogen to isolate and transmit through a cell line. . . . Even worse, some chemicals are neurotoxic and may produce symptoms that resemble anxiety attacks or mood disorders” (Needleman 1991, 33). Still more pessimistic is a public health physician who concludes that at present what is known about MCS “is insufficient to recommend programs for preventive strategies” (Bascom 1989, 36).

Adding to an already complicated theory is a premise that bodies are vulnerable to extremely low levels of chemical exposures: “below exposure levels for various chemicals established by the government, and usually below exposure levels tolerated by most people” (Pullman and Szymanski 1993, 17). This a difficult premise to test, however. If exposure levels are orders of magnitude below those deemed medically permissible, measuring concentrations of chemicals in soil, air, or water is unlikely to yield any useful information. If the concentrations are lower than permissible levels, the question still remains, How are they adversely affecting these bodies? The question is currently unanswerable empirically, though MCS suggests a theoretical rationale: Is it not possible that some bodies are more sensitive than others? Is it reasonable to sort bodies into nonsensitive, sensitive, and “hypo-sensitive,” where sensitive bodies are more reactive than nonsensitive bodies, and hypo-sensitive bodies “are more sensitive than sensitive”? (Bascom 1989, 10; Ashford and Miller 1991). At least one person with EI now sorts his world into new categories: “I use to think in terms of people who are good on the one hand and bad people. Now I’m more likely to wonder whether this person is supersensitive like me or able to tolerate everything.”

Complicating an already complex theory, another premise of MCS is that each chemical irritant may trigger a different constellation of
symptoms in each person and that every system in the body can be adversely affected. Thus, combinations of body systems and symptoms interact geometrically, creating, at least theoretically, a seemingly endless configuration of somatic miseries (Pullman and Szymanski 1993, 17; Ashford and Miller 1991; Cullen 1987). Consider, for example, an abbreviated list of EI symptoms distributed by the Chemical Injury Information Network, an MCS support group. Among the sixty-two symptoms listed are sneezing, loss of smell, nosebleeds, dysphagia (difficulty in swallowing), dry or burning throat, tinnitus (ringing in the ears), hearing loss, hyperacusis (sound sensitivity), coughing, shortness of breath, hyperventilation, high and low blood pressure, hives, constipation, thirst, spontaneous bruising, swelling of heart or lungs, night sweats, insomnia, poor concentration, and depression (Duehring and Wilson 1994).

Robert loses his balance and becomes disoriented when he is around fresh paint, while Diane is likely to become nauseated and tired. Both manifest different symptoms when exposed to different chemical agents, challenging the biomedical assumption that each disease is caused by a specific aversive agent affecting an identifiable body system (Freund and McGuire 1991). Symptoms simultaneously involving multiple body systems, but affecting each differently, violate a foundational assumption of biomedicine that diseases are classed as specific pathological configurations (Kroll-Smith and Ladd 1993). A physician-researcher who frequently testifies against plaintiffs who claim to be environmentally ill and sue their employers for negligence in the management of a chemical work environment writes, “The persistence of symptoms, worsening of symptoms, and appearance of additional new symptoms during therapy attest to a pattern of fear of the everyday environment engendered by an unfounded perception of an environmentally damaged immune system” (Terr 1987, 693). A theory of chemically damaged immune systems, however, is only one of several pathophysiology theories of MCS, as we will see in chapter 5.

Finally, people with MCS are likely to ascribe to a treatment regimen that emphasizes avoidance and lifestyle changes rather than drugs, surgery, or other invasive therapies (Bascom 1989; Ashford and
Healing the body is specifically not an invasive procedure. Rather, healing begins with removing the offending substances from the body and working to keep those substances at a safe distance. Avoidance and self-discipline are key elements of successful coping. Avoidance measures can be as subtle as moving away from a person wearing hair spray or cologne to moving into an environment built specifically to reduce chemical exposure. Wimberly, a small town in central Texas, has gradually become a chemically free refuge for people with extreme MCS. While only a small number of the chemically reactive move to such special environments, most are forced into some form of social and spatial exile to successfully manage their symptoms.

Avoidance can also be more proactive. Increasingly, people who theorize their bodies’ relationship to environments using some variant of MCS try to persuade others to change their personal habits, approach employers with specific requests that would reduce their exposure to offending substances, and appeal to local, state, and national legislatures to create “safe zones” free of dangerous chemicals.3

A strategy of avoidance based on escape and one based on changing habits, ordinances, or the materials of production are effectively redrawing the boundaries between safe and dangerous places, though with varying social and political effects. Families who leave Los Angeles and move high into the Sierra Madres to escape a chemically saturated world are building alternative, “ecologically safe” communities; they are not, however, directly challenging society to change. A wife who refrains from wearing a “toxic scent,” an employer who moves an offending copying machine from a nearby office, and a county board of supervisors that passes an ordinance establishing a “fragrance-free zone” in the local courthouse are examples of social and legal accommodations to the environmentally ill who petition others to change. When others change, the environmentally ill stand a chance of living within society rather than merely surviving by escaping from it.

