

CHAPTER 9

Paradise Poisoned: Nature, Environmental Risk, and the Practice of Lyme Disease Prevention in the United States

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Susan is an artist who lives with her husband and son in a farmhouse in western Connecticut.¹ Her studio is located in a barn that is adjacent to the house. From the windows of both buildings, the windswept fields and surrounding woods create verdant tableaux that are her art's inspiration. When I interviewed Susan at her home in 2010, she had been undergoing treatment for Lyme disease since 1994, when she discovered a "bull's eye" rash on the back of her neck.² In addition to the toll that 16 years of ill health had taken on her, Susan described being haunted by the fact that she continues to live in an area where she and her family are at risk for getting more tick bites. She explained,

A part of me would like to just get the hell out of here; part of me would like to move where there are no ticks. That's just the worst thing about being here. It's awful, it's like a scourge. It has definitely changed how I understand nature. I love the country so much, but I'm not going to walk out in those fields. I only walk on mowed lawn. There's no careless running through the forest anymore.

This chapter, which draws upon 18 months of ethnographic fieldwork among Lyme patients, physicians, and scientists in the northeastern United States, explores the complicated relationship between how individuals in Lyme endemic areas understand their natural environment and the ways in which they understand and act upon their health.³ Unlike other infectious diseases, the viability of Lyme disease depends upon a natural ecology suitable to the habitat preferences of the blacklegged tick, small rodents, and deer. And because the transmission of Lyme disease to humans requires exposure to this landscape, Lyme and other tick-borne diseases draw unique analytic attention to contemporary ideas about – and practical engagements with – nature. The first section of this chapter provides a broad historical context for the production of an aesthetic of nature in the United States. Here, I suggest that because an American aesthetic of nature encompasses the affective spectrum between attraction and repulsion – nature is beautiful, in part, *because* it is frightening – the contours of Lyme disease can be better understood through what I call an *epidemiology of affect*. That is, who gets Lyme disease and why is more than just a matter of demographic and geographic correlations of risk; it is also about how Americans in Lyme endemic areas understand and act upon their competing feelings toward their natural environment.

The second section examines the underbelly of an aesthetic of nature in the United States: environmental risk. The task here is to identify what constitutes “the environment” and what part of that environment individuals in Lyme endemic areas find risky. I suggest that, for some Lyme disease patients, Lyme disease is just one risk in a constellation of environmental risks that can be broadly described as a toxic environment. That this is so points to a reality in which the environment is not confined to the “outside” and where individuals perceive environmental risk to exist on an almost indistinguishable continuum between the inside and the outside.

The third and final section ends with an exploration of the practical consequences – in this case, prevention practices – produced by the tension between an attraction to nature and an awareness of environmental risk in Lyme endemic areas. Drawing from Saba Mahmood’s Aristotelian-inspired work on “exteriority as a means to interiority,” I explore a range of emerging “bodily practices” related to tick bite prevention and how they shape ideas about nature and environmental risk (Mahmood 2005: 134; Lock 1993). Here, I argue that, in the lives of the people who enact them, the *effects* of tick bite prevention practices – what they incidentally happen to produce across relations – become more important than their efficacy, and these practices constitute the active building of new individualized environments, or what biologist Jacob von Uexkull terms “environment-worlds” (Agamben 2004: 40).

AN AMERICAN AESTHETIC OF NATURE

It is not a coincidence that, during his 2012 presidential campaign, candidate Mitt Romney often quoted lines from “America the Beautiful,” a song that celebrates “spacious skies” and “purple mountain majesties above the fruited

plain”: in the United States, nature has become inextricably linked with ideas of beauty *and* with what it means to be an American. Environmental historian Roderick Nash observes in his now classic text, *Wilderness and the American Mind*, that as “the basic ingredient of American culture,” nature has, since the late nineteenth century, been understood as “beautiful, friendly, and capable of elevating and delighting the beholder” (Nash 2001: 4). But this was not always the case. Prior to the 1800s and the emergence of Romanticism in Europe, nature was considered to be unsightly, without moral merit, and a threat to “civilizing” tendencies. One of the most compelling examples that Nash provides is that of the mountain. Now emblematic of natural splendor – reaching the peak of which is, for many, the true test of a nature-compatible constitution – mountains in the seventeenth century were, as Nash describes, “generally regarded as warts, pimples, blisters and other ugly deformities on the earth’s surface” and were, fittingly, given such names as “Devil’s Point” (Nash 2001: 45). However, under the Romantics’ eyes, the boundless unruliness of forests, crevasses, and mountainscapes became a means to transcendence. More critically, philosopher Kate Soper, in *What is Nature?*, argues that although nature had been represented as a duality between terror and serenity since the days of Homer, the Romantics’ representations differed in that, for them, the “chaos” of nature became “endowed with its own aesthetic appeal” (Soper 1995: 222).

Nash describes how, like their European counterparts, American pioneers and frontiersmen also perceived nature to be “cursed” and “ungodly.” As journals and other narratives attest, living in proximity to the wilderness was not perceived to be a source of pleasure or inspiration but rather a forced necessity. However, as Nash also describes, the ideological momentum generated by the Romantic movement in Europe gradually translated to changing understandings of nature in America. And, for a former colony like America, nature and the unique features of the American landscape quickly became a means by which to distinguish itself from Europe. This was especially true for Henry David Thoreau, who saw in American wildness a clean slate for national moral growth. In *Thoreau’s Nature: Ethics, Politics, and the Wild*, political theorist Jane Bennett observes that, from Thoreau’s perspective, “the milk of (American) Wildness flows freely, and this is, as we know, crucial to recrafting the self. The Wildness of the American wilderness is the condition of possibility of a new man, a ‘new Adam’” (Bennett 1994: 114). In the eyes of Thoreau, what America once had too much of, it now had in enviable quantity and in kind conducive to moral advantage.

