Whose Lyme is it Anyway?: Discursive Representations of Gender in Chronic Lyme Disease

by

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Preface

The idea for this project came to me one day last spring when my very straight-laced biology professor suddenly informed our class that Lyme disease came from the Plum Island Animal Disease Center and got to Connecticut through ticks riding on the backs of deer as they swam across the Long Island Sound. She alleged that this research center for animal diseases, a site of Cold War biological weapons development, had created the disease-causing bacterium and accidentally set it loose on the island. She assured us that deer really do swim across the sound, and this is how Lyme disease arrived in Southern Connecticut in the early 1970s. I thought to myself, “Yes! This explains everything about Lyme disease and its controversy!” At the time, most of what I knew about Lyme came from an American Girl Magazine article about a girl’s mystery ailment being misdiagnosed for months and socially ostracizing her, which I read when I was nine. Basically, I did not know much. Cue more research (the Wikipedia entries for “Lyme Disease” and “Lyme Disease Controversy”).

The conspiracy theory approach to understanding Lyme’s controversy didn’t pan out as a thesis topic, but I still wanted to understand why a bacterial infection ostensibly treatable by antibiotics was so contentious in the present day. I also could name several celebrities who talked about their experiences with Lyme disease and wondered why this was happening. This thesis represents the culmination of the intervening months of research on the diverse discourses produced in American culture today around Lyme disease and its potentially chronic nature. This research would not have been possible without the support of a grant from the Davenport Committee that allowed me to begin research this past summer, and of course my advisor, Anthony Hatch, who fostered this project since last April and guided me tremendously throughout. This thesis is a true collaboration that could not exist without him.

Thanks to the Science in Society Program for training me to analyze scientific objects and practices from diverse disciplines. It is impossible to summarize what I have learned in this major and that seems like a great thing. Thank you also to Joe Rouse for unofficially mentoring me in my time here and for teaching me so very much.

I would also like to thank Ella Weisser and Luke Macdonald, without whom I would have lost hope for this project long ago. Your encouragement and sage advice propelled me and this thesis through the past seven months. Thank you to Katya Deve, Lara Hetzel, Kaitlin Chan, Alex Senauke, Bria Grant, and Anna Bisikalo for the solidarity and support you all generously gave me this year.

Thank you to my parents for everything, really. Thanks, Liliana for being my sister.

Ok. Let’s talk about chronic Lyme disease.
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Introduction

Lyme disease has emerged in today’s culture after a long history in the margins of medicine prior to its formal discovery in 1975. It was recognized with a crop of juvenile arthritis (normally an extremely rare disease) cases in the towns of Lyme and Old Lyme, Connecticut and the bacteria responsible for the disease was discovered by a medical entomologist, Willy Burgdorfer, a few years after. The creation of Lyme disease as a medical entity is significant in light of the controversy that has emerged since the 1990s over an illness known as chronic Lyme disease. Most doctors and the CDC agree that Lyme disease is a short-term infection treatable by antibiotics, but may have a severe impact on a patient’s health if left untreated (this is known as Late-Stage Lyme disease) (CDC 2016b). They also agree that after treatment some symptoms of the disease may persist, possibly as a result of the bacteria’s damage to tissues; this is called Post Treatment Lyme Disease Syndrome (PTLDS). Where the disagreement over symptoms, diagnosis, and treatment begins is chronic Lyme disease, which shares characteristics with PTLDS and Late-Stage LD, but may not necessarily be preceded by a typical Lyme infection. Sufferers of chronic Lyme disease claim a broad range of symptoms as signs of long-term infection with the Borrelia burgdorferi bacterium at levels too low to be detected on standard laboratory tests.¹ Chronic Lyme disease intersects with the process of biomedicalization² both historically and conceptually, and this has significant

¹ More specific features of chronic Lyme will be discussed below. Symptoms can range from musculoskeletal pain to neurological symptoms to psychiatric conditions (Burrascano 2005).
implications for how we consider this controversial condition. There is a vast breakdown in understandings of the epistemology, cultural context, and experiential validity of the condition known as chronic Lyme disease between those who believe in it (some doctors and many advocates and sufferers) and those who don’t (most doctors and medical institutions, such as the CDC and the Infectious Disease Society of America, the IDSA).

Lyme disease, in its most mainstream, typical sense, is a highly treatable, usually short-term infection caused by various subtypes (called genomospecies) of the bacteria *Borrelia burgdorferi* sensu lato (meaning in the broad sense). In the United States *B. burgdorferi* sensu stricto (in the strict sense) is the only subtype that is known to cause Lyme disease (Murray and Shapiro 2010). A tick bite from an *Ixodes* tick infected with the bacteria can result in a bulls-eye shaped rash at the site of the tick bite called erythema migrans (EM) in anywhere from 70-80% of patients, though as with most facts surrounding Lyme disease, this is contested, with many Lyme advocacy groups claiming that fewer than half of Lyme patients ever experience the rash (CDC 2016b, ILADS 2017) The EM rash is the first criterion doctors use in diagnosing Lyme, along with a reported recent tick bite (Stanek et al. 2012). The patient will usually also present with flu-like symptoms such as fever, chills, headache, muscle and joint pains, and swollen lymph nodes (CDC 2016b). Because ticks are very tiny, many people do not notice a tick bite right away, if ever, and the longer a tick has to feed, the more likely the chance of transmission. Usually this only occurs after at least 36 hours (Shapiro 2014). If the virus has disseminated through the skin’s blood vessels, additional erythema migrans rashes may be seen on other
parts of the skin as well (Stanek et al. 2012). In these early stages of infection serological testing for the disease is not recommended as the bacteria might not be present at high enough levels, and the tests have poor sensitivity. Often doctors will start patients on antibiotics and wait to confirm Lyme later as a precaution. In this early stage, treatment usually is effective and the patient can make a complete recovery (Stanek et al. 2012).

When a patient does not notice a tick bite or a rash, or otherwise delays treatment, the disease can become much harder to treat and diagnose. In the US a common presentation of untreated Lyme is arthritis, often in one knee (Shapiro 2014). Late stage Lyme, also called late disseminated Lyme as the bacteria has disseminated through the bloodstream and throughout the body, can also result in chronic neurological issues. According to Murray and Shapiro, treating late Lyme is much the same as for early stages of the disease, and a course of oral antibiotics is usually sufficient (Murray and Shapiro 2010). Arvikaar and Steere (a co-discoverer of Lyme disease) recommend IV antibiotics if the disease fails to respond to one or two 30-day courses of oral antibiotics (Arvikaar and Steere 2015).

Serological testing for Lyme disease is an accepted standard in diagnosis, especially in the absence of telltale signs such as an EM rash. The approach set out by the CDC is two-tiered; it involves first an enzyme-linked immunosorbent assay

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3 Lyme disease has been present and well-studied in Europe before it came to medical attention in the 70’s in Connecticut. In Europe, dermatologists from the early 1900s knew it as a rash (called *erythema migrans* here first) that responded to penicillin, and was thought to be caused by the European sheep tick, *Ixodes ricinus*. A different bacterium, *Borrelia azfelii*, causes European Lyme disease which manifests with more neurological symptoms than its American counterpart. From now on, I am speaking of the specifically American bacterial strain and disease.
ELISA) which detects antibodies produced by the immune system against *B. burgdorferi* bacteria, then if ELISA results are indeterminate or positive, a second test using a Western blot (another, more specific antibody-based test) confirms the diagnosis (Arvikar and Steere 2015). This approach is built to combat the uncertainty inherent to serological testing, where both false-negatives and false-positives are possible. In the early stages of the disease the bacteria may not be disseminated and so false negatives are common, and infection with other bacteria such as *Trepomena pallidum*, the causative agent of syphilis, can lead to false positives, so other diagnostic criteria such as living in a high-risk Lyme area are necessary to consider as well (Bratton et al. 2008). The ELISA is sensitive (can detect true positives), but not always specific, and equivocal results are tested again through a Western Blot, which has a higher specificity (the ability to determine true negatives). There are two kinds of antibody that the Western blot detects, IgM and IgG, and usually only IgG antibodies are accepted as confirmation of Lyme infection, as the presence of only IgM antibodies, which are quickly produced at the onset of infection and therefore less specific, is a common sign of a false-positive (Arvikar and Steere 2015).

According to the CDC, Lyme disease is endemic to parts of the Northeast as well as the Midwest, but this, too is contested by many in the battle for the truth about Lyme disease. Doctors in the south have noticed illnesses that strongly resemble LD among their patients, but have faced backlash from the CDC in trying to report these cases as Lyme disease (CDC 2015) (and Columbia medical center page, need to reformat citation). Though these diseases present remarkably similarly, they are transmitted by a different species of tick (the lone star tick in the South, vs the
blacklegged tick in the Northeast and Midwest) and so the southern version is called Southern Tick-Associated Rash Illness (STARI).