Whether they manage their symptoms by escaping society or chal-
lenging it, or some combination of the two, the environmentally ill are forced to carve up the meaning of space in a manner unfamiliar to most people. Thus, while their behavior can appear strange and untoward, perhaps insulting, to others, for them it is a reasonable response to the management of their symptoms.

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The exact number of people who claim to be environmentally ill is not known. The U.S. Department of Health and Human Services admits it cannot estimate their numbers (Samet and Davis 1995). Commonsense comparisons, speculation, and anecdotes are the fallback strategies for calculating the scope of the problem. The Labor Institute of New York notes: “While it is clear that a significant portion of the population is sensitive to irritants such as cigarette smoke, the percentage of individuals who are significantly affected by multiple chemical sensitivities appears to be much smaller” (Pullman and Szymanski 1993, 18).

Though it does not use the term multiple chemical sensitivity, environmental illness, or any of the other variants, the National Academy of Sciences (1987) suggests that between 15 and 20 percent of the U.S. population is allergic to chemicals commonly found in the environment, placing them at increased risk of contracting a debilitating illness. The National Research Council’s Board on Environmental Studies and Toxicology (1992) reports that “patients have been identified with a condition of multiple and often diverse symptoms that have been attributed to chemical agents in the environment” (5), though it does not specify how many.

Complementing this anecdotal approach to determining the breadth of the problem are several additional facts and figures that suggest that EI is more than a minor medical annoyance. A nonrandom survey of people who identified themselves as having MCS found sixty-eight hundred respondents (quoted in Ashford and Miller 1991, 5). The Chemical Injury Information Network lists multiple support groups for people with EI in forty-four of the fifty states. Support
groups also meet in Finland, Germany, Australia, Canada, Denmark, New Zealand, France, Mexico, Belgium, and the Bahamas. We identified twenty-nine newsletters circulating in the United States devoted to chemicals, bodies, and the environment.

The range of demographic groups reporting the symptoms of MCS suggest it is a pandemic problem:

A review of the literature on exposure to low levels of chemicals reveals four groups or clusters of people with heightened reactivity: industrial workers, occupants of “tight buildings,” . . . residents of communities with contaminated soil, water, and air, and individuals who have had… unique exposures to various chemicals. (Ashford and Miller 1991, 3)

This list implies that everyone is susceptible to the ravages of MCS. There is some evidence to support this unsettling idea.

Industry groups estimate that over a third of new and remodeled office and storage buildings harbor indoor air pollutants sufficiently toxic to increase employee absenteeism by as much as 20 percent (Molloy 1993, 3). In addition to the building materials themselves, the Occupational Safety and Health Administration counted a minimum of “575,000 chemical products . . . used in businesses throughout the U.S.” (Duehring and Wilson 1994, 4; see also U.S. Department of Labor 1988). In 1989 the U.S. Environmental Protection Agency estimated that employers lose approximately sixty billion dollars a year to absenteeism caused by building-related illnesses (cited in Molloy 1993, 3). Not every victim of a “sick building” becomes environmentally ill, of course, but “bad air” at work is a common explanation for the origin of chemical reactivity among the environmentally ill.

But the workplace is not the only source of El. Aerial pesticide spraying, incineration practices, and groundwater contamination are among the causes of MCS in neighborhoods and communities (Ashford and Miller 1991). In addition, the U.S. Environmental Protection Agency reported that one in four people in the United States live on top of, adjacent to, or near an uncontrolled hazardous waste site (1980; see also Szasz 1994).
Finally, consider a series of troubling statistics culled from several sources:

- In 1940 the annual production of synthetic organic chemicals in the United States was 2.2 billion pounds. By 1991 it had increased to over 214 billion pounds, an increase of 200 percent in fifty years (National Research Council 1991, 21).
- “The EPA’s Office of Toxic Substances is called upon to review approximately 2000 new chemical products a year” (Duehring and Wilson 1994, 4).
- The EPA can ensure the safety of only six out of six hundred active pesticide ingredients under its control (Duehring and Wilson 1994, 10).
- Less than 10 percent of the seventy thousand chemicals now in commercial use have been tested for their possible adverse effects on the nervous system and “‘only a handful have been evaluated thoroughly,’ according to the National Research Council” (Duehring and Wilson 1994, 4).
- The EPA has identified over nine hundred volatile organic chemicals in ordinary indoor environments including offices and houses (reported in Delicate Balance 1992, 9).
- Finally, an EPA Executive Summary on chemicals in human tissue found measurable levels of styrene and ethyl phenol in 100 percent of adults living in the United States. The Summary also found 96 percent of adults with clinical levels of chlorobenzene, benzene, and ethyl benzene; 91 percent with toluene; and 83 percent with polychlorinated byphenols (Stanley 1986).

