

Putting ethnographic flesh on new materialist bones: Lyme disease and the sex/gender binary

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In the United States, there is heated debate over the biological reality of chronic Lyme disease (the persistence of Lyme disease beyond standard antibiotic treatment). Like other bodily conditions whose biological basis is disputed, chronic Lyme disease is perceived to be more common among women, a phenomenon for which physicians and patients often provide gender-based explanations. However, influenced by the field of sex-based biology, Lyme disease patients and their physicians are increasingly navigating how and whether to make claims to biological legitimacy through the science of sex-based differences. Drawing on ethnographic research among Lyme disease patients, physicians, and scientists throughout the northeastern United States, I explore the mutually reinforcing relationship between feminist scholarship on the sex/gender binary and emerging ideas about sex and gender in the context of health.

Keywords Lyme disease, gender, new materialism, sex, United States

In the *New Yorker's* 2018 Summer Fiction issue, journalist Lidija Haas reviews *Sick*, a much-anticipated memoir by novelist Porochista Khakpour about living with Lyme disease, and asks, "Is Lyme disease a feminist issue?" (Haas 2018). It's a striking question because, as Haas notes, there is little that is obvious about the relationship between Lyme disease—a tickborne bacterial infection—and women. As some of the Lyme patients I spent time with were quick to remind me, "Lyme doesn't discriminate." And yet, the distance traveled between Lyme disease and critical questions about sex, gender, and health is shorter than anticipated because Lyme disease is also an intensely contested illness whose controversy hinges on whether it can persist beyond standard antibiotic therapy in the form of chronic Lyme disease. On one side of the divide, individuals who support the "mainstream" standard of care claim that Lyme disease is relatively easy to diagnose and treat. On the other side, those who support the "Lyme-literate" standard of care claim that diagnostic testing is unreliable and that Lyme disease can persist in the form of chronic Lyme disease, a condition that mainstream physicians describe as biologically unsubstantiated and, as a result, "medically unexplainable."¹ Like other contested illnesses, such as chronic fatigue syndrome and multiple chemical sensitivity, chronic Lyme disease is perceived to be more common among women.²

Between 2010 and 2011, I spent eighteen months conducting in-depth ethnographic research among Lyme patients, physicians, and scientists throughout the northeastern United States. As

a participant observer, I shadowed the clinics and private practices of physicians on both sides of the standard-of-care divide, and I regularly attended patient support group meetings, scientific laboratory and public health meetings, fundraising events, and scientific conferences.³ In addition to conducting hundreds of informal interviews at these sites, I conducted 145 semi-structured interviews with patients, physicians, and scientists, as well as with health officials, politicians, and patient advocates. In this article, I draw from time spent with Lyme patients, physicians, and scientists to explore the mutually reinforcing relationship between feminist scholarship and everyday ideas and practices related to sex (commonly understood as biological difference) and gender (commonly understood as the “social expressions” of biological difference) in the context of health (Lock and Farquhar 2007, 383). In particular, I focus on the work of feminist new materialists, and I suggest that ethnographic insights into how Lyme patients and their physicians understand sex and gender in their simultaneity *and* as an either/or proposition helps to put flesh on the bones of new materialist thinking about social and biological entanglement. I conclude with a reflection on how the striking absence of race’s mention among Lyme patients and physicians reveals the extent to which the enactment of the sex/gender binary is also racialized.

Beyond assumptions about the prevalence of chronic Lyme disease among women, Lyme disease is also a story about women because it was put on the map by two Connecticut “housewives,” who, upon observing unusual symptoms in their community, plied the medical establishment with questions until they were taken seriously. As one of these women, Polly Murray, wrote in her memoir,

I may have been one of the first to start asking questions back in the mid-1970s, but since then I've been joined by a chorus of voices from the field, most of them belonging to women... . And these women have tremendous power, for they are often driven by a primal instinct to protect their young. (1996, 292)

Since Murray's early advocacy work, most of the leaders in the Lyme advocacy world continue to be women.

Like Murray's gendered explanation for why Lyme advocates are primarily women, gendered explanations for why chronic Lyme disease might be more common among women abound. For example, Mary, a Lyme patient and support group leader, explained that because doctors are more likely to believe men's complaints, men are treated more quickly for Lyme disease and have fewer complications.⁴ She had come to this conclusion after observing her husband's experience with Lyme disease. She explained,

Men are a pain in the neck. They don't like to admit [they're sick], and my husband was getting really, really sick and got nasty... . Men complain a lot. They do complain a lot, but they don't do anything about it. If they do get into a doctor, I think they get more attention paid to them but they won't go. I mean, still now, he's relapsed and needs to go. He's starting to get really stupid again.