Blacklegged ticks live in the woods across the world and feed on deer and small rodents. Though their distribution is widespread, incidence of Lyme disease has restricted to the northeast because vector ticks do not always carry the bacteria. The bacteria are most commonly found in Northeastern ticks. Heavily wooded regions such as Connecticut that are also fragmented by roads and urban and suburban areas have an increased incidence of Lyme disease because these favor smaller animals, which are better vectors of the bacteria than large mammals like deer. While it was originally assumed that white-tailed deer were the chief reservoir for Lyme-carrying ticks, it was later discovered that they make very inefficient reservoirs compared to white-footed mice, which can infect 75-95% of the ticks that bite them (Ostfeld 2011).

In 1975, Allen Steere and colleagues were alerted to what appeared to be an outbreak of juvenile rheumatoid arthritis, normally a very rare disease, in tightly clustered cases within three communities in Southeastern Connecticut. Both adults and children—though children had higher rates of infection—were affected by intermittent joint swelling and many those affected reported a large, red, ringed rash (Edlow 2003). Steere and colleagues called the condition “Lyme arthritis” and predicted that an arthropod vector was responsible (Steere et al. 1977). Though they initially assumed a viral etiology, they eventually began testing antibiotics to treat the disease, and realized they were dealing with a bacterial infection. The bacteria which causes Lyme disease evaded discovery for years after the disease began to be studied.
Willy Burgdorfer, an entomologist at the Rocky Mountain Laboratory studying other arthropod and tick-borne diseases, identified the it by isolating corkscrew-shaped bacteria called spirochetes in both *Ixodes* ticks from Lyme hotspots and the serum of infected patients (Burgdorfer et al. 1982). The bacterium was named *Borrelia burgdorferi* in his honor. This class of bacteria use internal flagella to propel themselves in a spiral motion through their environment (Edlow 2003). This phylum—which also contains *Treponema pallidum*—remains mysterious in microbiology. The species was impossible to culture for years after its discovery, and its ability to avoid detection by the host’s immune response to has been studied (Kraiczy et al. 2002, Berndtson 2013).

Most mainstream accounts of Lyme disease follow a narrative such as the one above, wherein its discovery is more or less misrepresented as arising in Connecticut and its journey into the medical mainstream in America is presented often with an uncritical eye towards the doctors and scientists who began investigating what they thought was an outbreak of juvenile rheumatoid arthritis in Southern Connecticut in the mid-1970s. This is one version to the story, or more accurately many similar versions, which gloss over the long history of Lyme disease in Europe prior to its official “discovery” in Connecticut. It also elides the complicated and socially mediated investigative research process the Yale team experienced prior to their formal “discovery” of Lyme disease as we now know it, along with the 1982 discovery of *Borrelia burgdorferi* as the causative agent of the disease. It is through this more complicated and contingent history that accounts of chronic Lyme disease acquire coherence. A tidy medical history of Lyme simply does not leave room for a
controversial, nebulous condition to emerge from the straightforward short-term Lyme infection. I am not attempting a historical account of chronic Lyme disease in this thesis, but instead rely on historical and sociological accounts of Lyme disease below to clarify the context and emergence of chronic Lyme disease.

The Case of Chronic Lyme Disease

Chronic Lyme disease denotes the ability of *B. burgdorferi* spirochetes to persist in the body if treatment is delayed or ineffective. Proponents say spirochetes can disperse into various tissues and body systems, leading to diverse symptoms involving “the brain and nervous system, muscles and joints, heart and circulation, digestion, reproductive system, and skin” (LymeDisease.org 2017). The only difference between post-treatment Lyme disease and chronic Lyme disease is that most doctors and the CDC believe the former is real but rare, and possibly caused by damage to tissues after antibiotics have eliminated bacteria from the body, while they widely reject the possibility of a persistent *B. burgdorferi* infection causing Lyme disease to be chronic (CDC 2016a). Chronic Lyme advocates claim that the condition is debilitating and painful, and turn to “Lyme literate” doctors who are willing to diagnose and treat Lyme disease based off these diffuse symptoms that are widespread in the general population, especially among adults (Feder et al. 2007).

Chronic Lyme disease is a site where gender matters. Patients with Chronic Lyme disease are around twice as likely to be female, whereas those with Lyme infection or post-treatment Lyme disease syndrome are more evenly split by gender (Wormser and Shapiro 2009). The potentially chronic nature of Lyme disease is
highly significant to how gender works in this situation, because of how gender works in diffuse, “mysterious” chronic illnesses.

The fact of the matter is that Lyme is—epidemiologically speaking—not a women’s disease. Lyme is a vector-borne infection that ostensibly affects anyone walking around where ticks are and getting bitten, regardless of gender. However, features of both illness and femaleness in American culture connect chronic Lyme disease to gender. (I am specifically speaking about America as this is where Lyme has taken on enormous cultural power and sharply disparate meanings.) When women go to the doctor and report diffuse, complex symptoms, only to be disbelieved about their pain, gender is working in that situation. In October of 1975, when Polly Murray and Judith Mensch nearly simultaneously brought Lyme disease to the attention of medical authorities, they did so as concerned mothers and community members, seeing a mysterious illness affect many children their small-town Connecticut communities. That they struggled to be believed by their doctors at first can also be connected back to gender. Invalidism, hysteria, and hypochondria are labels that have all become attached to Lyme disease, and their gendered history and cultural significance can be traced from ideas about class, race, illness as they constitutively affect gender throughout American and Western History. These meanings profoundly alter how Lyme disease is viewed and understood today.

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4 This thesis analyzes chronic Lyme disease and its relation to gender in American culture. It also considers the role of class and its intersections of gender in this context, but I have largely left race out my analysis—though there are many interesting connections in the history and sociology of Lyme disease relative to race—primarily because my theoretical framework better accommodated questions about gender and class than about race, and because of time and space constraints.
A few doctors and historians/sociologists of science have analyzed this complicated history of Lyme disease in an attempt to explain how it has become a controversial, culturally prevalent, and distinctively American disease, despite its widespread occurrence and longstanding history in Northern Europe and straightforward bacterial etiology. These analyses, presented in Johnathan Edlow’s *Bull’s Eye: Unraveling the Medical Mystery of Lyme Disease* and Robert Aronowitz’s chapter of *Making Sense of Illness* on Lyme disease, “Lyme Disease: The Social Construction of a New Disease and Its Social Consequences,” use the historical and sociological context of Lyme disease’s emergence to show how it has come to be both present in the America cultural imaginary and highly contested and controversial from the 1990s onward.

Edlow takes a view of Lyme’s history that relies on the contingent factors affecting medical research to explain its contested status today. He writes of the unwillingness of the Yale team to initially consider a bacterial etiology for the disease they were studying, because they were unfamiliar with its connection to the Erythema Migrans rash described extensively in European medical literature, wherein doctors reported favorable outcomes in the sheep herders affected by the condition from antibiotic treatment (Edlow 2003). The medical uncertainty present since the beginning of Lyme disease’s history in America has carried over into the present day, according to Edlow, and ranges from debates in the early 2000s over a Lyme vaccine’s safety to insurance coverage of long-term antibiotic therapy. Edlow describes the divided medical opinion on chronic Lyme disease in terms of Kuhnian paradigms that are incommensurable and thus can each only be debated on their own
terms. He stresses the need for more research to occur if the alternative, chronic Lyme
camp is ever going to convince the conservative camp of their paradigm in diagnosis
and treatment (Edlow 2003).

Aronowitz gives a social constructionist account of Lyme disease to describe
how it has come to figure so heavily in the American medical and lay psyche. He
argues that diseases, even when they are not stigmatized, ambiguous in etiology, or
lethal, still abound with social meaning, although those specific categories have
previously been the sites of social constructionist analyses of diseases for their
powerful connotations. Diseases, within these criteria or otherwise, have always
figured prominently in American and Western culture (alongside notions of pain and
suffering), and discourses around particular illnesses form from relations of power
that define what it is to be ill (Strick 2014, Canguilhem 1989). In this case, Aronowitz
argues that Lyme disease was built as a “categorically new disease” by (crucially)
American rheumatologists, and that potential other social and scientific responses
could have emerged from the same biological phenomena (Aronowitz 1998, 58). Out
of this history, Lyme disease’s status as a new disease led to much greater fear and
panic among Americans, as “what is new is often more frightening” (Aronowitz
1998, 72).

Aronowitz also attributes the controversial nature of chronic Lyme disease to
Lyme disease’s newness in America. The clinical picture of Lyme disease, he argues,
is complicated by the current widespread use of antibiotics to treat the disease, which
leaves medicine without a picture of its natural history in the absence of antibiotic
treatment. (This exists for syphilis, the late stages of which were widely studied prior
to the discovery of antibiotics.\textsuperscript{5}) Testing for chronic Lyme is besieged with complications, but perhaps more importantly Lyme disease “is socially perceived to be a fashionable diagnosis with a large market,” leading to increased incentive for doctors and patients to land on a diagnosis of Lyme disease, regardless of the presence of “objective signs of disease” (Aronowitz 1998, 75). With chronic Lyme disease, doctors must rely on subjective symptoms like fatigue and pain, which creates a tension “over the patient’s reliability and psychological state” (76). Lay advocates for chronic Lyme disease often respond to this tension by seeking to privilege this subjective dimension to diagnosis, and may attribute physician hesitancy to diagnose from these features as “resulting from their ignorance of the ailment’s protean nature.” (76). Lay appeals to phenomenological understanding contain a contradiction, Aronowitz argues, in that “the depict value-neutral science as the ultimate arbiter of legitimacy while attacking the hegemony of contemporary medicine” (77). Aronowitz also turns to narratives to explain the stigmatizing power that chronic Lyme disease has come to hold. He says that “stigma results from doubts about whether the illness of the person with chronic Lyme disease is caused by disease” (78).