There is, in short, ample opportunity for individual exposure to a seemingly endless parade of chemicals whose effects on the body are simply not known.

While it is not possible to know with any certainty how many people claim to suffer from MCS, it is reasonable to assume the number is substantial and growing. At the very least, it is possible to imagine how a person might link an array of bizarre and debilitating symp-
toms to a disease theory based on a premise that the body is exposed to an extraordinary number of chemically saturated environments.

**EI and the Profession of Medicine**

People with MCS are theorizing what makes them sick, how specifically their bodies are changed (immune system, limbic system, and so on), and what can be done to decrease or manage their symptoms. When they speak of MCS, there is often a tone of certainty in their voices. While certain, they are not arrogant, however. The surety of knowing is typically accompanied by self-doubt, anger, fear of the future, and other troubling emotions. While a chemically reactive person is reasonably confident in his theory of what is wrong with his body, why, and how he can manage his symptoms, MCS is not recognized by the profession of medicine as a legitimate physical disorder.

Indeed, medical professionals are likely to admit that currently what they do not know about MCS is considerably more than what they know. A physician’s report to the Maryland Department of the Environment on the problem of EI, for example, is primarily a list of things medicine does not know about this nascent disorder, herein called chemical hypersensitivity disorder, or CHS.

- There is no single universally accepted terminology for or definition of CHS.
- There is no known cause of CHS.
- There is no prognosis for individuals with CHS.
- There are no criteria or procedures for reporting sensitivity disorders as diseases.
- There are no prevalence studies of CHS.
- It is not known if the incidence or prevalence rate of CHS is increasing.
- A “risk profile” for CHS does not exist.
- Educational materials on the subject of CHS are limited, and it is not possible to determine the accuracy of the information that is available. (Bascom 1989, 2–19)
Not surprisingly, the author concludes her report by observing that not enough is known about CHS “to recommend programs for preventive strategies. . . . There is no consensus as to the cause of CHS, the appropriate medical treatment, or the appropriate policy approach” (36–37). The U.S. Department of Health and Human Services concurs: while an increasing number of people are defining themselves as environmentally ill, the definition of MCS “is elusive and its pathogenesis as a distinct entity is not confirmed” (Samet and Davis 1995, 1). An occupational medicine researcher expresses his frustration over this elusive problem: “If the question cannot be answered as to what MCS is, how can there be approval of research protocols or acceptance of investigative results? In order to appropriately address the controversies surrounding this phenomenon we must know where we’re going!” (DeHart 1995, 38).

The first official recognition of MCS was probably a 1985 report by the Ad Hoc Committee on Environmental Hypersensitivity Disorders (1985) in Toronto, Canada. Two years later Dr. Mark Cullen, a medical researcher at Yale University, published a definition of MCS based on his observations of people exposed to chemical irritants at the workplace. While his definition is the most frequently cited in the biomedical literature, it clearly expresses biomedicine’s uncertainty regarding this nascent disorder:

Multiple chemical sensitivities is an acquired disorder characterized by recurrent symptoms, referable to multiple organ systems, occurring in response to demonstrable exposure to many chemically unrelated compounds at doses far below those established in the general population to cause harmful effects. No single widely accepted test of physiologic function can be shown to correlate with symptoms. (Cullen 1987, 655)

The biomedical research community is divided over the meaning of MCS and the numbers of people who have it. For some researchers, “evidence does exist to conclude that chemical sensitivity [is] a serious health and environmental problem and that public and private sector action is warranted at both the state and federal levels” (Ashford and Miller 1991, v). For others, however,
a great deal more research is needed before there will even be a consensus on a definition of chemical hypersensitivity. It is premature to classify CHS [chemical hypersusceptibility] as a purely environmental problem. . . . Health related environmental standards are based on normally accepted exposure units. They do not take into account individuals who may be sensitive to chemicals at limits far below the norm, perhaps at undetectable limits given current technology. (Maryland Department of Environment, letter to Governor Donald Schaefer, in Bascom 1989)

In striking contrast to the difficulty of the biomedical research community in reaching agreement on the meaning of MCS, the clinical medical profession speaks with one voice in rejecting the legitimacy of this proposed disorder. From its perspective, MCS is a fugitive, hopefully transitory, concoction of beliefs with no rightful claim to legitimacy.

