Bodies in Protest

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Published by NYU Press


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In the early nineteenth century, the air of European cities was thought to be the source of infection and disease. The word *miasma* entered popular conversation and meant, quite literally, dangerous, deathlike air. It was not acute toxicity that disabled the person, but noxious exhalations from open sewers and industrial effluents that together worked in a slower, more villainous fashion. Urban air was characterized as particularly sinister, and people prone to illness were advised to spend as much time in the country as their resources would permit (Sontag 1989).

In 1880 the American neurologist George M. Beard identified a pattern of symptoms he called “neurasthenia” or “American nervousness.” The reported symptoms included fatigue, short-term memory loss, and sore joints and muscles, among others. The etiology of neurasthenia, Beard argued, was none other than technological progress itself, namely, steam power, the printing press, and factories (Hileman 1991, 30).

The idea that fouled air or the achievements of modernity were the sources of disease was successfully challenged, however, by Pasteur and Koch, who discovered the role of germs in the cause of many illnesses (Dubos 1959). By the twentieth century, the medical community had abandoned the miasmic theory in favor of the germ theory. The subsequent development of the biomedical paradigm shifted attention away from an exogenous theory of disease, and an etiology that located disease origins in the physical, social, and spiritual environments, and toward an endogenous theory that located disease
inside the body (Dubos 1959; Young 1976; Freund and McGuire 1991).

In the late twentieth century, however, the idea of sinister air has returned in the form of a nascent physical disorder called, among other things, environmental illness, and multiple chemical sensitivity. A growing number of people claim to be “chemically reactive.” They firmly believe they are suffering from a disease caused by low-level, indeed subclinical, exposures to synthetic and nonsynthetic chemicals found in putatively safe environments. Living rooms, bedrooms, offices, stores, churches, parks, and other seemingly benign and predictable habitats are increasingly identified as chemically contaminated and pathogenic. If built environments and the products typically found in them are sources of pleasure, comfort, and symbols of success for most of us, for the chemically reactive they are often perilous worlds of debilitating health risks.

Expressed in the bodies of the environmentally ill is a blurring of the recognized boundaries between safe and dangerous places. Environments, of course, might well be a source of debilitating disease, but they are commonly recognized as extreme places, strikingly and conspicuously dangerous: a toxic spill, a munitions explosion, or a nuclear accident, for example. The immediate task here is to remove the body from the extreme environment to a nonextreme, safe place. The troubling message of the environmentally ill, however, is that what was once thought to be safe is now dangerous. Consider the words of a thoughtful essayist who suffers from this nascent disorder:

The contamination of our world is not alone a matter of mass spraying. Indeed, for most of us this is of less importance than the innumerable small-scale exposures to which we are subjected day by day, year by year. Like the constant dripping of water that . . . wears away the hardest stone, this birth-to-death contact with dangerous chemicals may in the end prove disastrous. Each of these . . . exposures, no matter how slight, contributes to the buildup of chemicals in our bodies and so to cumulative poisoning. (Lawson 1993, 30)
Thus the chemically reactive propose that disease is caused by more than nuclear accidents, toxic waste dumps, deadly mold spores, or DDT. For them, a seemingly endless array of environments and common consumer items are considered serious health risks. The stocked shelves of grocery stores, drugstores, and hardware stores pose immediate health risks. Churches and synagogues harbor caustic agents that threaten to overwhelm the body. Schools might be toxic. Hospitals are potential danger zones, brimming with hazardous effluents. Even birthday presents might be brightly wrapped threats. It is as if modern material culture lies in wait to ambush the body of the environmentally ill. Writing almost two hundred years ago, Jean-Baptiste Lamarck anticipated MCS when he observed: “We die when we ingest too much of the environment” (quoted in Crumpler 1990, 13).