Edlow and Aronowitz’s explanations allow me to engage a working history/sociology of medicine that accounts for the role culture and historical setting play in how we view diseases and their meanings. These accounts present Lyme disease as a site of controversy because of the legitimacy that infection with \( B.\)

\textsuperscript{5} Including, notably, in the Tuskegee Experiment, showing the racist history of syphilis research in America.
*burgdorferi* bacteria offers to patients with an apparent/clear illness but unclear disease. I am using Klienman’s distinction of disease from illness, acknowledging the personal import of illness alongside the cultural and personal legitimacy that disease explanations can bring to sufferers (Kleinman 1988). As I have said above, the controversy and prevalence within the American psyche that Lyme disease has acquired significantly operates through conceptions of gender as they relate to illness. Moving on from the historicizing and social constructionist arguments of Edlow and Aronowitz about Lyme disease, I will use the lens of gender to analyze how chronic Lyme has taken on its controversial role in 21st century America.

This history of chronic Lyme disease, with its concomitant context of biomedicalization, shows three particular sites of contestation over the meaning of chronic Lyme disease: its clinical, cultural, and experiential meanings. Each of these illuminates an important lens for understanding how meanings become attached to chronic Lyme disease and how various actors producing the discourse around chronic Lyme have come to disagree so starkly.

First, I will use the analytic framework of feminist epistemology and criticisms to objectivity in the sciences to critique what I see as the masculinist standards governing the creation and ontology (including diagnostic criteria and treatment) of chronic Lyme disease. When looking at chronic Lyme disease from a clinical angle, I believe that our empirical and scientific knowledge is contingent and underdetermined by the evidence at hand, which leaves room for chronic Lyme disease to hold legitimacy despite research critical of its reality. We can ask the question: to what extent is this controversy a medical, scientific dispute over how
knowledge surrounding disease is produced in our biomedical era? Criticisms to how most scientific research, including epidemiological data and norms of diagnosis and serological testing, enact a weak objectivity, creating a space for a feminist epistemological understanding of Lyme disease (Harding 1991). Feminist sociologists like Dorothy Smith and feminist philosophers of science like Sandra Harding and Donna Haraway have characterized this ideal of objectivity present in the social and natural sciences as a masculine norm that seeks to silence the possibility of knowledge from personal experience (one’s standpoint), and Ludwick Fleck, in describing how scientists discovered a blood test for syphilis, also leaves open the possibility for social and personal influences on the production of scientific knowledge.

From a cultural angle, illnesses have meaning far beyond their biomedical contexts, and this cultural situation of particular illnesses shapes how we understand illness in general, and should shape how we come to understand chronic Lyme disease. Gender (and class, and race) is at play in the cultural situation of Lyme disease and chronic Lyme disease in non-trivial ways. Illness and gender share a long history, detailed in works like *Complaints and Disorders: Sexual Politics of Sickness*, as well as many criticisms of psychiatry. This literature helps explain how culture influences representations, meanings, and perceptions of illness. We can ask: how does the nature of Lyme disease as both a scientific fact and a cultural artifact influence how it is conceived of by the medical community, lay advocates, and

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celebrities? Using the work of Paula Treichler, Sander Gilman, and Susan Sontag concerning how diseases attain cultural meaning and reflect this meaning back onto those afflicted (as well as the larger culture in which the disease and its sufferers are situated) allows me consider the ways in which gender alters cultural perceptions of Lyme and chronic Lyme. Notions of scientific objectivity are challenged, as the cultural meaning of a disease, though not established through objective scientific investigation, is nonetheless present, relevant, and crucial to understanding how the disease exists and impacts people’s lives.

There is another feminist argument to be drawn from Lyme disease and the chronic Lyme controversy, and this concerns the status of suffering and embodied experience that is granted (or not) to those with illnesses in American culture. I want to interrogate what is at stake in valuing and privileging someone’s lived experience of illness and suffering, even when there is doubt and uncertainty about the nature of their disease. Biomedical explanations of disease states have a power to grant legitimacy that conditions with no known biological cause do not possess, while meanings other than positivist, scientific explanations emerge through the experience of illness as felt on a human and even at a population level. These meanings come to matter just as significantly as the scientific meanings and standards that chronic Lyme advocates so adamantly contest, as well as matter on various social levels—gender, class, and race all affect how Lyme disease and chronic Lyme disease are understood by sufferers and the medical community. I examine the work of Andrew Kleinman, a psychiatrist who works with the critically and chronically ill, on how illness narratives that doctors and patients adopt, whether they are similar or disparate, come
to influence how the patient experiences their disease and the suffering that often comes with it. I also look at Leslie Jamison’s writing on recognizing human suffering and empathizing with it, without necessarily accepting personal explanations of suffering. When a disease is controversial or not accepted by the medical community Jamison argues that it’s sufferers are still suffering and therefore still deserving of our empathy. I also turn to Susan Wendell, a feminist philosopher writing about illness and disability as inherently enmeshed in gender. Wendell argues for a feminist epistemology towards disability and its sociocultural ramifications. These arguments complicate the notions of objectivity and truth that medicine as a discipline holds central. When a condition is seen as mysterious in etiology, it is often labeled as psychosomatic or attributed to a psychiatric origin, two designations that are much stigmatized and also subject to medical neglect or uncertainty (Sontag 2002, Kleinman 1988). An objective truth about a disease, diagnosis, or treatment plan may have little to no bearing on the reality that those who are affected experience, and their standpoints and embodied conception of their situation come to be effectively and crucially just as objective as mainstream biomedical discourse surrounding illness. This is a gendered issue because subjective knowledge has traditionally been associated with femaleness, and controversial illnesses also have a long history of subjugating women once labeled as insane.

Moving Forward

In the next chapters I will set up a theoretical framework with which to investigate two facets of chronic Lyme in more specific contexts. The first case, chapter 2, analyzes the discourse around the opinions and perspective of medical
researchers and doctors, lay advocates for chronic Lyme, and mainstream media accounts of the disease. Next, chapter three analyzes the discourse produced by celebrities and reality stars who take up the activism surrounding chronic Lyme and publicly perform this specific embodiment of illness.

Chapter 1 lays out a theoretical framework through which to view representations of chronic Lyme disease seen in the chapters that follow. I use three arguments to ground my analysis: criticisms to objectivity, cultural meanings of illness, and experiential, embodied meanings of illness. Forming the historical context of these three arguments is the concept of biomedicalization, which frames the cultural and clinical meanings of both Lyme and chronic Lyme disease. Biomedicalization informs how the chronic Lyme discourse is produced, and CLD’s status as a biomedicalized entity is a key site of controversy.

Chapter 2 follows the case of chronic Lyme disease through advocacy organizations, divided medical opinions, and mainstream media accounts of this entity, examining how meanings of chronic Lyme are produced through these different actors at different sites of discourse. The questions I ask are: (1) How do doctors, lay advocates, and the mainstream media construct meanings of chronic Lyme using gender and (2) How should we understand chronic Lyme disease, given the stark disparity between mainstream and alternative medical opinion on the subject? These sources reinforce and reiterate each other in various ways, with various results. Divergent medical sources regard with suspicion the power of the media and advocate groups to influence politics, while advocates resent or reject the
epistemic power that doctors and researchers have in elaborating conservative understandings of Lyme disease (Feder et al. 2007).

Chapter 3 turns to media representations of chronic Lyme disease as it appears in celebrity discourse and culture, including reality television, memoir, documentary, and interview. Various female celebrities have not only come out publicly about their struggles with chronic Lyme disease (explicitly or implicitly identified as such), but have allied themselves with advocacy for the condition. The impact celebrities have had on how meanings of the disease are shaped shouldn’t be underestimated, as celebrities have previously played an important role in meaning-making around diseases, such as Rock Hudson and Magic Johnson with HIV/AIDS (Treichler 1999). Using the three frameworks developed in chapter 1, the questions I ask are: (1) How do celebrities shape the meaning(s) of Lyme disease, (2) How does gender operate in this pop culture context to make Lyme disease legible, and (3) How does the aesthetic and affective representation of Lyme disease enacted through these forms specifically alter meanings of the disease as such? The position of celebrity in American culture shapes relationships to knowledge and ideals of empiricism, as celebrities act as cultural gatekeepers and authorities on subjects, making them legible and consumable for larger audiences (Gamson 1994, Marshall 1997). Culturally, celebrities are in a position of enormous power to shape meanings of illness, and subjectively they are relatable and thus make the suffering felt by many Lyme sufferers legible to broader audiences who are not personally affected by Lyme disease.
Chapter 1: Theoretical Framework

I will now set up a theoretical framework through which to view the case of chronic Lyme disease. This framework will consider biomedicalization as a dominating force in medicine today, and use it alongside three theoretical arguments I consider pivotal to understanding chronic Lyme disease. These are criticisms to objectivity, cultural meanings of illness, and the legitimacy of the embodied experience of suffering. These arguments draw on work in the history and philosophy of science, feminist science studies, cultural studies of health and illness, philosophical explorations of disability, and the writing of doctors and lay people on the experience of illness.