Local medical boards reportedly threaten to censure physicians who diagnose people with MCS (Hileman 1991, 27–28). National medical societies, including the American Academy of Allergy and Immunology (1989), the American College of Occupational Medicine (1990), and the American College of Physicians (1989) officially deny the reality of MCS as a physical disorder and caution physicians not to treat patients “as if” the disease existed. The executive committee of the American Academy of Allergy and Immunology could be said to speak for the other professional medical societies in its position statement on MCS:

The environment is very important in the lives of every human being [sic]. Environmental factors, such as chemicals and pollutants, have been demonstrated to influence health. The idea that the environment is responsible for a multitude of human health problems is most appealing. However, to present such ideas as facts, conclusions, or even likely mechanisms without adequate support, is poor medical practice. The theoretical basis for ecologic illness in the present context has not been
established as factual, nor is there satisfactory evidence to support the actual existence of . . . maladaptation. (quoted in DeHart 1995, 36)

The California Medical Association reported that “scientific and clinical evidence to support the diagnosis of environmental illness is lacking” (1986, 239). The report went on to argue that evidence supporting the existence of a low-level chemical etiology to such health problems is based on hearsay and anecdote, not controlled clinical trials (243). A study published in the New England Journal of Medicine found the clinical testing for MCS to be seriously flawed and the typical environmentally ill patient to be unusually stressed and personally unhappy (Jewett, Fein, and Greenberg 1990). In a report prepared for the State of Maryland, a health policy analyst summarized the hostility of the medical profession toward a biomedical interpretation of EI, observing that the “controversy surrounding the chemical hypersensitivity syndrome begins with a debate as to its very legitimacy as a distinct entity” (Bascom 1989, 8).

Results from a survey of physician members of the Association of Occupational and Environmental Clinics—the one medical society most likely to be sensitive to people who claim they are suffering from MCS—are also worth considering. First, the survey found that only 9 percent of the physician population believe EI is predominantly physical in origin. Sixty-four percent, on the other hand, believe it to be a psychological disorder (Rest 1995, 61). With this bias toward a psychogenesis model of MCS, we should not be surprised to learn that occupational physicians were more likely to consult psychiatrists and psychologists when treating a patient who theorized his misfortune as MCS (63). Similarly, 64 percent of the occupational physicians reported referring people who claim to be chemically reactive to psychologists or psychiatrists. Fifteen percent did so “always,” while 49 percent did so “at least half the time” (65).

A report in the Annals of Internal Medicine labeled people claiming to suffer from MCS a “cult” (Kahn and Letz 1989, 105).4 Adding insult to injury, an allergist reports that he can reduce the symptoms of
the disorder by “deprogramming” patients who internalize “environmental illness beliefs” (Selner 1988). A psychiatrist writes: “In the absence of objectively verified abnormalities detected in physical examination, the illness is subjective only. . . . Multiple Chemical Sensitivity constitutes a belief, not a disease” (Brodsky 1984, 742). A study of twenty-three people who identified themselves as environmentally ill found fifteen of them suffering from a mood, anxiety, or somatoform disorder (Black, Rathe, and Goldstein 1990). The authors of this study, published in the Journal of the American Medical Association, conclude that all people with EI “may have one or more commonly recognized psychiatric disorders that could explain some or all of their symptoms” (3166).

Finally, Gregory Simon, another psychiatrist and coauthor of a well-known article on MCS, “Allergic to Life: Psychological Factors in Environmental Illness” (Simon, Katon, and Sparks 1990), argues that MCS is simply a product of faulty reasoning. Recalling the classic anthropological question, “Can ‘primitive’ people distinguish fact from fancy or do they muck around in a hodgepodge of spirits, sprites, myths, and legends?” Simon and colleagues label the environmentally ill victims of, simply put, bad reasoning. Like Lévy-Bruhl’s primitive, they cannot discern what is real from what is imaginary. Thus for some experts MCS is a result of behavioral sensitization. People associate a smell or taste with a physical symptom, in spite of the fact that there is no clinical relationship between the two. For others, MCS is a consequence of a tendency to react unreasonably to physical symptoms such as a sore throat or a rash. Investing too much attention in these symptoms, they search for causes and find them in the local environment. Finally, for still others MCS is a result of a faulty mode of reasoning perhaps best called “displacement confusion.” Here a person avoids thinking about the “real” causes of physical distress, unhealthy lifestyles, excessive stress, and so on, and focuses instead on modern culture’s overconcern with the environmental causes of disease (Simon, Katon, and Sparks 1990; see also Simon 1995, 45).
What are we to make of this confusing array of biological and psychological accounts of EI? Those in the medical research community are more sympathetic than their counterparts in clinical medicine to the idea that MCS is a legitimate medical disorder. But research on MCS is just beginning. Indeed, as we write this book, there is not even a commonly accepted case definition of the problem. Thus medical researchers are still debating the essential question: What is it? The clinical medical community appears to be ahead of its research colleagues, at least in knowing what MCS is not. It is not a legitimate physical disorder. While there is some confusion over what MCS might be—a belief, a cult, a psychiatric disorder, or a process of faulty reasoning—it is not recognized as a physical disease by the medical profession.