Multiple chemical sensitivity is the latest evolution in a series of environmental warnings and technological accidents to occur in the latter decades of the twentieth century. In *Silent Spring* (1962) Rachel Carson wrote ominously of the perils of DDT and its effects on the biosphere. In the 1970s, labor demanded that management clean up the workplace and fairly compensate the victims of factory and shop floor injuries. The discovery of dangerous chemicals under a residential community in Niagara Falls, New York, in the late 1970s changed forever the public’s perception of parks, schools, and neighborhoods as environmentally safe. Love Canal alerted the nation to environmental dangers that were no longer limited to nature or industrial workplaces; now they could be found in backyards, basements, and playgrounds.

The nuclear accident at Three Mile Island, Pennsylvania, in 1979 highlighted the risks of splitting atoms to boil water. Massive cooling towers shaped, unsettlingly, like mushroom clouds, became icons of fear and distrust. The untold casualties from the Chernobyl nuclear fire in the Ukrainian republic of the former Soviet Union in 1986 confirmed the doubts and suspicions of many regarding nuclear energy. In 1976 twenty-nine people died of exposure to contaminated mold they inhaled while staying at a grand old hotel in Philadelphia. What
quickly became known as Legionnaires’ disease called attention to buildings as possible carriers of disease. The provocative phrase *sick building syndrome* soon entered popular conversation and increased further the number of potentially risky environments.

In the late 1980s and early 1990s EI emerged as a contentious health issue, exacerbated the debate over what are safe and dangerous environments, and provoked a political question: Who will control the definition of the human body and its relationship to the environment in the waning years of the twentieth century? This book examines this medical, social, and cultural conflict from the first-person accounts of the chemically reactive.

People with MCS narrate stories of their misfortune. They speak to themselves, to one another, and to those of us who do not dwell in their world of impairment. From our vantage point, EI begins with the simple idea that people who organize themselves around changes in their bodies are also organizing their minds to produce accounts of their miseries. Most of these accounts sound like biomedical theories of the body and its relationship to the environment. People who claim they are environmentally ill are theorizing the origins of their distress and its effects on the body, and are arguing for appropriate treatment strategies, using the complicated language of biomedicine. In this manner EI is a strategy for understanding a body that is becoming disorganized and unpredictable by providing it with a rational story to account for its untoward changes. Perhaps in theorizing its somatic distress, the self of the environmentally ill learns to live in a body that cannot live in putatively benign and safe places. Following the good advice of Susan DiGiacomo (1992), we will accord the voices of the sick people found in the pages of this book “an analytic status” (136).

This book is a story of bodies that no longer behave in a manner modern medicine can predict and control. It recounts the extraordinary efforts of people who inhabit those bodies to narrate plausible accounts of what went wrong. It is a story of ordinary people struggling to construct biomedical accounts of etiologies, pathophysiologies, and treatment regimens to explain and manage their debilitating
physical and psychological symptoms. It is, in short, the story of a struggle to wrest control of medical discourse from medical science and challenge the cultural definition of the body and its relationship to modern environments.

Our interest is in both the processes of classification, abstraction, and cause-and-effect reasoning undertaken by laypersons who are organizing a way of thinking about the strange changes in their bodies, and the products of these processes, the ideas themselves. Specifically, how do people whose bodies rebel in the presence of extremely low levels of putatively benign consumer products and environments fashion accounts of their misery? And, simply, what kind of body is embedded in their accounts? How does the environmentally ill body differ from the conventional biomedical body? How are the environmentally ill using their homespun theories to effect changes in the conventional, agreed-upon boundaries between safe and dangerous spaces? Finally, and closely related to the issue of safe and dangerous, how are important institutional others (friends, physicians, bosses, governments, and so on) responding to these accounts of bodies that no longer work properly? In short, it is not MCS as a medical reality that is the subject of this work. Our focus, rather, is on MCS as a biomedical account of imperfections in built environments and their debilitating effects on the body constructed by ordinary people who are frustrated and disappointed in the profession of medicine.

Multiple chemical sensitivity is a medical conflict that throws into stark relief the recent work of Anthony Giddens (1990), Ulrich Beck (1992, 1995), Alain Touraine (1995), and other theorists of late modernity. It is almost as if the environmentally ill are self-consciously dramatizing the crises and changes proposed in their work, although we venture to guess that neither the chemically reactive nor the theorists have heard of one another. The correspondences between abstract theory on the one hand and concrete human activities on the other is rarely so direct and unmediated.