1.1 Biomedicalization

Biomedicalization is critical to understanding how chronic Lyme is used in discourse because it provides the historical context for possible subject positions, moves, and knowledge production in medicine today. My three arguments that ground the theoretical framework of this thesis all rest on the assumption that biomedicalization is a driving force in medicine that shapes the epistemological, cultural, and experiential possibilities of this medical entity. Biomedicalization thus frames each of these framing arguments in turn, because it delimits and defines the biomedical possibilities of chronic Lyme disease in the present day. The primary question that arises when considering chronic Lyme disease alongside the process of biomedicalization is whether chronic Lyme is a biomedicalized condition.
In the US, Lyme disease was first brought under medical attention and authority in the 70s, a time directly preceding major upheavals in the fields of medicine and biology from the advent of molecular technologies and other technoscientific innovations. Biomedicalization is the process enacted by these technologies as they shape social conceptions of health, risk, and identity. This concept was introduced by a 2003 Clarke and colleagues paper seeking to examine and explain the dramatic changes they observed in the medical landscape and in public views on medicine. According to some scholars, we were previously in an era of medicalization, wherein medical explanations of previously nonmedical phenomena (homosexuality, PMS, ADHD) were created and implemented, converting them into medical (instead of moral, social, or legal) problems.\(^7\)

Biomedicalization began to emerge alongside increasing technological insight into human bodies and health, and the “bio” prefix used by the authors represents the human and nonhuman transformations at work through molecular technologies, genomization, transplant medicine, and biotechnology (Clarke et al. 2003, 162).

Critically, under biomedicalization, health has become both a commodity and a moral responsibility. Medicine is no longer concerned with simply treating ailments, but is centrally occupied with maintaining and preserving health through identification of one’s personal risk status for illnesses and surveillance technologies that enable tracking of demographic or lifestyle risk level. Risk and surveillance thus become a part of the medical gaze disciplining bodies.\(^8\) As a moral responsibility,

\(\text{---7}\) Peter Conrad, The Medicalization of Society. See also Irving Zola (1972), and in this thesis, Ehrenreich and English on page 45.
\(\text{---8}\) See Michel Foucault, *Discipline and Punish* and “Lectures at the College de France.”
health is seen as individually determined through lifestyle choices (inherited risk aside) and the failure to preserve one’s health is construed as a personal, moral failure. Concomitant with biomedicalization, the scope of medicine has shifted from treating acute (infectious) disease towards managing chronic conditions, and biomedicalization specifically has created a focus on “behavioral and lifestyle modifications (e.g. exercise, smoking, eating habits, etc.) literally promoted by the government among others” as a means of both warding off and managing chronic illnesses (Clarke et al. 2003, 182). In the case of chronic illness, one’s commitment to proper handling and management is similarly a moral obligation. Biomedicalization is also marked by the “co-optation of competing knowledge systems,” wherein alternative medicines like homeopathy and traditional Chinese medicine become more central to Western biomedicine in response to increasing consumer interest in and subsequent economic viability of these products, making them medically legitimate therapies (Clarke et al. 2003, 179).

But health is not just a “base or default state,” it is an “ongoing project composed of public and private performances” one enacts in line with the expectations our entire culture has around health (Clarke et al. 2003, 172). New individual and collective identities are produced under biomedicalization in response to technoscientific discoveries that create divisions not previously visible or considered, and these new social forms can organize around their identities in political and educational capacities. These identity groups have unprecedented control of biomedical knowledges through online discussion boards and patient advocacy group newsletters, resulting in complicated production, distribution, and access to
information which is uniformly presented as objective. It is often unclear, however, if those making medical claims have professional credentials or what outside financial or scientific influences these statements have behind them. Activists for these identities and causes view themselves as participants in the production of medical knowledges for the experienced viewpoint they hold, and some groups even attempt to shape medical research through direct funding.

1.2 Criticisms of Objectivity

Early, traditional philosophical understandings of science privilege empiricism, the notion that the basis of scientific claims and hypotheses can only legitimately reside in sense experience. Historically, Sir Robert Boyle’s experiments with the air pump at the Royal Society contributed to the rise of an experimental science that relied on what could be collectively—and virtually—witnessed among legitimate observers, who at the time were necessarily upper-class white men (Shapin and Schaffer 2011, Potter 2001). Empiricism privileges what can be sensed directly—and indirectly through technologies like microscopes which mediate our sensory experience—in forming knowledge claims. Objectivity is a value that emerges from empiricism concerning the position of the observer in making knowledge claims. Traditionally, the epistemological ideal is objective, meaning knowledge that does not come from a human, biased (i.e. subjective) perspective. Any observer sensing the same phenomena could arrive at the same conclusions, unaltered by personal experience and opinion. In science, this is necessary to positivism, the idea that all claims (posits) are based in sense experience, which emerges from empiricism. Science is thought to produce truthful knowledge because unbiased observers record
data from sensory experience and use it to test hypotheses and posit explanations from these.

The notion of objectivity has a “complicated and contingent history” across domains of knowledge, and originally had an aesthetic and moral significance before becoming integral to science in the nineteenth century, according to historian of science Lorraine Daston (Daston 1992). Daston characterizes the objective ideal present in science today as “aperspectival objectivity” (in contrast to other important forms, ontological and mechanical objectivity⁹), meaning that scientists’ knowledge claims have merit through their lack of contingency on idiosyncratic human experience and particularity. Scientists’ endeavors to produce knowledge from no particular human perspective were due to the changing nature of the sciences as they grew and expanded. While eighteenth century scientists used their situatedness (their class, education, and reputation) as a source of reliability and validity to their claims, the need to expand and divide scientific labor to accommodate larger projects necessitated the creation of tasks anyone, especially uneducated people doing cheap labor, could reliably do, such as working with arithmetic data tables as opposed to mathematical theories. The creation of a large-scale scientific community brought new standards to bear over individual knowledge as collaboration and communication created the need for an averaging of viewpoints so that everyone could work with the same ideas and theories and share data. The standards for what entailed reliable knowledge completely shifted in the history of science from the personal to the

⁹ Ontological objectivity “pursues the ultimate structure of reality”, mechanical objectivity “forbids judgement and interpretation in reporting and picturing scientific results,” such as in drawings of microscopic life (Daston 1992, 599).
apersonal, and though the history and meaning of objectivity, per Daston, is highly varied and contingent, this shift can be seen to have dramatically altered both scientific and commonplace understandings of truth. Daston makes a case for a moral history of objectivity, wherein it has become a “high-minded ideal” more than an a “sociological reality” in the sciences, and still carries weight as a moral imperative—in theory—for scientific conduct.

Any rational observer possessing all their senses could observe phenomena studied by scientists and arrive at the same conclusions, opinions, and worldviews completely absent from this process. When scientists create projects and experiments, however, they do so as humans who have lead certain particular lives, and these cumulative life experiences alter how one sees the world and what questions one considers important to study. In this way, we can say that no science is completely objective. The truths produced by science, which inform our understanding of the world, are affected by what is considered important—for economic, political, professional, whatever reasons—to study and understand.

This is precisely what sociologist Dorothy Smith argues in Conceptual Practices of Power; that objective knowledge is a manufactured concept created by and for those who hold societal power. Knowledge emerges from this relationship of power, and by making claims divorced from the personal and subjective, this status is maintained. That which is based on one’s subjective standpoint is discounted as unreliable and non-universal. Though Smith is writing and thinking from within the discipline of sociology, this understanding can apply to any field that takes the human as its subject, as medicine does. Knowledge produced about a subject comes from an
outside perspective, extrinsic to the subject’s understanding of themselves. Objectified knowledges created in academic settings are embedded in relations of ruling, for example epidemiological data, which is created by describing and categorizing bodies in order to more effectively rule over citizens and subjects. “Objectified knowledge stands as a product of an institutional order mediated by texts,” and it is central to Smith’s argument that women have been historically and systematically excluded from this relation of power. Further, “objectified knowledge, as we engage with it, subdues, discounts, and disqualifies our various interests, perspectives, angles, and experience,” all of which are intrinsic to anyone’s experience of the world and thus claims to knowledge, but especially to identities deviating from the norm of white maleness who must experience the world constantly in light of their situatedness. As Smith says, it is not news that women are considered outsiders to disciplines, academic or otherwise, that produce our cultural and social knowledges. What is of interest to Smith is instead that the knowledge represented by women as outsiders is taken as less objective, less reliable, or less credible, or even is reduced to “mere opinion” (Smith 1990, 101). Thus, the practices of the sciences (social and natural) are destined to reproduce oppressive systems of knowledge-making so long as aperspectival objectivity, as described by Lorraine Daston, is considered the sole purview of those in positions of power.