Thus, what happens when a person who has been closely monitoring his body, matching symptoms with environments, and organizing his local world to make some sense of his distress visits a physician trained to look beyond a patient’s account and examine the body as the source of disease?

**Doctors, Patients, and Paradigm Disputes**

When physicians receive patients’ complaints, it is their professional responsibility to translate them into a language that is created and controlled by the normal science model of medicine. Although they use the most sophisticated medical technology and are guided by the cultural authority of biomedicine to “define and evaluate their patients’ condition” (Starr 1982, 16), most physicians who treat the environmentally ill fail to heal them.

Imagine the physician presented with a patient such as Howard, complaining of nasal obstruction, sinus discomfort, chest pain, flushing hives, itching eyes, loss of visual acuity, fatigue and insomnia, genital itch, and nausea. Imagine that no accepted tests of organ system function can explain the symptoms. Imagine also that the patient is nonreactive to any conventional treatment plan the physician pre-
scribes. The complaints persist. Finally, imagine that the patient has a theory that explains the origins of the symptoms, but that such a theory does not correspond to any of the accepted etiologies within the biomedical model. It is not unreasonable to assume that patient and physician will tire of this cycle of frustration. The physician might suggest another doctor, or the patient might simply give up and go elsewhere. Whatever happens, the bioscience model of medicine has failed to provide the means for the patient to act like a patient and the doctor to act like a doctor; that is, the physician did not heal and the patient did not recover. If the enactment of biomedicine occurs at the moment its body of knowledge encounters a body, the body of the environmentally ill obscures that moment and effectively prevents the encounter.

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Why is the profession of medicine unable to certify MCS as a legitimate physical disorder? Perhaps it isn’t one. That is the simplest answer. It is more complicated and more interesting, however, to consider MCS as a theory of the body and the environment that contests both the medical profession’s responsibility to define bodies and several of its paradigmatic assumptions about disease.

First, medicine works closely with the state to define and regulate bodies in the interest of cultural and capital production (Foucault 1973; Turner 1995). Capitalism in the waning years of the twentieth century is interested in bodies insofar as they are able to work and consume, and do so in a flexible manner (Martin 1990; Harvey 1989). The healthy body, in other words, is one that goes to work regularly, purchases and consumes the products of its or others’ labors, and is capable of adapting quickly to changing modes of production and skill requirements. A putative somatic disorder that denotes change in the definition of the body in its relationship to common consumer products and domestic and workplace environments, therefore, is likely to be scrutinized closely before it is officially recognized as a disease. The environmentally ill body is, of course, anything but flexible.
But something more basic than an abstract political economy is at work here.

Howard’s unfortunate predicament suggests that a formidable problem for attending physicians is the result of the limitations of their diagnostic technologies in certifying something called MCS. Medical technology is built to measure and test the assumptions of the biomedical model. Among the many assumptions in this model are two that are particularly relevant to MCS. From classic toxicology comes the supposition that a relatively small number of individuals are sensitive to low, but nevertheless measurable, exposures to certain toxins. From allergy comes the classic IgE-mediated responses by atopic individuals with overactive antibodies that mistake ordinary environmental stimuli (ragweed, pollen, dust, and so on) for poison. What the biomedical model does not assume, however, is a third, entirely different, type of sensitivity.

A principal characteristic of MCS is that after the initial sensitization, there is no identifiable threshold or exposure level below which there is a negligible risk of becoming sick (Davis 1986, 12). People who identify themselves as environmentally ill report that an acute or chronic exposure to chemicals sensitizes their bodies to respond adversely to extremely low, subclinical exposures to a seemingly endless array of unrelated chemical compounds. (The term subclinical is used here to denote the absence of a diagnostic technology capable of identifying the quantity of chemicals that purportedly change the bodies of the chemically reactive.)

Canada’s Ministry of Health concludes in a report on MCS that “affected persons have varying degrees of morbidity and no single laboratory test including serum IgF is consistently altered” (Davis 1986, 35). Acknowledging this limitation, the National Research Council (1992) concludes quite simply that the “symptomatology related to multiple chemicals is a distinct feature of [EI] patients that is not classifiable by existing criteria used in conventional medical practice” (5). Multiple chemical sensitivity, in other words, is a medical anomaly; and like all scientific anomalies it is approached as an “untruth, a
should-be-solvable-but-is-unsolvable problem, a germane but unwel-
come result” (Mastermind 1970, 83).