Tina, a member of another support group whose meetings I attended, expressed a similar sentiment that men are louder complainers and less tolerant of discomfort, traits that are also perceived to lead to quicker treatment. Like Mary, she explained that women are less reluctant to seek medical care even if they are more tolerant of discomfort. She reasoned,

Men do not seem to suffer the way that women do. Women do seem to get it more. I've seen plenty of men with chronic Lyme disease over the years. They're not immune to it. It may be that women are proactive about it and not willing to suffer through it. And men complain a lot sooner, and are listened to, and get faster treatment up front.

Following Mary and Tina's line of logic, women, who are understood to be accustomed to sacrificing sleep and well-being to nurture their children and their careers, refrain from complaining about the same symptoms that, in men, would be addressed sooner and more quickly by physicians. And when women do see a physician for their symptoms, Mary and Tina reason, their symptoms are not taken seriously. In a similar vein, several women described how it took multiple appointments to be diagnosed with Lyme disease because, according to them, physicians assumed that their symptoms were a function of being "depressed," or "a busy Fairfield County mom," or "a mom that stays home with her kids and needed to find something worthy." One mainstream physician I spoke with came to the conclusion that a couple of his patients (whose reasons for their visits were "suspected Lyme disease") did fit the profile of a "busy, sleep-deprived mom" more than they did a Lyme patient.

Like patients, many mainstream physicians I spoke with provided gendered rationales for sex differences in chronic Lyme disease. For them, however, the fact that more women appear to have chronic Lyme disease—when acute Lyme disease affects men and women in equal numbers—substantiates the fact that chronic Lyme disease does not have a biological basis.⁵ As two physicians reasoned in an article that appeared in the *Journal of Women's Health*,

If chronic Lyme disease is directly related to ongoing infection with *B. burgdorferi*, one might expect that the proportion of men and women who have this diagnosis would be similar to the proportions among persons diagnosed with Lyme disease in the general population, as well as among those with post-Lyme disease syndrome. On the other hand, if there is a substantial difference in the gender of patients with chronic Lyme disease, it is additional evidence that this disease is unrelated to infection with *B. burgdorferi*. (Wormser and Shapiro 2009, 832)

Like these physicians, some mainstream physicians postulate that because the proportion of men and women who have chronic Lyme disease does not match the proportion of men and women who have acute Lyme disease, chronic Lyme disease must be "unrelated to infection with *B. burgdorferi*."⁶ For them, it seems more likely that what is diagnosed as chronic Lyme disease is actually fibromyalgia, chronic fatigue syndrome, or depression, disorders without a clear biological basis that also happen to be more prevalent among women.⁷ As one mainstream physician suggested at a grand rounds presentation, "The majority of these women are just depressed."

Because mainstream physicians contend that chronic Lyme disease does not have a biological basis and, as a result, is not correlated with sex differences, chronic Lyme disease's medically unexplained nature can sometimes be explained by unflattering stereotypes: women perseverate on negative details, have overly anxious personalities, are more easily frightened, or crave attention, all of which are consistent with the "age-old charge that women psychosomaticize their distress" (Murphy 2006, 152) and "a long history of nonorganic 'women's diseases,'" such as hysteria and neurasthenia, "that have been named, diagnosed, and treated by masculinist medical science" (Greenhalgh 2001, 318). However, as Tina also observed, the perception of being unwomanly can equally delegitimize women's illness experiences. Tina explained, "I'm always getting into trouble with my big mouth. We like big mouths, but we get labeled as pushy, bitch, and demanding. When a man is like that, he's taking charge." One physician I spoke with pointed to the broader dynamics of gender relations as a factor that contributes to the chronic Lyme disease phenomenon. He observed that in affluent areas, men often marry younger "trophy wives" only to find that they cannot keep up with them. He exclaimed, "A sixty-year-old executive can't keep up with a thirty-year-old babe!" As a result, he continued, these men psychologically corner their wives into playing the "sick role" of chronic Lyme disease to attain a better fit. Irrespective of whether they construct women as agents

of or *victims* to their own suffering, the shared effect of gendered rationales is the delegitimization of the biological reality of chronic Lyme disease, a phenomenon that sheds further light on how the sex/gender binary is enfleshed in everyday life.