Late modernity is a world populated by expert systems, expert knowledge, and an increasing awareness among ordinary people that
the world is an unpredictable and increasingly dangerous place (Giddens 1990; Beck 1992). Biomedicine is a good example of an expert system. It is a set of interrelated statuses and practices organized around scientific and technical ways of knowing that “systematically form the objects of which they speak” (Foucault 1973, 49). Theories of pathogenesis are confirmed by complex technologies designed to construct sick bodies and minds. Prescribed treatments are routinely founded on complex relationships between pharmacology and healing. It is physicians who enjoy exclusive access to this expert knowledge, and statutory authority gives their medical statements the power to create the objects of medicine.

Physicians, of course, are not interchangeable with ordinary persons. In the ideal world of the professions, “Medical statements cannot come from anybody” (Foucault 1973, 51). Ensuring that only licensed practitioners speak a language of expertise limits the use of expert knowledge to people whose identities and careers are linked closely to the interests of powerful elites. Thus, it is not surprising that expert knowledge is likely to be directed away from social criticism and toward regulating individuals. Medicine, in particular, locates individuals in the crosshairs of classificatory schemes and definitions that focus attention on their personal difficulties and shortcomings (Foucault 1973; see also Sontag 1989).

While states can use force to ensure compliance, most expert systems survive in part on the simple willingness of nonexperts to trust in their complicated and often mysterious powers (Giddens 1990). There are strong cultural pressures for people to follow the advice of their physicians, or at least not to resist receiving advice. People who narrate stories about bodies that are increasingly intolerant of ordinary places and things are routinely advised by their physicians to reduce the stress in their lives, or to medicate daily with allergy drugs, or to seek psychological or psychiatric help. The problem with this expert advice is, simply, that it doesn’t work. People remain sick or become even sicker when they follow their physicians’ recommendations.

Rather than rejecting biomedicine entirely, however, these people are appropriating the symbols of biomedicine—in effect, separating
the physicians from their language and shifting the site of biomedical theorizing from hospitals, clinics, and offices to kitchen tables, living rooms, and patios. The sick people encountered in these pages are not abandoning expert knowledge but they are moving away from the expert system. They perceive the need for expertise at the same moment they have lost faith in the experts and their administrative worlds.

What might happen to biomedical knowledge once it is separated from the profession of medicine and relocated in mundane, ordinary worlds? One thing seems certain: the constitutive authority of physicians to create and control the objects of medicine in the interests of the state is not likely to go unchallenged. Ordinary people exercising control over medical discourse are likely to bend and twist at least a few of its paradigmatic assumptions to fashion ways of knowing that help them explain their miseries. In theorizing their somatic distress, the environmentally ill, in particular, are locating the sources of their troubles outside of themselves, in the practices and habits of intimate and institutional others. They are claiming to know something biomedical about the body and environments that is at once an explanation of chronic somatic distress and a representation of imperfections in the body politic—at once, in other words, a theory and a social criticism.

Bodies do not talk, of course. We do. But bodies do make noises, tremble, break, change shapes, and act in unusual ways. In short, our bodies invite, if not demand, someone to speak for them. As bodies become increasingly exposed to environmental dangers whose immediate and long-term health effects are endlessly debated by experts, ordinary people are frequently compelled to speak for their own bodies. Problems with bodies and environments are challenging the orthodox boundaries between medical experts and lay forms of knowledge.

More generally, we might say that lay expertise is emerging as an alternative form of rationality, one that begins and ends with concrete human, indeed physical, experiences. A common denominator of these physical experiences, however, is their high degree of uncertainty, ambiguity, or, perhaps better said, mystery. If the cry “I am hungry” demands not reflection but concrete action, the cry “I am poisoned by
invisible chemicals whose presence is not detectable using standard monitoring equipment” is an occasion for reflection, deliberation, sorting out what is known from what is not known, testing, drawing conclusions, and checking them against some standard of validity (Beck 1992). Not surprisingly, the “I am poisoned . . .” mysteries must be transformed into puzzles, changing their status from things that cannot be known with certainty to things that can be figured out.