Many critiques of objectivity have come from the fields of feminist theory and feminist science studies. Sandra Harding is one such feminist philosopher centrally concerned with the ways science is created and used as a tool of oppression by those at the top of social hierarchies, who are able to utilize notions of objectivity to justify
racist, colonialist, or misogynistic research and knowledge claims. Harding identifies a traditionally-held conception of objectivity within the sciences as “weak objectivity,” and describes it as the idea that scientific discovery and justification proceed completely divorced from social, cultural, and historical contexts of this scientific work. Weak objectivity conceives of the context of justification as a sterilized, critically value-neutral process and that therefore is scientifically sound, while situating the context of discovery—the process whereby research is pursued, questions are posed, and hypotheses are designed—“as unexaminable within science by rational methods,” leaving it exempt from standards of objectivity in how this process occurs. This is too narrow a conception of objectivity, argues Harding, as it holds objective standards only to areas where issues of disagreement would not arise, since hierarchical social values that could affect research would not stand out to the racially and sexually homogenous members of most scientific communities, and ignores the need for objectivity in areas of science that certainly are influenced by social and cultural forces. Weak objectivity is also too broad, as it seeks to eliminate all potentially mitigating social values and interests from research, when in fact these forces have always shaped science, and not always to its detriment.

Harding wishes to propose instead “strong objectivity,” a way of doing science that reflexively, “scientifically [examines] the social location of scientific claims” (Harding 1991, 142). This involves legitimating the practices of “critical examination of historical values and interests” that are so pervasive and entrenched in a field “that they will not show up as a cultural bias between experimenters or between research communities” (147). This allows an unseating of a historically
dominant, largely white male perspective in science (that simultaneously denies its own perspectivality) in order to “ask questions about nature and social relations from the perspective of devalued and neglected lives” (150). Harding views objectivity as too useful to reject completely in favor of a cultural relativist view that acknowledges multiplicity in society and history but isn’t able to perform work in evaluating scientific claims.

The fact that science has historically used this program of weak objectivity (Harding calls the concept objectivism) opens it up to historical and contemporary critique from a feminist, postcolonial, or critical race perspective. Science has for centuries operated as a dominating male, white, western gaze in a power relation where the dominant force uses this perspective to exert control over the “Other” (Harding 2008, 156). When science is designed for and by those in positions of power, it turns out to be heavily supportive of those forms of power. Indeed, it is hard to even see women or non-western people as scientific actors outside of explicitly scientific contexts (the lab, the university) because the very “framework used to identify ‘real science’ turns out to be a Eurocentric one also [in addition to patriarchal]” (168). The cultural and gender biases present in sciences that Harding believes strong objectivity could correct are what allow science to persist in serving anti-democratic purposes. As she says, “incompetent and narrowly defined and designed sciences provide important resources for their anti-democratic practices” (169). These conceptions that science is carried out by dominant social actors, “identified only with the kinds of activities and concerns of interest to governments and corporations, from the design and management of which women have been
“excluded” allow the perspective of women and other subjugated groups to seem unscientific, their work to be considered folk knowledge, and their contributions to science to be easily ignored (168). Harding also stresses the interconnectedness of different oppressive forces that operate within society and the sciences that delegitimize certain voices, saying “gender and science projects cannot succeed in eliminating gender hierarchy in the sciences as long as the West vs. Rest hierarchy thrives, and vice versa” (210).

Feminist philosopher of science Donna Haraway similarly wants to reject aperspectival or weak objectivity in how we do science, and argues for what she calls situated knowledges in its practice. She denounces the “God trick of seeing from nowhere” that science attempts to perform with objectivity. This objectivity exists more in theory than in practice, as science is carried out by people who do not believe

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10 Further writing by Harding on the gendered underpinnings of the modernity/tradition as a binary allows a critique of this divide between women and science. A process of modernization or enlightenment is apparently not possible without a simultaneous devaluing and subjugation of women’s status and contributions to knowledge. Female, nonwestern, and other conceptions of “nature and social relations” are often considered “pre-modern” but this knowledge “is often more reliable than that certified by mainstream scientific institutions, such as medical and health institutions and the social sciences” (Harding 2008, 192-193). This is precisely because conceptions of modernity and even science itself are antithetical to privileging or even accepting a female (or otherwise “other”) perspective in these practices. The areas in which women have historically produced reliable knowledge are often considered “folk” contexts related to agriculture, manufacturing, or the body, and these understandings have often been just as, if not more, empirically sound as typically male (thus outsider) perspectives on these concepts that take the form of scientific and medical research. Some would argue, however, that there is a difference in kind between traditional knowledges and hard sciences, and that this difference allows science to bring about significant social progress. Harding disagrees that there is a difference in kind, and wants to legitimate traditional knowledges for their reliability and empirical rigor.

Modernization is characterized by Harding as a separation from a traditional, home-based past, a move from private to public economics and politics, and the use of scientific rationality and technical expertise to make economics and politics modern. There are also what Harding calls “obscured paternal narratives of modernization” at play in distinguishing modernity from tradition. She describes how processes of modernization, which seek to equalize social relations, democratize power, and improve living conditions, are only able to accomplish these goals via the subjugation of women. Modernization projects are apparently predicated upon “men’s escape from, and subsequent control of, women and whatever is associated with the feminine” (199).
in upholding any of the standards of objectivity that they might profess to in “elementary science textbooks,” they instead are beholden to their own perspectives and inherited cultural legacies in how they design experiments, the way their equipment works, how they interpret results, and so on. It is not sufficient to Haraway that this simply support an argument for social constructionism, the idea that any scientific truth is a reflection of and direct consequence of the social values of the scientists positing these truths. Calling all knowledge socially constructed simply does not leave us with enough insight into what might be “real” in the world. It does not allow for any conception of objectivity, if we are always assuming a subjective perspective in the production of our knowledge. Out of this line of thinking Haraway suggests the concept of feminist critical empiricism, from which emerge “situated knowledges,” the only true objective knowledge there can be. These situated knowledges are also embodied knowledges, they can come from positions that are considered other to the norm of white, male, heterosexual personhood. Anyone not of this position has their status outside of it made explicit and their knowledge claims discounted, yet knowledge purported to come from no subjective position is “irresponsible” according to Haraway, as it is “unable to be called into account” (Haraway 1988, 583). This claim to totalizing knowledge purports to have no perspective, and thus potentially any and all perspectives, despite the clear impossibility of this. Because “only partial perspective promises objective vision,” various subjective perspectives must be taken into account in order for a claim to have any chance of telling the truth, so to speak (583). Haraway’s argument for a rigorous analysis of any knowledge claims purporting to be objective is best
elaborated in her own words: “We need the power of modern critical theories of how meanings and bodies get made, not in order to deny meanings and bodies, but in order to build meanings and bodies that have a chance for life” (580).

These problematized and contingent conceptions of aperspectival objectivity presented by Smith, Harding, and Haraway come to a more specifically medical context in Ludwik Fleck’s 1935 book *Genesis and Development of a Scientific Fact* about the development of the Wasserman reaction, a blood test for syphilis. Fleck argues that historical contingencies and what he calls “prevailing thought styles” entirely dictated what research was undertaken in the search for a syphilis test. The title of the book is a reflection of this belief and posits that facts are not discovered but created and developed through concerted efforts of scientists. A prevailing thought style is Fleck’s description of widely held and accepted views within communities (called thought collectives) which circulate and heavily influence what facts and discoveries are produced out of them. In line with this model, Fleck argues that how a given disease is defined determines what conclusions are made about it, and the direction research concerning it will go. Syphilis was understood for centuries as a disease of impure blood without any knowledge of its etiology, and this association is what Fleck alleges led researchers to look for a test of the disease in blood. For this reason, the history of concepts (particularly illnesses) matter to how we understand them today, as this understanding is so entirely contingent.

It is also significant to consider thought collectives and thought styles today with regards to their rigidity and resistance to alternate viewpoints. Fleck argues that these collectives act as a closed system of viewpoints which “resist contradiction and
“revision” and may only be changed by significant remodeling of views within the thought style (Fleck 1979, 27). As he says, “new facts can be discovered through new thinking” (27). The relevance this bears to Lyme research cannot be overstated; both Lyme and syphilis are caused by only moderately understood spirochete bacteria, and serological testing in Lyme disease is one significant locus of controversy. Further, much of the most mainstream medical literature on Lyme disease is written by the same people.

Bringing these (largely 20th century) ideas to bear on our current 21st century biomedical context reveals the legacy that objectivist, male-dominated science continues to have in the medical field. Biomedicalization’s ability to bring previously socially-understood illnesses under the jurisdiction of increasingly molecular and technological medical practice has created an opportunity for Lyme disease sufferers to pursue biomedical recognition of their illness. Chronic Lyme, especially, seems primed to take on a biomedical conception of itself as biomedicalization has shifted medicine’s focus from acute to chronic conditions. Where chronic Lyme breaks from the biomedical mold is in its bacterial etiology. It is interesting that sufferers of chronic Lyme disease, rather than accept a more biomedically-aligned diagnosis such as Chronic Fatigue syndrome or depression, rally around an explanation that dates back centuries and is largely considered curable. The nuances of the bacterial cause of Lyme disease remain unclear, but a bacterial explanation affords certain clinical consequences for those who accept and embody it.
1.3 Cultural Meanings of Illness

I now move from a history of facts and objectivity to an overview of how illness is understood culturally. Susan Sontag attacks meanings that get attached to illnesses completely separately from the medical or lived reality of those who experience them in her essays “Illness as Metaphor” and “AIDS and its Metaphors” (Sontag 2002). Various diseases, she says, are understood mythically and often morally; they are given meaning beyond their clinical presentation. This is especially true in the cases of poorly understood diseases: “any important disease whose causality is murky, for which treatment is ineffective, tends to be awash in significance” (58). This significance can reflect on the ill person positively or negatively, but regardless, sickness acts to individualize sufferers, setting them apart uniquely from the healthy, writes Sontag.