In addition to attributing the perceived prevalence of chronic Lyme disease among women to gender, the reflections of these patients and physicians highlight what anthropologist Susan Greenhalgh has described as the “asymmetrical character of the doctor-patient relationship” between women and male physicians (2001, 307). Because of this asymmetrical character, Greenhalgh argues, women patients often enact “self-silencing, other-centered routines of femininity” of being “compliant” and “pleasant,” but they also have the power to reject them (308). In the case of Lyme disease, only eleven of the fifty-six physicians I interviewed were women. Yet, as feminist author Maya Dusenberry suggests, “gender bias in medicine runs much deeper than the gender of its practitioners”; that is, “it is largely unconscious and systemic, and women doctors are not immune to it” (2018, 11).

In this way, Lyme patients’ experiences with their predominantly male physicians also reflect the broader institutionalization of gender bias in medicine, the effects of which exceed the impact that a physician’s gender has on patient care. As Dusenberry observes, what little research there is “paints a fairly consistent picture: women are often not taken as seriously as their male counterparts when they enter the medical system” (4). For example, she continues, “women wait sixty-five minutes to men’s forty-nine before getting treatment for abdominal pain in the emergency room,” “young women are seven times more likely be sent home from the hospital in the middle of having a heart attack,” and women “experience longer diagnostic delays in comparison to men for nearly everything, from brain tumors to rare genetic disorders” (4). Similarly, a 2012 review of the medical literature on gender disparities in health care concludes that “despite the fact that women are more proactive in the use of preventive care, disparities between men and women exist in the diagnosis and treatment options that are recommended to them” (Kent, Patel, and Varela 2012, 555). Together, these observations point to a reality in which “women’s accounts of their symptoms are too often not believed” (Dusenberry 2018, 11), a reality that is particularly pertinent to chronic Lyme patients, who often present with a range of perplexing symptoms in the absence of clinical signs.⁸

Given mainstream physicians’ claim that chronic Lyme disease does not have a biological basis, it is unsurprising that their narratives to explain its prevalence are often cast in terms of gender.⁹ But in light of Lyme patients’ quest for medical legibility through the recognition of the biological basis of their suffering, it is striking that very few of the patients and Lyme-literate physicians I interviewed offered a sex-based explanation.¹⁰ For example, Lyme-literate physicians’ retorts to the idea that women were more likely to have chronic Lyme disease were often couched in gendered terms, even if they also entertained the idea that there might be a biologically based difference. During my interview with a Lyme-literate psychologist who also happens to be a woman, she exclaimed,

It’s more common in women than men? That’s just disgusting. Women are more willing to recognize it than men. Men aren’t willing to go to doctor. It’s a biased sample. Women are more willing to acknowledge that they’re struggling, more likely to be multitasking, more likely to run into trouble. Women are much more comfortable with their feelings. All you have to do is be in a relationship to see this. Much of this relates to how we’re socialized. It’s also the brain. There are studies that show that there are differences between male and female brains.

Another Lyme-literate physician reflected,

Being a woman, more women come to me. In response to the idea that more women have Lyme disease: that's very sexist. Women tend to have fatigue, but men also have fatigue. Connecticut housewives do tend to be more needy, but you can discern those kind. In general, women are more expressive; women need to be loved a lot. We are nurturers. I think Lyme affects and aggravates autoimmunity more than other infectious diseases.

Although these practitioners briefly considered the possibility of sex-based differences (e.g., differences between male and female brains and a predisposition toward autoimmunity in women), their primary emphasis—like that of Lyme patients—was on gender. The question, then, is why? In addition to the fact that attention to sex-based differences might be perceived to distract from the broader goal of gaining recognition for the persistence of bacteria in the bodies of *all* chronic Lyme patients, another compelling answer is the historical impact of the movement within social scientific and feminist scholarship to enact social equality in the face of biological difference. Initiated in the 1970s and 1980s as an important corrective to early scientific discourses that justified social inequality through biological determinism, meaningful sex differences across fields of inquiry were bracketed in favor of analytical attention to gender. As anthropologists Margaret Lock and Judith Farquhar observe,

To account for the many empirical variations in the social practice of gender, ... it was useful for mainstream social scientists to hold sex constant—usually seeing it as biological and consequently unproblematic—while focusing on the social fields in which variable gender roles—men, women, homosexuals, etc.—were determined. (2007, 383)

As a result, anthropologist Elizabeth F. S. Roberts suggests, “the sex/gender distinction prevented the conflation of biology with social, psychological, and cultural attributes, countering the biological determinism that equated women with their reproductive and domestic capacities” (2016, 111; see also Herrmann and Stewart 1994; Rubin 1975; Vogel 1995).