While at the beginning of the nineteenth century many Americans distinguished themselves through the unique wilderness of their national landscape, environmental historian Daniel J. Philpion (2005) argues that, toward the century’s end, the suburban garden came to assume an equally important place as a natural refuge. Just as the Romantics saw the wilderness as a site for moral instruction, early suburban architects saw in the proximity of suburbs to nature the possibility of social uplift. Of these architects and planners, Philpion suggests that Andrew Jackson Downing was among the most influential. Through texts like *Treatise on the Theory and Practice of Landscape Gardening* (1841) and

Architecture of Country Houses (1850), Downing argued that daily exposure to natural beauty would strengthen individual integrity and reinforce family values. In a piece entitled *Rural Essays*, he wrote: “in the United States, nature and domestic life are better than society and the manners of towns ... hence, all sensible men gladly escape, earlier or later, and partially or wholly from the turmoil of cities” (Philippon 2005: 77).

Finally, over the last three decades, nature and one’s exposure to it have not only become about a better life, but also about a healthier one. Of course, ideas about the health benefits of nature are longstanding. In the late nineteenth century, physicians began to advocate for pure mountain air as a treatment for tuberculosis and other lung diseases. And by the mid-nineteenth century, the abovementioned suburban architect, Andrew Jackson Downing, edited a gardening book targeted at white, middle-class women in the hopes that it “would increase, among our own fair country women, the taste for these delightful occupations in the open air, which are so conducive to their own health, and to the beauty and interest of our homes” (Philippon 2005: 77). But contemporary understandings about the health benefits of nature – whether that nature is located in the wilderness of Alaska or in the suburbs of Fairfield County, Connecticut – are myriad and range from obesity prevention to the abatement of neurological conditions to the reduction of childhood behavioral disorders. As a result, a movement has coalesced around concerns that individuals – and children in particular – are suffering from nature deprivation. One of the most vocal advocates for this movement is Richard Louv, who coined the term “nature deficit disorder.” In his book, *Last Child in the Woods: Saving our Children from Nature-Deficit Disorder*, Louv (2005) argues that increasing diagnoses of childhood behavioral disorders, such as attention deficit disorder, are not a result of increasing pathology but of the absence of the biophysical benefits of nature in individuals’ lives. To support his argument, he cites a range of studies that show that children who live and play closer to nature are better able to concentrate and are less obese (Louv 2005: 39–54).

In the case of Lyme disease, however, Louv’s means to health (nature) is also a threat to it. Indeed, due to the natural ecology of Lyme disease, individuals who tend to contract Lyme are either those who prefer to live near the woods or those who like to spend time in the woods. This fact lies at the heart of my argument for why tick-borne disease, and Lyme disease in particular, can only fully be understood through an *epidemiology of affect*. As a cornerstone of public health, epidemiology can be defined as “the study of how often diseases occur in different groups of people and why.”⁴ Traditionally, epidemiological explanations for disease incidence among particular populations are based on statistical analysis of demographic and socioeconomic factors including age, racial and ethnic background, and income status. However, Lyme disease makes a strong case for the role of affect in the incidence and distribution of tick-borne disease. Understanding how people navigate the tension between their competing feelings of affection for *and* aversion to nature helps to shed light on who gets Lyme disease and why; it also helps to explain why Lyme disease prevention proves to be so challenging, as the primary “risk” for acquiring Lyme disease – exposure

to “nature” – is simultaneously and collectively valued as a personal and cultural “benefit.” Following an epidemiology of affect, then, an aesthetic of nature tends to be particularly strong among patients who *end up* having Lyme disease.⁵ Although there are many Lyme patients and physicians who have a dramatically estranged relationship with nature after their experience with Lyme disease, there are as many for whom the aesthetic, moral, and health benefits outweigh its risks.

Take, for example, Regina and Mary, two women who founded and lead a Lyme disease support group that I attended almost every month for 18 months. Both Regina and Mary describe enduring long struggles with Lyme disease. They, as well as their children, have been treated for Lyme disease over the years, and, although they report that they have recovered, they explained to me that their children continue to struggle with symptoms, a reality that often triggered tearful conversations during support group meetings. For Regina and Mary, however, the importance of living near the outdoors continues to be paramount – so much so that Regina moved her family from Texas back to Connecticut when her three children were young so that they could “grow up near Nature.” “I wanted them to have what I had,” she explained. “Horseback riding and fields to run in. If only I knew that moving here is what would make my children sick.” During our interview together, Mary echoed the same sentiments: “We were always big outdoors people. We loved to camp and stuff. And I struggle with, I just can’t live in a house. I need to be outdoors, you know, so I just can’t live in a vacuum and I think my kids are the same way. I wouldn’t let them go running in a field, but ...” her voice trailed off. It was clear from Mary’s expression that, as much hardship as her family had gone through *because of* nature, the thought of living *without it* was impossible to imagine.

For individuals like Regina and Mary, the importance they ascribe to nature influences how they choose to navigate environmental risk. In the case of Lyme disease, the salience of nature’s aesthetic, moral, and health dimensions makes possible the idea of *risks worth taking* and transforms what in other contexts would be perceived as irresponsible and reckless behavior into noble and courageous action. This tension is nicely captured in the blog entry of one Lyme disease patient, who writes:

I hope that you may take heart and continue to explore wild, wooded places free from concern about menacing, infectious ticks and vector-borne illnesses. Just rock the pants-tucked-into-socks look and have an OCD friend check you for unwanted guests afterward. No illness, or threat thereof, should keep you from enjoying the breathtaking beauty and majesty of nature.

Another revealing example is that of Dr. Childs, a mainstream Lyme physician whose practice I observed on several occasions. Dr. Childs is a self-identified nature enthusiast who wakes up early before work to row on the Connecticut River and spends weekends bird watching with his wife. He loves to hike, and, during the time I spent with him, he was often busy planning his next outdoor adventure in a country that he had never visited. One of the few photos in his office is of him and his children triumphantly astride the peak of a mountain

range. Dr. Childs found it hard not to share his enthusiasm for the outdoors when he discovered that his patient was also an outdoors enthusiast; and he seemed particularly pleased when a patient was determined to continue their outdoor activities. One patient described how much he loved hiking in the woods and how he was excited to get back in the woods when his knee got better. “That’s the spirit!” Dr. Childs chimed in. Another patient exclaimed, “I’ve hunted and fished all my life. And nothing, not even Lyme disease, is going to keep me from hunting and fishing!” Dr. Childs nodded approvingly in agreement.