But MCS is more than an awkward fact for the profession of med-
icine. Indeed, medical anomalies are common. At this time, for ex-
ample, the etiologies of Sjögren’s syndrome and idiopathic pulmonary fibrosis are simply unknown and treatments difficult to prescribe. A new strain of tuberculosis is resisting proven antidotes and spreading to dangerous levels in urban areas. And AIDS continues its deadly course, labeled but eluding cures. But most medical anomalies, includ-
ing those just mentioned, are puzzles whose solutions will not change the cultural definition of the body. Multiple chemical sensitivity, on the other hand, is more a mystery than a puzzle. If a puzzle is a game to exercise the mind by encouraging a search for the solution, a mys-
tery admits of no solution unless the rules of the game itself are changed. More than a puzzle or awkward fact, MCS would change the rules of the game by changing what is known about bodies and supposedly safe environments.

At the heart of this undecided battle are the environmentally ill, challenging the received wisdom about the body by linking their somatic disorders to rational explanations borrowed from the profes-
sion of medicine. It is not, in other words, the languages of the occult, New Age, or Eastern philosophy that are adopted by the chemically reactive to interpret their somatic misery. It is not crystal therapy, homeopathy, past-life regression, or obeisance to self-appointed gurus that serves as a resource for knowing. Rather, these individuals are apprehending their bodies using the rational, Enlightenment language of biomedicine. If Carl Sagan (1996) truly laments the modern revolt against science and the resurgence of a “demon-haunted world,” he should be pleased to hear of ordinary people who are struggling to know something logical and reasonable about their bodies.

The environmentally ill are likely to apprehend their somatic mis-
ery using the technical language of biomedicine rather than some vari-
ation of New Age knowledge for at least one rather obvious reason: they experience their bodies changing in the presence of consumer items commonly regarded as safe and in ordinary environments com-
monly regarded as benign. Consider, for example, the following field note describing an incident that occurred during an interview with a person who claims to be environmentally ill:

I sat roughly twenty feet from Jack. We were in his living room. Jack’s house is set up for someone who is environmentally ill. Air-filtering machines are running in several rooms. Magazines, newspapers, and other printed materials are noticeably absent. A plastic housing covers the TV screen to block harmful low-level electromagnetic waves emitted from the picture tube.

I am properly washed and attired. (That is, I showered without using soap and am wearing all cotton that has been washed dozens of times.)

Shortly after starting the interview, Jack became visibly agitated, lifting himself from side to side and up and down in his chair. Red blotches appeared on his arms and face. He started to slur his words. He explained that he was reacting to something new in the house. Since I was the only new thing around, he started to ask me questions: Was I wearing a cologne? Was I wearing all cotton? Could I have washed my clothes using a fabric softener? And so on. With the exception of the cotton question, I answered “no” to each query.

His symptoms were increasing in severity. He looked at my pen and asked if it contained a soy-based ink. I told him I bought it at a bookstore without checking the chemical composition of the ink. He smiled knowingly and asked me to put the ink pen outside. Within a few minutes his symptoms subsided.

The question is not whether Jack’s body changed in front of me. It did. The question, rather, is how to interpret the change. Using a process of elimination, Jack concluded that the one foreign item in his house responsible for his somatic distress was an ordinary ballpoint pen. Remember, the distance between Jack and the pen was approximately twenty feet. I asked him to explain how he knew the cause of his symptoms was the pen and how an ink pen that was twenty feet away could affect him so seriously. He told me about the synthetic chemicals in ink and their particular effects on him. He explained how the air circulator in the living room was pointing at my back and fac-
ing him. Thus, it blew the offgassing ink from the point of my pen toward him.

Jack’s carefully thought-out explanation of his somatic distress struck me as interesting, if debatable. Every move in his “first-this-and-then-that” style of reasoning is grounded in a testable assumption. And Jack was not surprised when his symptoms subsided after the pen was removed from the house. “What else could it have been?” he reasoned. Jack is in the habit of theorizing his illness by constructing what for him and, at least some, others are reasonable accounts of the causes of his misery. For Jack, theorizing his illness in a language of instrumental rationality allows him to explain his body to others and, importantly, allows him to live with some degree of self-respect in a very sick body.

For some people, however, Jack’s story is questionable, indeed bizarre. He tells a fantastic tale about bodies and environments. Moreover, he requests that others modify and change what have always seemed benign, if not aesthetic or pleasurable, behaviors. If they do not do so, they are implicated in the exacerbation of his illness. His spouse, a friend, the teller at the corner bank, an office mate, a sociologist who requests an interview, and even a complete stranger become potential sources of acute, debilitating distress; once safe, innocuous places are now health risks. Jack approaches his new life as environmentally ill armed with an explanation of his body and its complicated relationship to common consumer items and local places.