The sex/gender binary has been vigorously theorized and critiqued in subsequent years, and the continued salience of this framing is particularly notable within academic and popular understandings of infectious disease. For example, infectious disease prevalence and severity are often correlated with geography, demography, and social behaviors, but they are much less often correlated with sex. And as I previously mentioned, the Lyme patients I spent time with affirmed the perception of infectious disease’s democratic nature by telling me on several occasions that “Lyme doesn’t discriminate.” For Lyme patients and Lyme-literate practitioners alike, the imperative to emphasize equality in the context of biological difference often seemed to exceed the impulse to claim biological legitimacy through the perceived sex differences at the root of chronic Lyme disease, which is an important dimension of how Lyme’s sex/gender binary is enfleshed. And yet, while many Lyme patients and Lyme-literate physicians at the time of my research resisted the possibility of Lyme’s sex-based differences, feminist scholars and biomedical scientists were beginning to pay more attention to sex-based biology. For feminist scholars, the shift from “social constructionism” (in which gender is understood to be a flexible social construction and sex is understood to be a fixed biological constant) to “constructionism” (“where the material world or what has been framed as nature is also understood as contingent”) has been accompanied by an interest in “new materialism” (Roberts 2016, 115).¹¹ Also referred to as the “biological turn,” new materialism is characterized by an attention to the “entanglement, a non-separability, of biology with/in sociality” (N. Davis 2009, 76) and the “processes and activities” whereby the “ongoing mutual shaping of the biological and the social” produces “encultured biological organisms” and “biocultural creatures” (Frost 2014,

322-23). This approach is exemplified by the work of feminist biologist Anne Fausto-Sterling (2005). Through the example of bone development, she suggests that the body is "simultaneously composed of genes, hormones, cells, and organs—all of which influence health and behavior—and of culture and history," the result of which is that we are "always 100 percent nature and 100 percent nurture" (1495, 1510).¹²

Like feminist scholars, biomedical scientists have also become increasingly interested in sex-based biology, particularly in the context of infectious disease (even if, as Fausto-Sterling observes, much biomedical research "seems strictly to deal with sex in the 1970s feminist meaning of the word" and there remains "a lot of confusion about the terms sex and gender" [2005, 1497-98]).¹³ In the feature article of the Spring 2011 issue of *Johns Hopkins Public Health* titled "Science of the Sexes: Why Hasn't Infectious Disease Research Reflected Fundamental Differences in Women and Men?," Maryalice Yakutchik describes the work of scientist Sabra Klein, which demonstrates that women mount a stronger immune response to the flu than men. As Yakutchik explains, "[Women] don't just feel worse. They don't just visit doctors more or complain more. They literally experience worse disease than males" (2011, 25). Klein's work has been one of a series of tectonic shifts in the field of sex-based biology, which includes, among others, the 2006 founding of an academic society called the Organization for the Study of Sex Differences, the formation of centers for the study of sex-based biology, and calls for the reevaluation of the dosage of viral vaccines administered to women.

At the time of my research, some Lyme-literate physicians, whose approach is tied to the biological reality of chronic Lyme disease, had taken an interest in Klein's work and were hopeful that future clinical studies might shed light on the relevance of sex differences in the disease they treat. As a researcher who collaborates with a Lyme physician concluded in the article above, "These are people who were told by their physicians that they are just depressed... . Well, if they weren't depressed before the rash, then there's got to be more to it. That can't be the end of the story" (Yakutchik 2011, 29). In the years since my research ended, interest in the relationship between Lyme disease and sex differences has continued to grow, a trend that signals new ways in which the lived experiences and ideas of Lyme patients, physicians, and scientists might continue to put flesh on new materialist bones. For example, one study conducted by scientists who position themselves between Lyme's two camps found "clear sex-based differences in initial and later CCL19 reactivity [immunological response] to early Lyme disease" (Rebman et al. 2014, S1), while another study conducted by mainstream Lyme scientists concluded that "males and females with culture-confirmed early Lyme disease had similar clinical features, rates of seropositivity, and long-term outcomes" (Weitzner, Visintainer, and Wormser 2016, 493). And on January 6, 2020, a Lyme advocacy organization published a blog post titled "Lyme Disease Prevalence: Does Sex Matter?," which included a video presentation by a Lyme-literate physician to explain "how males and females with Lyme disease might differ" and announced the "launch" of a study on this topic using data from the organization's patient registry (Johnson 2020).