Paula Treichler similarly examines meaning in illness through responses to the AIDS crisis in her book How to Have Theory in an Epidemic. Like Sontag, Treichler views this illness as heavily subject to signification, to the extent that the illness cannot be understood without examining the attached social and cultural meanings. Analyzing how the illness is represented allows an understanding of the relationship between language and reality, because the words we use to describe phenomena alter how we see and understand them. As she says “illness is metaphor” (arguing for the inevitability of the metaphorizing of illness that Sontag protests) and so the semantic work of “making sense [of illness] must be done” in order to have an understanding of illnesses even beyond a biomedical one (Treichler 1999, 15). She asserts that “there is a continuum…not a dichotomy, between popular and biomedical

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discourses…and these play out in language” (15). This ties into issues of representation, as those affected by an illness are subject to outside interpretation of their bodies, biologies, and actions as they seek medical attention and experience dramatically new parts of life with their illness. In the case of AIDS, Treichler notes “people are dying and the question still remains how they are being represented” (Treichler 1999, 4). Of course, the mortality of Lyme is hotly contested and certainly incomparable to that of AIDS, but the merit and urgency of questions of representation and signification in illness remain in the case of Lyme disease, as the sick and afflicted are still sick when being portrayed as crazy, or malingerers, or attention-seekers. As Treichler says, “we cannot afford to let scientists or any other group of experts dismiss our meanings as “misconceptions” and our alternative views as noise that interferes with the pure process of scientific inquiry” (39).

Sander Gilman addresses questions of cultural meaning and representation around diseases in his book *Disease and Representation: Images of Illness from Madness to AIDS*. Gilman connects the aesthetic manifestations and renditions of illness in art, literature, and science to “our anxiety about self-control”; we hope to maintain control over our bodies and health and recognize illness as a source of terror for its ability to interfere with this. “Seeing disease” is an act in itself that is situated socially and must be understood as a complicated assemblage of meanings, shaped by perceptions of the patient that emerge through culture. Gilman describes this as a code behind how we view sickness, and names two specific levels the code works on: “first, on the level of the social construction of categories of disease; but then, perhaps even more important, on the level of the internalization of such images in
groups who are labeled as being at risk” (Gilman 1988, 4). These categories are constructed because we fear disease for its randomness and thus ability to strike anywhere, and so “we must construct boundaries between ourselves and those categories of individuals whom we believe (or hope) to be more at risk than ourselves” (Gilman 4). These categories are social and not medical and therefore bracket those who are sick or may become sick based on social differences or cultural values. Those who appear wealthier or more attractive have historically been associated with healthiness, and patients belonging to the lower class have been seen as much sicker, despite class being their only marker of difference. Culturally produced and situated images of sickness affect those experiencing illness at the level of their medical care and also their own understanding of their situation, including the “complex interaction of social and biological forces that we call ‘disease’” (Gilman 7). Gilman writes, “the infected individual is never value-neutral, that is, solely a person exhibiting specific pathological signs or symptoms. Like any complex text, the signs of illness are read within the conventions of an interpretive community…” (Gilman 7). Critically, the cultural situation and social construction of disease don’t lessen the reality of the suffering of those who experience sickness. Though socially determined, the pain felt by the patient is inherently real. Problems arise for the sick when “those who deny the reality of the experience of disease marginalize and exclude the ill from their own world.” (9).

Biomedicalization comes to matter in how we perceive illness culturally as it has effected a transformation in how we expect biomedical subjects to control their illnesses. This takes the form of a moral imperative to health or maintenance of one’s
chronic condition. Additionally, under biomedicalization, new individual and collective identities are formed which alter how individuals interact, leading to new contexts within which chronic Lyme sufferers can self-identify and gain legitimacy through a shared, collective identity.

1.4 Legitimacy of the Embodied Experience of Suffering

The last argument through which to consider chronic Lyme disease is an experiential, embodied one which privileges the suffering of those affected by illness and legitimates their perspective, even in contrast to dominant medical discourse. This is elaborated in *The Illness Narratives* by Arthur Kleinman, a psychiatrist who has worked with the chronically ill. He argues for individualistic understandings of illness from a medical perspective, wherein doctors consider the narratives and conceptions of illness that patients create from their own experiences on equal or elevated footing to the clinical understandings of disease that doctors learn in their education and professional experience. The position of the illness narrative is paramount here. Kleinman states that interpreting the narratives which patients tell doctors and themselves is utterly as important as the narrative told to the doctor by the body through signs and symptoms. With the advent of biomedicalization, this practice has “atrophied” in modern medicine and medical training as more technological, molecular, and consequently impersonal techniques permeate the medical and clinical fields (Kleinman 1988, xiv). These narratives “tell us about the cultural values and social relations that shape how we perceive and monitor our bodies, label and categorize bodily symptoms, [and] interpret complaints” (Kleinman 1988, xiii). When people construct an illness narrative out of their disease, they are
making sense and meaning out of a confusing array of experiences, emotions, and phenomena by articulating these things into a cohesive form. Significantly, these narratives are often evaluated normatively and socially when doctors encounter patients, and as Kleinman says that “there are perceived normal and appropriate ways of being ill and inappropriate ways” (Kleinman 1988, 5).

Normative conceptions of the body provide the basis of illness meanings, and these in turn arise from the organization of social reality, which Kleinman describes as “so organized that we don’t question meanings of illness” (Kleinman 1988, 9). It is these conceptions that are pushed against when a disease entity is particularly vague, poorly understood, or controversial; it is precisely the confusing physiological manifestations of such diseases that make them devastating for sufferers. Doctors approach patient experience from their training in “‘real’ disease entities” where symptoms of a disease exist abstractly outside of individual manifestations and can be empirically investigated to determine a diagnosis; doctors tend to “regard patient narratives with suspicion” (Kleinman 1988, 17). What gets ignored when doctors privilege their (usually biomedical) understandings of disease is the patient experience of suffering, and this suffering often comes to carry significant weight in the patients’ experience of being sick.

Leslie Jamison similarly discusses the question of personal suffering within a medical context and grapples with the question of how to empathize with illnesses that are hard to understand, hard to believe, or hard to explain. She does so in the context of Morgellons, a poorly understood medical condition that had arisen largely in the age of the internet, where online message boards allow the rapid sharing of
experiences and molding of identities, constitutive of biomedicalization. Morgellons is a disease far on the periphery of mainstream medicine, and largely believed by doctors to be psychosomatic, so is not on equal footing with Lyme disease, a largely accepted medical condition with persistent disagreement over diagnosis, treatment, and duration. I believe the case of Morgellons (a disease wherein sufferers believe they are infected with a parasite or other microscopic organism that causes open sores with fibers growing out of them to form on the skin) is a more extreme instance than Chronic Lyme along a continuum of illnesses the medical community would largely like to ignore. Jamison argues for face-value acceptance of even bizarre and uncomfortable-to-witness forms of suffering as signs of a shared human currency of emotion, wherein all have equal access to both suffering and sympathy without worries about legitimacy or justification of one’s pain (Jamison 2014).

Another theorist whose work I will draw on in my analysis is Susan Wendell and her book *The Rejected Body: Feminist Philosophical Reflections on Disability* (Wendell 1996). This work attempts to bridge epistemic and ontologic issues of disability with feminist ethics, a connection Wendell says has been undertheorized and underdeveloped on both sides, but especially from feminist thinking. The connection of illness to disability is explored repeatedly throughout the work, but I have chosen to draw from ideas primarily applicable to illness, which Wendell writes has previously been separated by disability groups for the additional stigma illness can add to disability, though the two can be considered together in her account.

Wendell writes about the power symbolic meanings can have in disability/illness, such as the symbol of “the power to control the body” being lost,
and the profound effect this can have on a person. There are also cultural meanings of
disability that can converge on cultural associations with gender, and Wendell,
quoting Fine and Asch (1988)\textsuperscript{11} writes that “cultural associations of disability with
dependency, childlikeness, and helplessness clash with cultural expectations of
masculinity but overlap with cultural expectations of femininity, so that a disabled
man is perceived as a “wounded male,” while a disabled woman is redundantly
fulfilling cultural expectations of her” (Wendell 1996, 62). Disability also becomes
associated with the failure of science to control nature “in societies where Western
science and medicine are powerful culturally,” and those whose illnesses and
disabilities cannot be healed by medicine carry the stigma of symbolizing this failure
(63, 96).