For Jack, MCS is not only a chronic sickness; it is a vocabulary of motives, a type of “justificatory conversation” (Mills 1967). The “truth” of Jack’s story can be measured in the degree of accommodation people make to his disabled body. The success of the environmentally ill in convincing others of the threat to health posed by mundane environments and ordinary consumer items, while also claiming the right to institutional recognition of their sickness, depends, as we will see, on the ability to borrow liberally from the vernacular of biomedicine to lobby for the transformation of their illness experiences into an official disease.
What is true for Jack is true for thousands of people living with bodies they believe are made sick by the environment. Multiple chemical sensitivity is a nascent theory of bodies and environments. It is a novel form of theorizing the relationships of people, bodies, and environments that unhinges an expert knowledge from an expert system and links it to historical and biographical experience to make a particularly persuasive claim on truth. It is a local knowledge, constructed in situ by people who believe they need to reorganize how they think about their bodies and the environments that surround them. Power may be a source of knowledge in a post-Enlightenment world, as Foucault announced, but rational knowledge nevertheless remains a powerful social resource. Indeed, if modernity has a commandment it is to act in accord with reason. Rational knowledge is always an assertion of the correct, the logical, the appropriate. If something is accepted as true, then rational organizations and human beings are expected to organize their conduct to reflect this truth. Rational knowledge “is always a legitimating idea” (Wright 1992, 6). In fact, it is self-legitimating insofar as its claim to truth rests on the premise that “all that is real is rational, [while] all that is rational is real” (Lyotard 1992, 29). Thus, to accept someone’s account as rational is to tacitly commit to the line of conduct and belief embedded in that account, or to risk the charge of behaving irrationally.

Society places a particular premium on the authority of rational knowledge to regulate nature and health (Wright 1992; Touraine 1995; Freund and McGuire 1991). Knowing nature, including the nature of the body, depends upon a detached observer trained to identify by means of calibrated instruments the intricacies of biological and physical systems. It is not surprising, therefore, that the privilege of theorizing the body and its relationship to the environment is limited to people educated and licensed by the state to speak the language of biomedicine.
It is the chemically reactive, however, and not the medical profession, who are classifying and explaining their anomalous medical condition. People who identify themselves as environmentally ill are shifting the social location of theorizing bodies and environments from medical professionals to nonprofessionals, from experts to nonexperts. When theorizing somatic distress in the language of biomedicine shifts from experts to laypersons, it enters a new social world, one governed by purposes other than institutional legitimation. Thus, when expert knowledge is separated from its institutional moorings and taken into another world, it is likely to be fashioned into a new cultural tool, or, as Geertz (1983) would have it, a “practical epistemology” (151). While Geertz leaves this term purposively vague, we will mean by it a technical, rational way of knowing that is responsive to the immediate personal and communal needs of nonexperts. A practical epistemology, in other words, joins the world of personal and biographical experiences to forms of instrumental rationality. Jack’s story of an ballpoint pen is a good example of a practical epistemology at work. The state-sponsored owners of biomedical knowledge most likely would dismiss his account as nonsense, if not evidence of delusion. Jack, however, borrows liberally from biomedicine and common sense to conceptualize and organize a world of signs that allows him to explain and respond to a body his doctors cannot understand.6

It is not a desire to engage the medical profession in spirited debate, however, that is motivating the environmentally ill. A person who confiscates the privilege of physicians to explain bodies in relationship to environments is thinking about something more elemental than an epistemological dispute, to wit, simple survival. “We are always searching for ways of explaining to others what we have,” acknowledges a woman with MCS, “and I guess . . . to explain to ourselves too.” An engineer with a long history of the disorder recalls that “at first it was a search for a vocabulary that could express what I, or I guess my body, was going through. Crazy-sounding words like ‘toxic toys’ and ‘VOC reactivity’ became a standard way of talking for me; and still is.” The efforts of the environmentally ill to find the words
necessary to apprehend their misery constitute one part of this study; the specific ways they use these words to alter the social landscape and change their life circumstances constitute the other.

The environmentally sick use their theories of the body and environment to ask others to understand their misery, alter their behaviors, allocate time and money, and, generally, change the world to accommodate their illness. Specifically, rational theories of chemical reactivity become rhetorical idioms for assigning moral significance to previously amoral behaviors or habits and traditionally inconsequential environments and consumer products. When a chemically reactive husband requests that his wife of twenty years refrain from using her usual dry skin lotion, she will probably ask him why. If we listen to his reply, we are likely to hear a biomedical explanation of the effects of such chemicals as butylene glycol or phenoxyethanol on his immune system or his central nervous system. Whatever the particularities of his response, he is likely to make a causal link between chemicals in the lotion and his somatic troubles. In this fashion, what he knows about his illness becomes a lingual resource for both managing his somatic distress and critiquing behaviors, products, and environments that are routinely defined as appropriate, safe, and benign.