Furthermore, from an analytical perspective, the field of sex differences and disease invites an anthropological engagement that simultaneously takes into account sex and disease. As Annemarie Mol observes, while it "may seem that 'studying perspectives' [of disease] is a way of finally attending to 'disease itself,' ... the body's physical reality is still left out," and "the disease recedes behind the interpretation" (2002, 11-12). As a corrective, Mol calls for an ethnography of ontology that, in "foregrounding practicalities, materialities, events," attends to how disease is "done" (12-13). Taking its cue from Mol and the new materialists, anthropological attention to sex and disease would

require that we move beyond Judith Butler's (1993) intervention of examining the materialization of the body through the performative enactment of linguistic signification to the materiality of the body in interactive practice.¹⁴ Where Butler asks, "How is sex materialized?," an attention to sex and disease pushes us to ask, "How does materiality enact sex?" If, as the *Biology of Sex Differences Journal* observes on its website, "the function of cells and organs depends on their sex, determined by the interplay among the genome and biological and social environments," then sex is neither located in the predetermined status of genitals, chromosomes, and hormones, nor merely in linguistic formation, but, as philosopher of science Georges Canguilhem observes, in the continuous and contingent interaction of the nonbinary materiality of the "living" with the social and historical "signals" and "excitations" of its "milieu" ([1965]2008, 111).¹⁵ What dimensions does the relationship between sex and gender gain or lose when sex is understood to be produced by the interactive materiality of the living within a particular "time and space" (E. Roberts 2016, 120)? And, as knowledge about the implications of sex differences in Lyme disease continues to cross the porous boundary between laboratory and life, how will it inform the way individuals understand sex and gender in the context of disease, and which emancipatory and/or exclusionary ideas and experiences will it enable or foreclose?

Hints of answers to these questions can be found in the way that some physicians I interviewed between 2010 and 2011 were already entertaining the simultaneity of sex and gender in their approach to Lyme disease. For example, one Lyme-literate physician spoke at some length about the relationship between sex and gender in Lyme disease. She explained, "If it means anything, I would say—and I'd be kind of guessing—but I would say for every male Lyme disease patient I used to see in my office, I would see four or five females. So there's definitely a good ratio of four or five to one. There are definitely a lot more women." And as for why this is the case, she explained,

I think, well gee, it's probably multifactorial. I think a lot of women are so busy that they may not be paying attention to a tick bite or a rash or some vague symptoms. And so it may take them longer to get to the doctor only because we know that women tend to multitask a lot more than men. From a pure biological standpoint, I think that men may actually feel—as much as they say you can't feel the ticks and you can't feel them bite because they have the local anesthetic in their saliva and da, da, da—I think the hair, the extra hairiness of men may be protective. Or there may be some type of pheromone that's not attracting the ticks to a male as opposed to a female. We know it's the CO₂—I don't know if there's a difference in CO₂ content between men and women. But anyway, so that's that.

She continued,

And then another biological aspect is that hormones and estrogen play a big role in symptomatology. The reason I say that is that little girls who are diagnosed with Lyme and treated before puberty tend to be cured, for all intents and purposes. But if they have Lyme disease and they're not completely treated and they've already entered puberty and they start with all their cycles, it's a lot more difficult to treat them afterward. So there's got to be some link with estrogen and progesterone. And I think, just speaking frankly, a woman going to a male physician, many times the male physician doesn't take the woman's symptoms seriously. I mean look at what happens with heart attacks and chest pain. And that's because women tend to have atypical symptoms when it comes to heart disease. I mean they're not going to have the typical angina-type symptoms that a man would have. So that's why they have a higher mortality rate, too, because it takes them so much longer to get attention. So I think that's part of it with the Lyme.

Another physician echoed these thoughts when he exclaimed,

It comes down to gender differences and immune responses! It's the perfect storm: there's something biological happening in which women are developing a different immune response to infectious disease and are prone to bad outcomes. It's the way that they're wired that predisposes them to feel this way. And then, socioculturally, society tells them they're goofy and makes them neurotic because the system treats them like garbage. That's not the cause, that's the result.