This power science has in our culture and especially over the experiences of
people with disabilities and disabling illnesses forms a significant part of the
hardships disability/illness can entail. Wendell argues that there is a “myth of control”
in Western scientific medicine that leaves those with incurable or medically
unexplainable illnesses outside the realm of the miraculous, life-saving, highly
technical interventions that biomedicine values. This leads to diagnoses of
psychosomatic illnesses when doctors are unable to discover a biomedical cause of
the patient’s suffering. Wendell writes:

Diagnosis of psychosomatic illness props up myth of control in two ways.
First it contributes to the illusion that scientific medicine knows everything it
needs to know to cure us (provided we cooperate fully), because there is no
physical problem for which it cannot provide a diagnosis. Second, it transfers

\textsuperscript{11} Fine, M. and A. Asch (1988). "Disability Beyond Stigma: Social Interaction, Discrimination, and
responsibility for controlling their bodies to the minds of those patients who cannot be cured; the problem is not that medicine cannot control their bodies, it is that their minds are working against them. (Wendell 1996, 100)

Further, Wendell writes that in our culture there is a cognitive and social authority of medicine, meaning that a medical worldview becomes a reality that has social power (this is the cognitive authority), while the social authority of doctors and other medical professionals comes from this cognitive authority as well as the social institutions and status of the medical profession, with its concomitant professional and social connections (Wendell 1996, 117). Wendell writes that this cognitive and social authority medicine has over how we describe our bodies “affects how we experience our bodies and our selves, how our society describes our experiences and validates/invalidates them, how our society supports or fails to support our bodily sufferings and struggles and what our culture knows about the human body. It also affects profoundly the relationship of medical providers to patients and the quality of medical care” (Wendell 1996, 118). This authority also delegitimizes bodily experience as a source of bodily knowledge in favor of the third-person, physical descriptions that medicine offers. Medicine is thus able to ignore bodily experiences that it cannot explain, and so poorly understood, mysterious, or controversial illnesses have the power to “destroy the cognitive and social authority of any individual” because the precarious position of one’s own bodily knowledge relative to the power of scientific medicine over the same bodily facts (Wendell 1996, 126). This stops the flow of information from patient to doctor, when phenomenological descriptions of one’s illness carry the risk of deeming them to be insane or somaticizing.
Biomedicalization offers avenues for legitimation and recognition of the pain Chronic Lyme disease can cause. Individuals can participate in online forums, and personal narratives of struggle with CLD proliferate on various blogs and advocacy websites. The moral responsibility to health under biomedicalization enforces a feeling of failure or powerlessness on the part of sufferers, and again, new individual and collective identities may return some power to those affected, as they are able to willingly take on an identity relative to their sickness.

Methodology

Here it is worthwhile to make note of the underlying methodology of my investigation and subsequent analysis of chronic Lyme disease. I have employed discourse analysis in order to fruitfully examine the disparate, multivalent, and often irreconcilable viewpoints on this issue, as expressed in written narratives, academic articles, popular journalism, memoir, documentary, and reality television. This methodology seeks to unearth the way meanings are constructed and circulate within cultures, where people often sharing the same meanings. Language is central to this process as it allows meaning to be expressed and to circulate between people. My conception of discourse comes from Michel Foucault, who argued that meanings emerge from signs connected not only within cultures, but derived from or constitutive of power relationships within societies.12 Analyzing this discourse allows for an understanding of the ways meaning is fixed around specific cultural entities such as diseases or the concept of “health,” and can help show how this meaning is

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produced and transmitted between actors in culture and society who have a stake in the issue (in this case) of chronic Lyme disease.

I am relying on the framework and understanding of discourse and how it can be used to understand images and meanings laid out in the book *Representation*, edited by Stuart Hall, Jessica Evans, and Sean Nixon. Hall writes that meanings are produced within cultures and within discourse, as “nothing meaningful exists outside of discourse” (Hall and University 1997). Discourse provides frameworks for understanding and interpreting signs (words and images), in view of what is possible to say and how relations of power influence what is said. Like Foucault, I want to consider the historical nature of representation, knowledge, and claims to truth present when looking at a discourse, and so seek to historically situate my analysis of chronic Lyme disease around understandings of illness and health as they have existed through history, prior to the formal discovery of Lyme disease, and afterwards as medicine became increasingly techno-scientifically driven through biomedicalization.

The work of Adele Clarke is also critical for foregrounding my methodology of discourse analysis and relies heavily on her program of situational analysis, which seeks to analyze discourses from within their social, cultural, and historical settings. Discourse analysis emerges by asking “three core questions about the production of discourses: (1) Who produced the discourses and with what resources? (2) Under what political, economic, and historical conditions were the discourses produced? And (3) How are the meanings of the discourse shaped by these economic, political, and historical conditions?” (Clarke, Friese, and Washburn 2016). This framework
allows me to engage questions of discourse production with the materials I am analyzing. These range from medical opinions, media accounts, and online information from Lyme and chronic Lyme advocacy organizations, to personal narratives, movies and TV segments, memoir, and social media of celebrities with chronic Lyme disease.
Chapter 2: Gendered Discourses of Chronic Lyme

This chapter follows the case of chronic Lyme disease through advocacy organizations, divided medical opinions, and mainstream media accounts, examining how meanings of chronic Lyme are produced through these different actors at different sites of discourse. The questions I ask are: (1) How do doctors, lay advocates, and the mainstream media construct meanings of chronic Lyme using gender and (2) How should we understand chronic Lyme disease, given the stark disparity between mainstream and alternative medical opinion on the subject? Divergent medical sources regard with suspicion the power of the media and advocacy groups to influence politics, while advocates may resent or reject the epistemic power that doctors and researchers have in elaborating conservative understandings of Lyme disease (Feder et al. 2007).

2.1 Theoretical Background on Contested Illnesses

2.2.1 Contested Illnesses

Chronic Lyme disease is one in a long history of illnesses with contested definitions, symptomology, and explanations. That these illnesses affect more women than men or are associated with womanhood is no accident, as femaleness has been pathologized throughout history and women have differential experiences under the medical gaze than men (Ehrenreich and English 1973). Other illnesses with similar symptoms to chronic Lyme disease include fibromyalgia, chronic fatigue syndrome, multiple chemical sensitivity, and Gulf War syndrome (Patrick et al. 2015, Maloney 2016, Swoboda 2006). These have all been characterized by fatigue, musculoskeletal pain, and neurological deficits, without a clear cause. In fact, a study demonstrated a
A high degree of clinical and diagnostic similarity between chronic fatigue syndrome and chronic Lyme disease, indicating a potential overlap between the conditions (Patrick et al. 2015).

Medically unexplained symptoms and illnesses have long frustrated doctors and patients alike, as doctors feel powerless to ameliorate patient suffering and patients feel demoralized and depressed over their lack of treatment options and possibility of recovery (Kleinman 1988, Ali et al. 2014, Dumit 2006, Rebman et al. 2015, Nettleton 2006). In the clinical setting, these illnesses constitute a breakdown of biomedicine’s ability to identify etiologies and treat diseases and so emerge as contested cultural objects that serve to delegitimate the experience of illness and suffering for those affected.

Nettleton analyzes the experiences of people living with medically unexplained symptoms and identifies the lack of a cohesive narrative as contributing to the precarious legitimacy and understandings of these conditions. The importance of illness narratives has been discussed in Kleinman, but Nettleton also draws extensively on Arthur Frank, who writes about both the chaos and restitution narrative.\textsuperscript{13} We expect restitution narratives out of illnesses, wherein someone becomes sick and seeks restitution through medical care and healing. The chaos narrative, typical of chronic illnesses for which there is no cure and little medical recourse, is marked by a lack of understanding over ones condition and a lack of structure; the illness may have no clear beginning and no “actual or imagined” end.

These chaotic experiences of illness are alienating for sufferers who face frustration from doctors, friends, and family because, as Nettleton writes: “not only is a story which lacks a narrative structure difficult to listen to, it is also difficult to ‘hear’ because it brings the listener’s bodily contingency into sharp relief” (Nettleton 2006). Nettleton analyzes patients’ accounts of their illnesses and finds them characterized by interconnected themes of morality, chaos, and ambivalence:

Accounts reveal a strong moral dimension, in that the experiences are inseparable from people’s sense of self and the maintenance of their identities. In the absence of any biomedical etiology, diagnosis or prognosis, illness trajectories are devoid of coherence and are thus characterized by chaos. These circumstances resulted in a degree of ambivalence most particularly towards medicine, and health professionals. (Nettleton 2006)

There is a cultural fear, Nettleton—quoting Shildrick—writes, of the “unreliable body” that appears normal from the outside but is intrinsically “unreliable and unruly.” It “cannot be placed into the tidy category of ‘the absolute other’” but instead resembles any of us and so represents the potential for us to be betrayed by our own bodies (Nettleton 2006). Shildrick via Nettleton characterizes this unreliable, unruly body as postmodern, and Frank connects the chaos narratives endemic to chronic illness as “the triumph of all that modernity seeks to surpass. In these stories the modernist bulwark of remedy, progress, and professionalism cracks to reveal vulnerability, futility, and impotence” (Frank 1995). These chaos narratives, writes Nettleton, “are also anomalous—the illness which is not anchored in biomedical

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explanation because the body of the ill person is found to be pathologically normal is matter out of place (Douglas 1966). It is abnormal normality” (Nettleton 2006).