Even those who continue to admire nature, however, often recognize that they no longer feel comfortable *in* it, a recognition that is met with a certain degree of sadness and nostalgia. A physician I interviewed named Dr. Reed explained:

I like the outdoors, always have. I love to camp. I’m also an assistant scout leader. I used to feel safe, but now I don’t. I’m constantly worried that a bug will bite me. Now when I go into the woods, I have gaiters that I put on. I lay them down and spray them with permethrin. And then I put DEET on my skin ... and I STILL don’t like to go into the woods. My family looks at me like I’m nuts, but so far, knock on wood, we haven’t found a tick on any of our family members.

The regime of bodily practices that Dr. Reed engages just so that he can feel safe enough to enjoy the woods that he still loves will be discussed in the final section of this chapter. What is important here, and what I have explored in this section, is the difficulty that individuals like Dr. Reed face in navigating the gap between their love for and fear of nature. In 2009, the *New Yorker* published a cartoon depicting Adam and Eve in the Garden of Eden. As Adam inspects a lifted leg, Eve says, “It’s Eden. You don’t have to keep checking for ticks.” For Thoreau, American nature was a prospect more hopeful than the actual Garden of Eden because “it remains to be seen” how the “backwoodsman in America” – the “Adam in the wilderness” – turns out (Bennett 1994: 114). Thoreau, it seems, could not have anticipated that, for some, the rise of Lyme disease would be a fall from nature as disillusioning as that which followed the original eaten apple.

ENVIRONMENTAL RISK OUTSIDE IN

As the previous section made clear, ideas of nature are intimately linked to perceptions of environmental risk. Sociologists Alan Petersen and Deborah Lupton observe that the limitation of “nature discourse,” or what I describe as an American aesthetic of nature, is that nature is also “responsible for death, destruction, (and) disease” (Petersen and Lupton 1999: 106). However, identifying what actually *constitutes* environmental risk is no easy task (Beck 1992; Douglas 1992; Harthorn and Oaks 2003; Pidgeon, Simmons, and Henwood 2006). In the case of Lyme disease, ticks and the pathogens they carry might appear to be the most obvious environmental risk for Lyme patients. But as I came to learn, in Lyme patients’ everyday lives, Lyme disease is just one part of a larger constellation of environmental risks that can be described as “toxins”

and, in general, individuals' concerns tend to be more broadly centered around environmental *toxicity*, whether man-made (e.g., pesticides) or natural (e.g., tick-borne pathogens). In this way, environmental risk is located less in the wildness of nature and more in the diffuse and ubiquitous quality of a toxic environment. In light of this, I suggest that the practices and ideas surrounding Lyme disease help to shed light on a broader emerging relationship between the body and the environment, in which the risk of the environment is not a matter of the "outside" but of an immanent environment that we engage with – and in – irrespective of whether we are inside or outside.

For example, during one of my many conversations with a mainstream Lyme physician named Dr. Elway, she asked, "Did I tell you what I find so interesting about chronic Lyme patients? In general, they tend to be really concerned about toxins – about the potential harm of what they're putting in their bodies – and yet they seem to be perfectly fine with exposing their bodies to years of antibiotics." While it is true that chronic Lyme patients are often concerned about exposure to toxins, their concerns are not unique. In the last couple of decades, many Americans have come to perceive toxins – both inside and outside the home – as an increasing menace to health and wellness. Among the most effective vehicles for the construction and operationalization of the body as a site of toxicity have been biomonitoring studies. The first, conducted by the Centers for Disease Control and Prevention and published in 2001, confirmed the presence of 27 chemicals in American bodies.⁶ The most recent report in this series was published in 2009 and expanded the list of chemicals to 212, many of these known carcinogens.⁷ No longer theoretical, the traffic between the outside and inside of the body is now variously visualized and responded to in everyday practice. As one woman observed at a Lyme disease support group meeting, "The skin is the largest organ on the body. (Why wouldn't I be) afraid of chemicals getting inside of me?"

In *Shopping Our Way to Safety*, sociologist Andrew Szasz (2007) describes individuals' response to what they perceive as an increasing toxic threat – and the porousness of the boundaries between toxins and their bodies – as the "inverted quarantine." The inverted quarantine describes a shift from a popular understanding of the "classic" quarantine, in which the underlying assumption is that "the overall collective environment is basically healthy," to one in which the "whole environment is toxic, illness-inducing" (2007: 5). Practices that proceed from this shift include a range of behaviors centered around isolating the body from "disease-inducing surroundings," including installing water and air filtration systems, purchasing organic produce, wearing organic clothing, using toxin-free cosmetics and cleaning supplies, and ensuring that building materials adhere to the strictest regulations for toxicity (2007: 5). In a move that mirrors trends in public health toward a greater emphasis on individual responsibility, the inverted quarantine operates under the assumption that individuals can circumvent failures in mass regulation by protecting themselves and the ones they love. Szasz argues that there is not only no way to shop our way to safety, but that the illusion of doing so translates to further neglect of mass regulation.