The chemically reactive are not the only people who find the rational explanations of legitimate medical authorities to be fuzzy and confusing, if not incoherent, accounts of their troubles. Multiple chemical sensitivity is an example of a broader populist revolt against the hegemony of expert medical systems in what Giddens calls “late modernity” and Beck calls the “risk society.” Participants in this revolt do not reject medical knowledge; rather, they refuse to allow it to be identified solely with the interests of state-sponsored professions. Participants, in other words, are likely to criticize the medical profession while appropriating its complex theories.

A recent article on the AIDS movement in the United States describes activists who

wrangle with scientists on issues of truth and method . . . [and] seek to reform science . . . by locating themselves on the inside. They question not just the uses of science, not just control over science, but sometimes even the very contents of science and the processes by which it is produced. . . . They seek to change the ground rules about how the game is played. (Epstein 1991, 37)

In a similar manner, citizens are claiming to know about “women’s health, fetal tissue research, and recombinant DNA research” (Epstein 1991, 36). The current controversy over the etiology of the unusual symptoms and diseases experienced by veterans of the Gulf War is pitting the ordinary soldier against the health machine of the Veterans Administration (see chapter 7). Workers are learning about accident rates and types of technology to argue for a safer workplace (Nelkin and Brown 1984). And the problems of chronic fatigue syndrome and
repetition strain injury are sending citizens to the libraries in search of answers physicians cannot provide (Lawson 1993; Bammer and Martin 1992). The problem of MCS joins a new class of hazards that are characterized by the absence of concrete, tangible measures of cause and effect, that are not apprehended immediately but require rumination, deliberation, cogitation—in short, the construction of abstract explanations, theories if you will.

Theorizing is a task normally assigned to scientists and intellectuals, while nonexperts are likely to improvise ways of knowing that occur well below the level of genuine theory construction (Berger and Luckmann 1966). Today, however, an increasing number of average citizens are appropriating the privileged voice of the theorist to construct coherent groups of general propositions to use as principles of explanation and persuasion. Consider Ulrich Beck’s (1992) rhetorical question:

Why shouldn’t laypeople—who are no longer what they used to be, namely, just laypeople, and who ultimately have to pay for all the benefits—ask questions that are forestalled by the false a priori of scientific theory, and in that way provide a critical supplement to the model of experimental testing? (55)

Problems of health and disease are only one example of a popular struggle to wrest control of a rational knowledge system from its institutional moorings and challenge society to change based on a claim to know something “true” or “scientific” about how the world works. Public hearing testimonies offered by citizens organized to define and control disposition of nuclear materials at the seventeen Department of Energy sites in the United States argue in the languages of nuclear engineering and toxicology for their version of appropriate cleanup criteria (U.S. Department of Energy 1991). Other citizens are mastering the intricacies of zoning and planning regulations to hold industrial developers accountable for various land-use initiatives involving hazardous or toxic materials (Couch and Kroll-Smith 1994; Minor 1994).
Human agency in liberal democracies has always depended on the ability of people to articulate their concerns and grievances using the discourses of civil rights. Today, however, what is just and unjust is often confounded with claims to know the world through categorization, calculation, and measurement. Civil rights, in other words, are increasingly dependent on the capacity of ordinary people to appropriate the languages of instrumental rationality and cast their arguments for equality and justice in the measured cadence of expertise.

Note, however, the distinction drawn here between acquiring expert knowledge and soliciting the counsel of experts. As people are becoming aware of their increasing dependence on expert knowledge they are also increasingly distrustful of experts. Perhaps this explains, in part, Beck’s observation that “monopolies on knowledge…are…moving away from their prescribed places” and found increasingly in popular arenas (1992, 154). In this new history, to modify Bauman, “one [must] steal the expertise and play with it, boldly, one’s self” (1993, 17).