In theorizing the origins, pathophysiology, and effective management of their illness, the environmentally ill understand why their symptoms intensify and subside in accordance with the presence or absence of mundane consumer items and the personal habits and practices of people around them. Knowing what makes them sick and learning to avoid debilitating symptoms are cognitive resources for personal survival. With these resources these individuals can inhabit bodies that are routinely out of control with some degree of self-assurance.

Among its many manifestations, MCS is a dispute over the privilege to render a rational, in this case biomedical, account of a disabled body and the peculiar content of that account. It is a dispute over the ownership of expertise. It is a story about how institutions learn in a historical period wherein nonexperts wield languages of expertise to
persuade influential others to modify their habits, regulations, and laws.

Narratives of the Environmentally Ill: 
A Word about Methods

It is said that human misery is bearable only if we can tell a story about it. Perhaps it is because each of us is a storyteller that our lives have a measure of coherence and clarity. Life without narrative would be discontinuous, formless, seemingly random. Narrators create story lines, linking occurrences and ideas into plots, and give time and space a linear order. Moreover, “Personal experience must be assigned a central role in accounting for the understandability,” and, we would argue, origin, “of theoretical categories and concepts” (Calhoun 1995, 86).

Except for those whose symptoms are truly severe, who cannot write or talk without considerable discomfort, most people with MCS are willing to talk about their distress. To learn about the experiences of the environmentally ill, the first author attended an environmental illness support group for approximately ten months and conducted separate interviews with each of the four members who regularly attended the group. Each person was interviewed on several occasions, and a biography of his or her illness experience was constructed. Illness biographies were written in this fashion for twelve additional people with MCS who were not members of this support group.

To provide a rough check on the reliability of these illness biographies, we subscribed for two years to four nationally circulated newsletters distributed by organizations for the environmentally ill: Our Toxic Times, the Wary Canary, the New Reactor, and Delicate Balance. We searched these documents for personal accounts of the origins of the illness, its pathophysiology, and suggested treatment regimens. Comparing the newsletter accounts with our illness biographies, we found striking similarities in the interpretive strategies people use for understanding their bodies and environments. Next, we
examined two biographies written by people with EI (Lawson 1993; Crumpler 1990) and again found considerable overlap in the types of explanations typically used to make sense of bodies unable to live in ordinary environments.

Reasonably confident that the patterns of theorizing MCS discovered in the initial interviews and confirmed in newsletter accounts and biographies were generalizable to the population of people who are chemically reactive, we obtained the membership directory of the Chemical Injury Information Network. While no list can be representative of the universe of the environmentally ill, this directory is the most exhaustive list we found, and perhaps the most exhaustive list in existence. It identifies people with MCS in every state of the Union and eleven foreign countries.

We constructed a simple, open-ended questionnaire designed to solicit information on how people experienced the illness and what specifically they thought about it. We mailed this questionnaire to seventy-five people listed in the membership directory. We also asked several newsletters to print a short notice announcing our study and directing people who were interested in participating to write or call. Between the seventy-five questionnaires mailed to directory addresses and the appeals in the newsletters, we obtained an additional 147 interviews. The quality of these interviews varied. Some people responded in short, curt sentences to each question, making it difficult to learn much from their answers. Responses to 42 interviews were too cursory to be of much help.

Other people wrote between ten and twenty pages—essays steeped in reflection and pain. Still others answered the questionnaire in five to ten pages. Narratives of this length were brimming with insights into how people organized their thoughts to apprehend their miseries. Through this technique we obtained 105 interviews. Combined with the 16 interviews we conducted during the first several months of work, we collected a total of 121 usable interviews.

In addition to the interviews, we searched Med File and other library databases for medical studies of MCS. We also purchased the
Chemical Injury Information Network’s bibliography on toxic chemicals and human health, which contains 1,106 entries. These secondary materials were also treated as stories of the illness.

Finally, we took our emerging conclusions back to several of the environmentally ill to ask for their comments. While a few people did not see the political importance of this type of work, expressing some disappointment that it was not a forthright call for public support, others found our story personally affirming, validating their hard-fought claim to know something important about modern bodies and environments. We are pleased to report that no one with EI who commented on our story disagreed with it.

While it is the stories of the environmentally ill that interest us, we are ever mindful of the importance of these stories to the identities of the narrators. And we are also mindful of the importance of these stories to the success of this project. The real strengths of this book are not found in our abstract musings (though we hope some readers find them useful) but in the compositions of the environmentally ill, their often insightful and always revealing accounts. We were privileged to hear and read these stories and report them in this book.

Chapter 2 continues our discussion of MCS, practical epistemology, and social critique. It develops further the conflict between the environmentally ill and the medical profession, and places this conflict in a broader historical movement identified by Alain Touraine as the return of the Subject (1995).