I would push Szasz's argument one step further and suggest that even as many individuals create barriers to toxin exposure, many also recognize the limitations of these barriers. That is, they recognize that there is only so much they can do. The result of this understanding is an emerging and focused attention on toxin *removal*. Accordingly, while the consequence of a diminishing gap between the inside and the outside is that *no* place is safe anymore, the solution is that, once toxic, the body can often be *detoxified*. This is no more so the case than it is for Lyme patients. When I began to observe Lyme patient support group meetings, I was surprised to discover that a significant part of most meetings was occupied by strategies for eliminating toxins from the body. This reality is rooted in an idea shared by many chronic Lyme patients and Lyme-literate practitioners that Lyme disease is particularly pernicious, not merely in and of itself, but in its synergy with other ailments of the body, most notable among them being toxicity. At support group meetings, seasoned members often tried to communicate to newcomers that addressing Lyme disease is only addressing one piece of the unwellness puzzle. One woman explained, "If you have a toxic swamp in your body, that's what Lyme prefers. You have to get rid of toxic soup." For many Lyme patients, heavy metals are perceived to be a frontrunner of toxicity, but toxins like "xenoestrogens," "yeast," "bacterial die-off," and the antibiotics that many patients credit as critical to their recovery are close behind. When it comes to removal, what has worked and what has not worked for patients spans the spectrum: loofah scrubs, Epsom salt baths, sweating out toxins by sitting in saunas or exercising, colloidal silver, chelation, colonic enemas, diets and fasts, and herbs like milk thistle and dandelion root.⁸

If a toxin can be both biological and chemical and can be found inside and outside, it also happens that one substance can be toxic or beneficial depending on its context. The subtle distinctions that constitute when and where something is or is not a toxin plays out, for example, in the case of mold. As one Lyme patient explained,

After we detox, I can come home and smell mold. I smell the mold from the ground, which isn't a problem, because it's outside and I don't have a problem. You can't stop living outside; you *can* remedy it in your home. I felt like I've always been sick in my house because I wake up every day and have a dull headache.

Perhaps most striking here is the reason for why outside mold is not a toxic threat, while inside mold is. The issue is not that one type of mold is more toxic than the other; they are perceived to be the same mold. The issue is that the ability to control outside mold is out of one's hands, while inside mold is perceived to be controllable. The extent to which something is perceived to be controllable is a good barometer for how it will be perceived as a toxin. As one patient explained, "I like to focus on the things I can control."

Another good example of the environmental toxin's contextual nature can be found in Lyme patients' use of the Rife machine and the seemingly contradictory actions some take to limit their exposure to other electromagnetic frequencies. The Rife machine, a contraption that emits electromagnetic frequencies,

was developed in the 1930s by a researcher named Royal Rife. A subscriber to the school of thought that cancer has a bacterial or viral basis, Rife created a machine that he believed targeted bacteria and viruses at their own unique frequencies and, in doing so, “devitalized” them (Hess 1996: 664). Initially taken seriously by medical institutions, the machine was tested in clinical trials conducted at University of California, San Francisco and University of Southern California, only to become the center of a heated lawsuit and meet the fate of being banned by the California Department of Health (Hess 1996: 664–665). As of this writing, the Rife machine has yet to be approved by the Food and Drug Administration. Patients and alternative practitioners have continued to use the machine for a range of maladies, and they have done so in an underground fashion by purchasing the machine in parts and assembling it on their own. Because the machine costs upward of a couple of thousand dollars, patients often collectively purchase one and share its use.

Among Lyme disease patients, the Rife machine is increasingly used in conjunction with antibiotics or on its own. However, the same patients who use the Rife machine to achieve health benefits are often simultaneously concerned about the risks of their exposure to everyday electromagnetic frequencies. Like concerns about toxins in general, concerns about an electromagnetically toxic environment are not unique to Lyme patients. As questions about the potentially harmful effects of everyday electronic devices, like cell phones and laptops, have become more common in popular media, many Americans have begun to take precautionary action, such as using cell phone headsets to create a perceived safe distance between the phone’s output and the ear or placing a lap guard on one’s lap for laptop use. But for many Lyme patients, even these efforts taken by some concerned consumers are not sufficient. Several support group meetings I attended were spent strategizing about how to best limit exposure to electromagnetic frequencies. Some members suggested removing all electronic equipment from one’s bedroom. Others thought that just turning off the wireless router at night would be sufficient. Still others suggested more aggressive action, recommending that filters or nodes be applied to all electromagnetic devices that a person owns in their home, office, and cars. One patient named Nancy explained, “I have electromagnetic sensitivity. All I do is read. I can’t sit in front of the computer or the television.” To protect herself from what she understands are the harmful effects of electromagnetic radiation, Nancy has installed technology throughout her home that is purported to interfere with frequencies and “renaturalize” them so that they are no longer harmful. “It’s expensive, but it works,” she said. “I can feel all my cells open up. It makes me feel more open.” Another support group member agreed. “I’m so much less sleepy when I drive,” the woman exclaimed. “I can tell immediately when the node is not in place.”

The tension in this example turns on the fact that while Nancy and other chronic Lyme patients go to great lengths to accommodate “electromagnetic sensitivity” and to prevent themselves from being exposed to electromagnetic frequencies, many are nevertheless willing to use an electromagnetic frequency machine to target the bacterium that causes Lyme disease. The difference, of

course, is that in the case of everyday exposure, the exposure is not on these patients' terms and is outside of their control. In the case of the Rife machine, the exposure is on their terms and within their control. And unlike everyday exposure, the Rife machine has a targeted and expected health effect. In the end, the toxicity of electromagnetic frequency is not necessarily gauged according to dose – on how much or how little is used – but on the intent and outcome of its use.

If Lyme patients often perceive their health predicament as of one of choosing *between* toxic environmental evils (i.e., strategically accommodating one toxin to mitigate the toxic effect of another), it makes sense that, when it comes to pesticides, the environmental toxin par excellence, Lyme patients are often its greatest proponents. During a conversation with a mother of two daughters, all three of whom were being treated for chronic Lyme disease, the mother exclaimed, “We’re almost completely organic except that we spray the most horrible toxins on the yard. We also spray ourselves like crazy!”⁹ Another woman I interviewed had made it her year’s mission to persuade her local drugstore to provide a continuous supply of an insecticide called permethrin to its customers. For these Lyme patients, even in the face of their concern for toxin exposure, there is no such thing as being too careful when it comes to tick eradication. As the woman above explained, “We try to have our lawn sprayed at least six times per year.” Another patient admitted, “Of course I spray my lawn! I’m a nut job – I’m very careful. I also take permethrin, spray it on cotton balls, and stuff it in paper tubes. Squirrels and chipmunks nest in there and it kills the ticks. Ever since I began spraying, I haven’t found one tick on my property.”