In a provocative image of the problem, Ulrich Beck (1992) argues that society is changing from one in which “being determines consciousness” to one in which “consciousness determines being” (53). In the new society, class becomes less important in shaping thought and experience, increasingly displaced by the production of knowledge among confederates (arguably representing many classes) who define themselves as imperiled by unanticipated changes in the biosphere and unable to trust the opinions of experts. If consciousness, and not material circumstances, is shaping late-modern lives, it should also be recognized that somatic states and conditions are shaping consciousness, a point we will return to throughout this book.

Looking Ahead

Chapter 1 describes the conflict between the medical profession and the environmentally ill, paying particular attention to the difficulties physicians and medical researchers experience when they attempt
to define MCS. While the medical profession is skeptical and uncertain regarding the idea that bodies are changing in relationship to ordinary environments, for the environmentally ill, MCS is a practical epistemology—a strategy for knowing the world that works to reduce or make manageable a human trouble. Chapter 2 examines two essential ways of talking (technical and emotive) and how they are used by the environmentally ill to transform themselves from objects of biomedicine into active agents who are inventing and constructing bodies by the skillful use of an expert language. The image of science joined with biography is an uncommon one in our society and is important to our account of MCS as a practical epistemology. Finally, we introduce three descriptive processes that account for how people become disenchanted with experts, borrow expert languages, and seek public recognition of their troubles.

Chapters 3 through 5 use narratives of the environmentally ill to describe in vivid detail the problems of living with a contested disease that challenges not only the biomedical definition of the body but commonsense thinking about the relationship of bodies to environments. In these chapters we encounter the work people do to make their obscure bodies intelligible by locating them in theories of etiology and pathophysiology that lead often to effective treatment strategies. Following Geertz’s pragmatic idea, we refer to these local theories as practical epistemologies (1983, 151).

Chapters 6 and 7 shift attention from a phenomenological account of MCS to a consideration of its political and economic effects. Introducing the idea of representation, we look closely at those arenas of social and cultural life that are changing to accommodate and, in turn, recognize the chemically reactive body. To the extent institutional others are modifying routines or policies, passing legislation, or creating commodities to assist the environmentally ill body, MCS is becoming a disease in spite of the medical profession’s current refusal to acknowledge it. In the final chapter we suggest that the amount of interpretive space created by problems with bodies and environments is growing. By interpretive space we mean simply the room available
for theorizing. When citizens or laypersons step into this space, they appropriate the languages of expertise and join them to subjective, personal experiences to create an alternative rationality, at once a local and an abstract knowledge. A discussion of popular epidemiology suggests it is not only the individual body and environments that are opening up space for interpretation. Populations of bodies in the form of neighborhoods, communities, and so on are collectively proposing citizen theories of disease clusters and contamination.

Multiple chemical sensitivity and popular epidemiology are among a number of citizen science movements that are hinting at the emergence of a new history—not one they are making by themselves but one whose making they both illustrate and contribute to. This new history is neither modern nor postmodern. Modernity rested on a simple two-step formula: surrender the sovereignty of the personal, local, and subjective, and embrace the promises of abstract, rational knowledge administered by experts. Modernity offered little space for first-person stories. While they can entertain and are of some importance to social relationships or the occasional news stories—indeed, they are called “human-interest stories” in newspaper jargon—they could not be the basis for administrative decisions, legislation, or policy making. Postmodernity, it would seem, emerged to counter the formula for modernity by creating a privileged space for the personal narrative. In this society, self-stories displace expertise, which is shown to be just another self-story anyway, wrapped up in fancy language.

The environmentally ill and their counterparts in other citizen medicine movements are neither modern nor postmodern. They do not surrender their self-stories to the administration of medical expertise, as good moderns do; nor do they abandon this expertise to revel in the pure subjectivity of their stories, as good postmoderns do. Rather, they join the self-story to expertise, constructing narratives of their sick bodies using the complicated languages of biomedicine. In this fashion, MCS is a critique of both modernity and postmodernity and an invitation to revisit these important ideas as we think about the history we are making.
We wrote this book, in part, to make the environmentally ill more comprehensible than they now are—to make the “other,” we might say, familiar. We invite the reader to enter their world, stay a while, and recognize the possibility that our species survives in part by its irrepressible drive to understand the significance of things, though agreement on what is or what is not significant often eludes us.