In their observations, these two physicians gesture to the processual, interactive, and mutually constituted possibilities of sex and gender in the formation of Lyme patients' illness experiences, where the "something biological" of "different immune response[s] to infectious disease" meets a "sociocultural" "system" that produces "gender differences." With an intersectional eye toward the exclusionary possibilities of the sex/gender binary, what these physicians do *not* say is equally important. In this case, the absence of race's mention also reveals the extent to which the enfleshment of the sex/gender binary is racialized. Indeed, all thirty-four patients I formally interviewed were White, and in all of my interactions with patients at advocacy events, conferences, and physicians' practices, I cannot remember meeting a person who was not White.¹⁶ Although the topic of race did not arise within these "white spaces" (Anderson 2015), there is a shared perception among physicians and scientists that Lyme disease is less common among African Americans. For example, a Centers for Disease Control (CDC) study that analyzed 2002 data from the National Notifiable Diseases Surveillance System found that the incidence rate for Lyme disease among White Americans is "approximately 11 times greater" than it is among African Americans (Adekoya 2005).

A prevailing assumption within the medical literature has been that Lyme's racial disparities can be "attributed to differences in risks of exposure, primarily due to area of residence" (Fix, Peña, and Strickland 2000, 756). The one study that explicitly examined Lyme's racial disparities, however, sampled a rural Lyme-endemic area in Maryland with a larger than national average representation of African American residents and found that, although there was a "diminution in the differences in incidence of Lyme disease between Whites and African Americans in a rural area of endemicity," there were also discrepancies that could not be explained by area of residence risk alone (Fix, Peña, and Strickland 2000, 758). The authors proposed "difficulty in recognizing the rash [because of skin color]," "lack of awareness of the significance of the rash," "poor access to health care," and "bias of diagnosis by health providers who believe that Lyme disease is relatively rare in African Americans" as other possible causes (758). Furthermore, in the almost two decades since that study was published, American suburbs have undergone substantial demographic changes, with minorities representing "at least 35 percent of the suburban population" in "36 of the 100 largest metropolitan areas" (Frey 2018, 159). This trend further complicates the assumption that Lyme's racial disparities are due to differences in area of residence risk alone.

What other explanations remain? Data on the impact of clinician bias on racial disparities in pain management—in addition to the impact of "medical racism" on clinical care more generally (D.-A. Davis 2019; see also Bridges 2011; Rouse 2009)—support the idea that Lyme disease, whose clinical diagnosis often relies on patients' subjective reports of discomfort, might suffer the same fate (Hoffman et al. 2016; Singhal, Tien, and Hsia 2016).¹⁷ Coupled with the assumption that "Lyme disease is relatively rare among African Americans," one can continue to speculate about the diagnostic failures that might occur when African Americans—and patients of color, more generally—present with nonspecific symptoms in the absence of a rash that conforms to the rashes seen on White bodies.¹⁸ [Correction added September 21, 2020, after first online publication. The word "typically" was removed from the previous sentence following "rashes."] As a result, it appears ever more likely that the invisibility of individuals of color within the Lyme landscape—in both

the CDC's statistics and at Lyme support groups—is due, in large part, to the enduring structural violence of, among others, reduced access to health care, insufficient information dissemination, and medical racism within the health care system. By revealing how the sex/gender binary is disrupted and reinforced in everyday life, in addition to how its enfleshment is deeply racialized, Lyme's ethnographic insights provide nuanced empirical grist for new materialist thinking about the lived configurations of being "biocultural."