For most patients with whom I spoke, the decision to use pesticides was a choice between two personal health risks: the risk of pesticide exposure and the risk of Lyme disease infection. As one patient explained, “When it comes to applying repellants, some people believe that it’s dangerous to them. I respect that because that’s pretty much where I was coming from, too. But you get neurological Lyme and you have Lyme long term and you start reevaluating your opinions.” Some individuals also considered the environmental impact of pesticides when making their decision. For example, one chronic Lyme patient I interviewed, a 25-year-old college student, reasoned, “It might be horrible for the environment, but of course I’m going to spray pesticides. What’s the point of having a world if you can’t live in it?” Another patient, a middle-aged government employee, exclaimed, “I’ve always been a really ecological friendly person. But there wasn’t hesitation when it came to my health and protecting my family. That outweighed the possibility of the effects of it leaching into the Farmington River. The immediacy of Lyme disease, that made the difference. When it comes to ticks, I don’t care what I have to do.” In both cases, the risk of Lyme disease was almost always prioritized over the risk of pesticides to human and environmental health.

As the examples in the section have demonstrated, one answer to the question posed by Dr. Elway in the beginning of this section is that the simultaneity

of Lyme patients' use and avoidance of substances that they recognize as toxic is not contradictory. Rather, toxin avoidance is merely an attempt to limit further exposure to a toxic environment of which, through their antibiotic and pesticide use, Lyme patients are an inextricable part. From ticks and mold to electromagnetic frequencies and pesticides, the case of Lyme disease makes clear that what constitutes the "environment" in the United States is often much more than just the "outside" and that, for many individuals in Lyme endemic areas, ticks are just one risk in a range of environmental risks that are perceived to be "toxic."

THE PRACTICE OF LYME DISEASE PREVENTION

While the previous two sections examined *how* individuals in Lyme endemic areas who are concerned about Lyme disease navigate the tension between their attraction to nature and their fear of environmental risk, this section concludes by examining the practical consequences of that tension – more specifically, the emerging bodily practices that individuals increasingly enact to keep ticks off them. Here, I argue that as a way of being in and engaging with an environment whose salience to the self is constantly changing, tick prevention practices become less about whether or not they actually work and more about what they incidentally happen to produce across social relations. As I demonstrate in the example of the tick check, a personal prevention practice that often requires the help of someone else, it is the *effects* of these practices – for example, quality time spent between parents and children, intimate time spent between partners, and a collective feeling of greater safety – that individuals come to value over the efficacy of the practices themselves.

Described by first-century Roman naturalist Pliny the Elder as the "foulest and most vile of creatures," ticks, which attach to a host and draw blood unnoticed for up to three days, have long made humans uneasy (Edlow 2003: 84). In 1749, a Swedish naturalist named Pehr Kalm, documenting his travels through the northeastern United States, wrote of ticks: "To these I must add the woodlice, with which the forests are so pestered, that it is impossible to pass through a bush without having a whole army of them on your clothes, or to sit down, though the place be ever so pleasant" (Stafford 2007: 1).

The dense annoyance of ticks that Kalm experienced in 1749 changed, however, at the turn of the twentieth century, when forests were cleared for farmland and deer (which are tick carriers) were hunted out of the landscape. Entomologist Kirby Stafford describes how an entomologist in 1872 declared ticks to be nearly extinct along the path that Pehr Kalm had traveled 100 years before (Stafford 2007: 2). It was not until after World War II that the perfect storm of reforestation, deer reintroduction, and the expansion of suburbs into forested areas allowed for the return of the tick. As a result, Americans, often preferring to live close to the woods but not in them, became increasingly familiar with and wary of tick encounters.

In *Cure Unknown: Inside the Lyme Epidemic*, journalist Pamela Weintraub describes how this threat of tick encounters estranged her from the nature she had always loved. She writes:

Before I realized our environment was making us sick, I viewed the natural beauty around me as a gentle, beneficent luxury, a reward for my success. . . . Before Lyme, I threw parties on my forty-foot deck, going out at dusk to barbeque skewers of mushrooms and steak, all the while dazzled by another red sunset beyond the pines. After Lyme, I woke up at dawn and, venturing out on my forty-foot deck, saw twenty deer grazing in my yard. I'd clang my pots loud, making them bolt and run. Before Lyme, I hiked deep into the woods, smelling the cool moist breath of pine needles and moss. After Lyme, I hesitated even stepping on the grass in Chappaqua without high socks and boots, my suburban version of the Hazmat suit. What had once seemed pristine now felt toxic and ruined. (2008: 105)

Like Pamela, many of the individuals I spoke with during the course of my fieldwork moved to or remained in forested suburbs to be “close to nature.” But “after Lyme,” many described an experience of becoming “prisoners of their own paradise.” As one patient exclaimed, “I don’t go out. I used to always go out. I love nature and I love animals. Now I don’t like grass or walking through the woods. If I see people walking through the woods, I want to say, ‘You’re going to get sick!’” Another patient explained,

The deck outside is my world. It’s way above the ground. I don’t go on the lawn. I don’t go to picnics. My life is totally changed. I used to be outside camping, hiking, hiking 80 miles per week. Now I walk on the pavement and come back. That’s it. I’m afraid to go on any grasses. Also, I heard that a tick came in on someone’s Christmas tree, so I’ve have been putting up artificial ones for the past couple years.

Yet another patient, a television producer in his early forties who, unlike the other two women, continues to venture outside, explains that he does so with great unease. “Now I’m freaked out,” he admits, “even when I take the dog for a walk. And now that it’s summer, I see a tick waiting to jump off every leaf. My perception of where ticks are has changed – ticks are totally on my radar screen.”

Because the greatest risk for tick exposure occurs in one’s backyard, Lyme disease has transformed mundane domestic objects – like lawns, playgrounds, and stone walls – into frightening and difficult-to-decipher menaces. One father I met, whose children were not allowed to walk on the lawn without permission, recounted how his young son, in reaction to a pile of leaves he had raked together, exclaimed, “Look, Dad, a pile of ticks!” Upon later seeing a cartoon depicting children playing in leaves, his son asked, “Why would their parents let them do that?” Another woman described a recent Christmas-shopping-in-July outing where she passed over some deer-themed Christmas cards because the sight alone had made her cringe. In a similar instance, another woman explained, “When I see kids playing in the grass or people walking dogs in the grass, I grimace. We hear stories about Lyme every day. I feel bad, because kids want to go out in the backyard, but my granddaughter will never go in my backyard. It’s a shame, I love the woods. All those big rock formations in the back!”

Some families, overwhelmed by the idea of living in such close contact with ticks, have moved to non-Lyme endemic areas (and many have at least contemplated it). But most stay, for a variety of reasons. One woman explained, "I've lived my whole life in Connecticut. My family is here and my husband's whole family is here. So I just can't imagine. I've heard that people have moved to California, though." Other patients I spoke with, like Regina and Mary who lead the support group meeting I described in this chapter's first section, gestured to their constitutional incompatibility with city life. "We could move to New York City and not have grass, and that's not the kind of life I want. I like grass. It's nice." Another woman echoed this sentiment: "I know that there are enough things that you can do to prevent Lyme disease without moving to the concrete jungle. We would never move. But I also don't let my kids go in the woods. Isn't that crazy? I live in a rural area and don't want to go in the woods!"

In making the decision to stay, many turn to what they describe as the only thing at their disposal: prevention. Tick bite prevention includes an ever-expanding range of bodily practices, such as tick checks, repellants, knee-high socks, wearing socks with sandals, tucking pants into socks, light-colored clothing, wearing a hat, avoiding grass, avoiding leaf litter, keeping animals outside (or at least not letting them in bed with you), only having pets with white fur, spraying the yard with pesticides, putting clothes in the dryer after coming inside, and bathing after coming inside. Some individuals and families conscientiously engage in as many of these practices as they can. As Sue, a stay-at-home parent with two daughters, explained,

When we're in the garden, we wear khaki pants with white socks. We also wear hats and socks on our hands. And, of course, we spray ourselves like crazy. When we come inside, we take our clothes off in the garage and then shower. We also try to find other things we like to do, like bike riding and skiing. And we try to spray six times per year. The other thing is that knee highs have come back in fashion, so it's much easier to get my girls to wear long socks.

In a similar vein, another woman explained,

I cannot get bitten again. I have to take all the precautions that I can in order not to get bit: tick checks, repellants, pesticides, you name it. We even have a protocol for washing clothes: we take off clothes in garage and then put them in a garbage bag until they go to laundry. They also get twisty tied.

Others find focusing on just one or two prevention practices more manageable. For instance, one woman explained how if she walks through her yard, she wears rubber boots. Another man, who lets his dog sleep on his bed, pulls down the covers every night and looks for ticks. He added, "And I insist on only solid sheets. It's the only way you can see the ticks."

In general, some prevention practices are rarely done. As one patient with whom I spoke rhetorically asked, "Who's going to wear long pants on a hot summer day?" But some, like tick checks and remembering to shower after coming indoors, have, for many, become part of the daily repertoire of bodily

hygiene. Eileen, a 43-year-old woman who used to work at an optical lens factory explained, “Am I using permethrin? No. Am I using DEET? No. Just last weekend I was outside just doing a very little bit of yard work and then I was inside taking a shower. My husband’s also following me saying, ‘Take a shower.’ That’s one of the most effective things.” Echoing Eileen, Judy, a 60-year-old woman who works as a freelance writer, explained, “I have two sons and we all take showers immediately when coming back in. We also use loofahs. It’s basic hygiene really. Some people I look at and think, ‘Hello, you haven’t taken a shower for a week, no wonder you’re crawling with ticks!’”

That tick checks and showering after coming indoors have become part of some individuals’ “basic hygiene” is notable given that personal hygiene as a means to a disease-free life has, over time, become a less urgent priority for many Americans. Indeed, in the United States, everyday attention to and care for the body, as a functional barrier between the contagion of the outside and the health of the inside, has become the stuff of outdated parental expressions like, “Don’t forget to wash behind your ears.” Broadly speaking, public health measures, like waste management, municipal drinking water, and vaccines, have dramatically reduced the menace of communicable diseases that produced vigilant inspection of the body’s planes and folds up until the middle of the twentieth century. In the *Gospel of Germs: Men, Women, and the Microbe in American Life*, medical historian Nancy Tomes observes how, in the early 1900s, “revelations that skin, hair, and body cavities harbored millions of germs provided abundant material for heightening anxieties about bodily hygiene” (Tomes 1998: 165). For women, germ anxiety took the form of a nationwide campaign to wear shorter dresses and skirts, so that hemlines would not become Petri dishes of contagion. For men, it meant a new aesthetic that valued shorn, beardless faces (Tomes 1998: 159). This broader shift in public health from collective to individual responsibility in the form of personal hygiene behaviors became institutionalized through public education. For example, Suellen Hoy, in *Chasing Dirt: The American Pursuit of Cleanliness*, describes how schoolteachers in the mid-twentieth century conducted toothbrush drills and required daily inspections of hair, hands, ears, and necks (Hoy 1995: 128).