Notes

- 1 Proponents of the mainstream standard of care diagnose early Lyme disease by a rash known as erythema migrans or a positive antibody test, treat with two to four weeks of antibiotics, and, in doing so, adhere to the clinical guidelines formulated by the Infectious Diseases Society of America (IDSA) and adopted by the Centers for Disease Control and Prevention (CDC). In contrast, proponents of the Lyme-literate standard of care diagnose Lyme based on a complex manifestation of symptoms with or without a positive antibody test, treat patients with extended oral and intravenous antibiotics, and, in doing so, adhere to the clinical guidelines published by the International Lyme and Associated Diseases Society (ILADS), the professional organization created in opposition to the IDSA in 1999.
- 2 Because the CDC does not recognize chronic Lyme disease, chronic Lyme is not epidemiologically surveilled, and its demographic distribution is largely a guessing game.
- 3 Although the specialty of the Lyme-literate physicians I observed was primary care, those of the mainstream physicians I observed included infectious disease and rheumatology, in addition to primary care.
- 4 All names used in this article are pseudonyms.
- 5 I use the term "biological" in the context of chronic Lyme disease to describe an organic pathophysiological process. Because mainstream physicians argue that the bacterium that causes Lyme disease does not persist in the body at pathogenic levels after standard antibiotic therapy, they classify chronic Lyme disease as an "illness" (a subjective experience of physical distress) rather than a "disease" (a condition substantiated by biophysical markers that warrants biophysical intervention). Although mainstream physicians use the term "post-treatment Lyme disease syndrome" to describe what they perceive to be the small number of patients who continue to experience symptoms after treatment for acute Lyme disease, they argue that the majority of chronic Lyme disease patients do not have this syndrome.
- 6 *Borrelia burgdorferi* is the bacterium that causes Lyme disease.
- 7 When chronic fatigue syndrome (CFS) first emerged in the 1980s, it was described as the "yuppie flu" because it was perceived to be more prevalent among affluent, highly educated women. Like CFS, chronic Lyme has also been described as a "yuppie disease" because of the perception that it disproportionately affects affluent women. Feminist author Maya Dusenberry argues that CFS only appeared to be more prevalent among this demographic because, due to the "structural violence" of economic and racial inequalities, these are the individuals who "had the resources to pay for repeated doctor's visits" and "enough authority to repeatedly reject those doctors' conclusions that they were just 'depressed'" (Galtung 1969; Dusenberry 2018, 261). For further reading on perceptions of the relationship between wealth and ill health in the context of Lyme disease, see Dumes (2020).
- 8 For further interdisciplinary reading on women's experiences in biomedical clinical settings, see Fee and Krieger (1994), Pringle (1998), Russell (1995), Todd (1989), Vertinsky (1994), and Waitzkin (1991).
- 9 Lyme-literate physicians would also occasionally provide gendered explanations to desubstantiate the biological reality of chronic Lyme disease. For example, one physician exclaimed during our interview, "You've seen those moms, the 'Greenwich ladies.' There's a lot of overprotection there. A lot of overamplification of their children's symptoms. Some of their kids are not that sick."
- 10 One woman at a support group meeting did muse about whether the overrepresentation of women among chronic Lyme disease patients could be hormonally related.
- 11 For further new materialist readings, see Alaimo and Hekman (2008), Barad (2003), Coole and Frost (2010), Hekman (2010), Hird (2004), Keller (2010), C. Roberts (2007), and Wilson (1998, 2011).
- 12 For insightful reflections on whether analytical attention to materiality "produc[es] a politics that does not really matter" and the need for a "contextualized and situated materialism" that engages with postcolonial science studies, see Washick et al. (2015, 77) and Roy and Subramaniam (2016, 36), respectively.
- 13 Since 2012, members of the Sex and Gender Women's Health Collaborative at Brown University have expanded on the field of sex-based biology through the creation of "sex- and gender-based medicine," the primary aim of which is to "foster the integration of a sex and gender approach into medical education to improve

- healthcare for all." <https://www.brown.edu/about/administration/biomed/women-in-medicine-and-science/sex-gender-womens-health-collaborative-sgwhc>. Accessed August 22, 2020.
- 14 In later work, Butler seems to pivot slightly by suggesting that "sexual difference is neither fully given nor fully constructed, but partially both" (2004, 186). However, even here she reaffirms a nonentangled division between the biological and the social by concluding that "what is constructed is of necessity prior to construction, even as there appears no access to this prior moment except through construction" (186).
- 15 <http://www.bsd-journal.com/>. See also Fausto-Sterling (2018).
- 16 In capitalizing "White," I follow Eve L. Ewing (2020), who argues that capitalization attends to the "specificity and significance of Whiteness" and helps to dismantle "its seeming neutrality" and "power to maintain its invisibility." See also Painter (2020) and Appiah (2020).
- 17 Hoffman et al. found that "disparities in pain management" are correlated with clinician biases about biologically based racial differences, including the belief that "blacks age more slowly than whites" and that their "nerve endings are less sensitive" (2016, 4298), while Singhal, Tien, and Hsia found that "there are significant racial-ethnic disparities in opioid prescription and administration for non-definitive conditions" (2016, 11).
- 18 See Nolen (2020) for a discussion about Lyme disease and how "patients of color are grossly underrepresented in medical educational material" (2490).

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