Unlike tooth brushing and hair washing, which, for some, have become habits of an aesthetic nature with little conscious attention to health (let alone life and death), tick checks are bodily practices explicitly enacted in health’s pursuit and with a keen attention to risk of disease. But they are also a new breed of bodily practice in that they are acts of personal hygiene that are inherently social (Lock 1993). This is, in large part, because of the habits of ticks themselves. Built for moist environments, ticks leave leaf litter only to, when they happen upon a human, make their way to the floral equivalent of the human body: armpits, the bra line, hairlines, around the anus, and tucked within the creases of male and female genitalia. The irony is that these most intimate places, which most would prefer to inspect in privacy, are not easily inspectable by their bearer and require the help of another set of eyes and hands. It is in this way that the sociality of tick checks is always already linked to questions of intimacy, sexuality, and the obscene.

For example, at a tick-borne disease prevention conference in the spring of 2011, an entomologist stepped up to the microphone during a question and answer session. Frustrated with the gap between concept and practice, and working on a hunch that most people do not do thorough enough tick checks, the entomologist said, “Without someone to check me, a tick guy like me needs a tick guy sized mirror.” He proceeded to bend over, so that his rear faced the panel, and then mimed spreading his cheeks open, his head peering around his body as if looking into the imaginary mirror before him. The discomfort in the audience was palpable. One could only imagine that it was a discomfort operating on two levels: discomfort with the idea of checking one’s own body in that way and discomfort with the idea of having to check someone else’s body in that way. The entomologist’s simple mime also reinforced the idea that ticks prefer hard-to-reach intimate places and that ticks checks are better performed by intimates than by the self, even if both practices might, at times, be perceived to be unpleasant.

However, as has been the theme of this chapter, revulsion and attraction are two sides of the same coin. Helped along in no small part by country legend Brad Paisley’s song, “Ticks,” which cleverly seeks to persuade a woman to walk into the sticks so he can check her for ticks, the term “tick checks” has also become a sexual innuendo with the same clinical valence of something like, “Let’s play doctor.” The salience of this term was confirmed during an interview with a male Lyme patient. After talking at length about hunting and camping and other outdoor activities, I asked the patient whether he performed tick checks and, transitioning from an up-until-then serious tone to one that was markedly mischievous, he responded, with a knowing smirk, “Only for fun.” And in a letter penned in support of a Lyme advocacy group by a famous Hollywood actor who also happens to have been a Lyme patient, the actor wrote, “Tick checks are great foreplay. Enjoy them!” Vector-borne disease health officials had hoped to capitalize on the emerging colloquial traction of the term by coining the prevention message, “Get Naked,” but I was told by a health official at another conference in the fall of 2010 that this idea was only too quickly given the kibosh by STD health officials who warned that anything having to do with nudity and sexuality was infringing on their public health marketing territory.

Given all of this, it is easy to see how tick checks can quickly become a sensitive subject between parents and children. As one patient I interviewed explained,

When my son was a baby, we used to have what we called “tick patrol” and I would bring him in and strip him down every night and we would check every area of his body and I can tell you, I took a tick off his penis. I mean that’s ... I remember that ... but I would check him constantly. But he’s 18 now. I’m hoping ... well, I tell him he has to check himself.

Like this mother, parents whom I spent time with often complained that once their children reached a certain age, they and their children no longer felt comfortable doing certain types of tick checks with each other. Even though they had taught their children to check themselves, they worried that they would not

do them thoroughly enough or, more likely, that they would forego the check completely. As another mother asked, “Can you imagine getting a 12-year-old boy to take a tick check seriously?” On the other hand, limited tick checks (of the hair, back, and shoulders) very much remain within the bounds of family intimacy. One physician explained how his children, now teenagers, still asked to be checked for ticks because they just liked it. “It’s one of the things that they grew up doing with me,” he explained. In the end, the intimate tick checks that families enjoy and the more sexual tick checks that Brad Paisley croons about are not as thorough as the miming entomologist would like them to be, while the thorough tick checks that he advocates for are not the ones that most people want to do.

In addition to the limitations of when and where tick checks are considered appropriate, tick checks are also plagued by the problem of ticks’ small size. The juvenile, or nymphal, stage of the blacklegged tick is the size of a period and is understood to be the primary vector of *Borrelia burgdorferi* to humans (Clover and Lane 1995; Diuk-Wasser *et al.* 2006; Embers *et al.* 2013). As demonstrated by the boy in the example above who conflated leaves with ticks, ticks *are* so small that they could be anywhere and anything, and, for all intents and purposes, they might as well be leaves. As one mother admitted, “We’re very religious about checking them for ticks but I’m also, you know, they still roll around in the grass and hike in the woods and I have two boys. They both have long hair. If my older one gets a tick, I’m not going to find it, you know, he’s got curly, long hair.”

More disconcerting still is when the ambiguous *there* of the outside becomes the ambiguous *here* of the body. For example, several informants described the experience of watching a mole grow, only to discover too late that the mole was, in fact, a tick. By then, the tick had already had a full blood meal and was given plenty of time to transmit infection, its removal no longer an act of prevention but a mere detachment. Central to the experience and practice of tick checks, then, is the idea of *the one you do not find*. Because most Lyme disease cases are the result of a tick that was not found (or found too late), tick checks are haunted by the specter of their own inefficacy. That is, irrespective of how many ticks are found during any given tick check, they are always a reminder of the one tick that might not have been and, therefore, the one tick that might have mattered.

Oddly enough, the inefficacy of tick checks is the very thing that leads to their continuation, to their being performed again and again, for the limitations of realizing that a tick might not have been found is simultaneously the acceptance of the infinite possibility that there is *always* a tick to be found. It is a cycle propelled by absence rather than presence. Failure also inheres in the rest of the things that people do to keep ticks off them. A public health official I interviewed explained that although most tick prevention practices seem to be commonsensical, we “really don’t know if most of them work.” For example, in the case of the application of pesticides to lawns, this official said that, in the absence of relevant studies, the recommendation to do this merely operates on an assumption that lower tick populations translate to lower Lyme disease infection

rates.¹⁰ Among the patients with whom I spent time, however, I was not surprised to hear that, irrespective of outcome, many felt that they would rather do something that *might not work* than *nothing at all*. Indeed, if not everyone likes tick checks or believes that they are effective, then many, at least, have gotten used to doing them and, in doing them, have come to value their effects.

This section built on the previous section by examining how an environment that is increasingly immanent and less and less defined by the divide between inside and outside is *also* produced in and through individuals' practical engagement with it. In 1909, biologist Jacob von Uexkull coined the term *Umwelt*, or "environment-world," to give expression to the idea of a "surrounding world" (Agamben 2004: 40; Buchanan 2008: 147). Uexkull argued that, when it comes to the relationship between organisms and their environment, attention should be paid to "subjective universes," whereby each organism creates its own environment through interaction. As a result, "the environment" becomes "environments," with the potential for there to be as many environments as there are organisms (Buchanan 2008: 22). When it comes to Lyme disease, I have suggested that, in the context of the increasingly affective relationship between humans and their environments, the emerging bodily practices of tick bite prevention constitute the active building of new "environment-worlds." And the environment-world of tick bite prevention practice is one in which protecting the self is also a matter of knowing the other, and where tick checks, whether they work or not and although exacted on the individual body, are increasingly, if not incidentally, made meaningful across human relations.

CONCLUSION

Together, this chapter's three sections explored why a Lyme patient like Susan, who lives in nature and whose art is inspired by nature's "beauty," is also terrified of nature. As tick-borne diseases like Lyme disease become an increasing threat in the United States, individuals who live in Lyme endemic areas face the difficult task of negotiating the competing demands between their attraction to nature and their concerns over the health risks of a "toxic" environment, an environment that crosses the boundary between "inside" and "outside" and of which Lyme disease is just one small part. In doing so, these individuals must also navigate and make choices about which toxins – from bacterial pathogens to antibiotics to pesticides – are "less risky" than others. Drawing from interviews with and observations of Lyme patients, physicians, and scientists throughout the northeastern United States, I have argued that the experience of having and preventing Lyme disease can be better understood through the construct of an "epidemiology of affect," whereby individuals' feelings about nature inform their engagement with it and produce an emerging range of everyday prevention practices uniquely characterized by affective social relations. More broadly, this study highlights the importance of ethnographic attention to human experiences and practices in better understanding the changing landscape of environmental health.

NOTES

- 1 To protect the privacy of my informants, all names used in this chapter are pseudonyms.
- 2 Lyme disease is a tick-borne bacterial infection that was discovered in Lyme, Connecticut in 1982 (see Bullied and Singer, this volume). Since then, there has been heated debate over how to diagnose and treat it. While proponents of the “mainstream” standard of care claim that Lyme disease is easily diagnosed and treated, proponents of the “Lyme-literate” standard of care claim that diagnostic tests are unreliable and that Lyme disease can persist in the form of “chronic Lyme disease,” a condition which mainstream proponents do not recognize but which Lyme-literate proponents argue should be treated with extended courses of antibiotics. In this chapter, I use “Lyme patient” to describe any patient who identifies with having or having had Lyme disease, irrespective of their medical history. Although most of the patients whom I interviewed and observed described experiences with Lyme disease marked by chronicity, I do not make a distinction between chronic Lyme disease and Lyme disease when referring to the ideas and experiences of these patients because most patients and Lyme-literate physicians understand chronic Lyme disease to be one point on the timeline of the Lyme disease experience and not a qualitatively different disease state from acute Lyme disease. Moreover, although patients often refer to themselves as chronic Lyme patients, they also perceive the use of this term by mainstream physicians as a means to distinguish them from what mainstream physicians perceive to be “real” Lyme patients. Because I am only interested in the ideas and experiences of my project’s participants, the terms I use in this chapter reflect the positionality of the individuals who use them, as well as the social contexts in which they are used.
- 3 The research methods I used were a familiar anthropological combination of participant observation, unstructured and semi-structured interviews, and popular, academic, and virtual media analysis. As a participant observer, I shadowed physicians on either side of the standard of care divide, and I regularly attended critical sites of discourse and practice in the Lyme disease controversy, including patient support group meetings, scientific laboratory and public health meetings, fundraising events, and scientific conferences. In addition to conducting hundreds of informal interviews at these sites, I also conducted 145 semi-structured interviews with patients, physicians, scientists, health officials, politicians, and patient advocates. Finally, because a significant portion of Lyme disease discourse takes place online, I tracked the daily publication and circulation of relevant articles, blog posts, and listserv e-mails. Together, the data derived from the range of methods I used allowed me to piece together analytical insights into the lived experience of Lyme’s controversy.
- 4 <http://www.bmj.com/about-bmj/resources-readers/publications/epidemiology-uninitiated/1-what-epidemiology> (accessed December 2, 2015).
- 5 I emphasize the phrase “end up” to underscore the contingency of the relationship between having Lyme disease and loving nature.
- 6 <http://www.cdc.gov/media/pressrel/r010321.htm> (accessed December 2, 2015).
- 7 <http://www.cdc.gov/exposurereport/pdf/fourthreport.pdf> (accessed December 2, 2015).
- 8 Chelation therapy is the ingestion or injection of a chemical compound that binds with metal ions. The result is a chemical complex that is water-soluble; it then enters the bloodstream and is excreted in the urine. While chelation therapy for heavy metal poisoning is used for acute cases in mainstream medicine, its popularity among some complementary, alternative, and integrative medicine practitioners for subclinical cases has been the subject of much scrutiny.

- 9 For some, the opposite is true. Another woman I interviewed said that she would not spray her yard because she did not want to be exposed to any more chemicals. But when I asked her if the same logic applied to her food, she replied, “No. A little funny, huh? Anything but. You know what, if I had all the money in the world, I’d probably eat organic but, to me, it’s too expensive. Every once in a while I try and buy, like, chicken that doesn’t have antibiotics or whatever in it. A lot of people say well you have to at least do the organic milk and I don’t even do that.”
- 10 To address this evidence gap, the CDC (Centers for Disease Control and Prevention) initiated a study in the spring of 2011 to test the relationship between a single lawn application and Lyme disease infection rates.

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