2.1.2 Contested Illnesses and Gender

The cultural background presented above addresses the complicated space contested illnesses occupy, but further explication of the connection between these illnesses and gender is warranted. Ehrenreich and English have written about this connection going back to Victorian times, wherein upper class women were seen as inherently sick and therefore subject to medical control (often at the behest of male relatives and husbands), while lower class women were seen as “sickening” in their ability to transmit diseases but were not expected to become sick themselves, lest they lose workdays and productivity (Ehrenreich and English 1973). The medical gaze fixated on upper class women in this time, serving to both further the financial success of Victorian doctors and keep women subordinated under constant regimens of bedrest following the slightest emotional provocation, or, just as often, childbirth (Ehrenreich and English 1973, 15, 19). In this way, womanhood was set up as inherently fragile and necessarily open to medicalization. Conditions did not have to be clearly defined or explainable for women to seek or experience medical treatment.

Additionally, it is a fact that “women are far more likely than men to have medically unexplained disorders” (Malterud 2000). Because of this, work in the sociology of medicine has explored this connection and its effects on women with such illnesses. Swoboda analyzes the experiences of women with contested illnesses

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through interviews, specifically looking at embodiment, described by Turner\textsuperscript{16} as the “ensemble of corporeal practices which produce and give a body its place in everyday life ... the lived experience of the sensual or subjective body.” Illness alters embodiment, according to Frank; “in illness, individuals have problems continuing to be bodies, particularly the sorts of bodies they have always been” (Swoboda 2006). Through analyzing these women’s narratives, Swoboda finds that the women in her study experienced changes in embodiment because of their illnesses related to medical control, relatedness to their own bodies and to their social circles, and desires for what they want to be and what they want their bodies to be. For these women, “relating to and making sense of their bodily reactions became a type of situated, embodied knowledge in juxtaposition to the myth that one can escape the body through biomedical regulation” (Swoboda 2006). They view themselves as lay experts because of the specific, embodied knowledge their illness has given them, and want greater control of the discourse around their illnesses, specifically the recognition of their illnesses as biological and legitimate, as well as acknowledgment of biomedicine failure to offer any effective treatment, despite patient’s belief that their illness is biomedical in nature.

The last site of gender’s intersection with chronic illness I will draw on comes from an affective stance towards these issues. Two books of essays, When the Sick Rule the World by Dodie Bellamy and The Empathy Exams by Leslie Jamison use creative nonfiction to explore the experience of chronic illness and seem to

understand, both tacitly and explicitly, that chronic illness is inevitably about gender. Bellamy writes in the title essay of her book on her experience with multiple chemical sensitivity (though she does not explicitly name it) and its gendered resonances. Her naturopathic doctor is female and childlike, and when she goes to a community specifically for people with her illness (in the essay referred to simply as “the sick”), two women are guarding the entrance, saying they can smell the organic olive oil she put in her hair, and that it is giving one of them brain fog. She references “the one sick guy in the group (emphasis mine)” speaking at a discussion section. Regarding medical uncertainty with MCS, she writes “there is no such thing as a hypochondriac; there are only doctors who cannot figure out what is wrong with you” (Bellamy 2015, 34).

In an essay titled “Devil’s Bait,” Jamison writes about attending a conference for sufferers of Morgellons, a mysterious illness that causes sufferers to find fibers coming out of sores on their skin and believe they are infected by a bacteria, virus, or parasite. Doctors widely believe the condition to be psychiatric in origin and psychosomatic. In Jamison’s account, women, too, guard the entrance into the realm of sick people. She writes “a cluster of friendly women stand by the entrance greeting new arrivals,” and learns “that 70% of Morgellons patients are female—and that women are especially vulnerable to the isolating disfigurement and condescension that come attached to the disease” (Jamison 2014, 30). In talking to one sufferer at the conference, she hears that the woman was told “it was anxiety, in [her] head, female stuff.” Jamison writes:
I ask her about this phrase: *female stuff*. It’s like heart disease, she explains. For a long time women’s heart attacks went unnoticed because they were diagnosed as symptoms of anxiety. I realize her disease is part of a complicated history that goes all the way back to nineteenth-century hysteria. Dawn says her coworkers—the nurses, not the doctors—have been remarkably empathetic; and she suggests it’s no mere coincidence that most of these nurses are women. (Jamison 2014, 32)

These writers effortlessly integrate femaleness and the controversy these diseases face. Jamison is drawing on Susan Sontag’s work *Illness as Metaphor* in thinking about Morgellons, she is aware that her “every attempt to metaphorize the illness is also an act of violence—and an argument against the bodily reality its patients insist upon” (Jamison 2014, 32). Yet she finds it hard to resist, so rich is this illness is metaphoric potential, despite and because of its contested nature. Ultimately, these writers are presenting an embodied (whether personally in the case of Bellamy or voyeuristically in the case of Jamison) perspective on contested illnesses, and their standpoint as women may be what makes them receptive to a gendered view on the illnesses.

2.1.3 Chronic Lyme as Contested Illness

Chronic Lyme disease shares many symptoms with these other chronic, unexplained conditions such as fatigue, musculoskeletal pain, sleep problems, and neurological deficits (Ali et al. 2014, Rebman et al. 2015). While sufferers of fibromyalgia, chronic fatigue syndrome, and multiple chemical sensitivity may suspect an external, biomedical cause of their illness (that has yet to be discovered by modern biomedicine), chronic Lyme sufferers strongly believe they know the cause of their illness, as well as the necessary treatment. Rebman and colleagues (2017) write how this affects the patient experiences of this illness, using the same illness
narrative framework created by Frank to explain how a biological trigger to this contested, chronic illness converts the expected narrative (one of restitution through seeking an accepted biomedical cure) into a chaos narrative that is out of place for the accepted etiology of chronic Lyme disease amongst its sufferers and advocates.

Though the disease status of chronic Lyme disease is disputed, the designation still offers relief and validation to patients, possibly for its biomedical grounding (Rebman et al. 2015). This disease is nonetheless included by Ali et al. and Rebman et al. alongside more disputed illnesses like Gulf War syndrome and multiple chemical sensitivity because the experience of illness in these patients “can also be situated in the literature on chronic illness” that bypasses “purely medicalized understandings of chronic illness limited to physical signs and symptoms in favor or a broader understanding of lived experience” (Rebman et al. 2015).

As stated before, chronic Lyme disease has been shown to share a phenotype with chronic fatigue syndrome (Patrick et al. 2015), but the cultural situation and experience of sufferers of chronic Lyme disease cannot be fully explained simply by subsuming it under another, equally controversial diagnostic category. Lyme patient’s use of long term antibiotic therapy sets them apart medically and socially from those with contested illnesses who resort to managing their own symptoms through lifestyle changes, as shown in Rebman et al.’s example of a woman’s PICC line being derided by an infectious disease specialist seated next to her at a dinner party (Rebman et al. 2015, Swoboda 2006).\footnote{See section 2.2.1.} Chronic Lyme is perhaps also notable in its emergence from

\footnote{See section 2.2.1.}
a well-defined, agreed upon medical entity. In a 1993 paper on “The Biological and Social Phenomenon of Lyme Disease,” Alan Barbour, one of the co-discovers of Lyme disease from the Yale team of rheumatologists, describes the emergence of controversy over the persistence of Lyme disease as “dilemmas in diagnosis and case management,” and identifies chronic fatigue syndrome and fibromyalgia as potential differential diagnoses for “lingering or recurrent symptoms” (Barbour and Fish 1993). The authors also identify a movement pushing to broaden the definition of Lyme disease and the growing power of patient advocacy in influencing medical discourse towards these views.

Chronic Lyme is also entangled with gender in its epidemiology—a 2009 study in the Journal of Women’s Health found that chronic Lyme patients were significantly more likely to be female than patients of either Lyme disease or post treatment Lyme disease syndrome (Wormser and Shapiro 2009). This suggests that chronic Lyme disease mirrors other chronic and unexplained conditions, and in this chapter I make a case for understanding chronic Lyme as inherently enmeshed in gender and the state of womanhood. In this next section, I consider how the medical gaze constructs women and gender and the status womanhood occupies relative to the discourses I analyze.

2.2 The Case of Chronic Lyme

2.2.1 Medical Literature

Chronic Lyme disease appears in medical literature in a few principal contexts: in sections of medical articles primarily concerned with early Lyme disease that nonetheless address the potentially chronic (and controversial) nature of the
disease, in review articles that take a critical stance to the validity of the disease entity’s existence, and in medical sociology articles that investigate the experience of having chronic Lyme disease, regardless of its medical legitimacy. There is also a body of literature looking at *Borrelia burgdorferi* in the lab to identify indicators of a chronic character to the disease. These include the formation of cysts *in vitro* as well as the identification of “persisters,” bacteria that are able to survive antibiotics through dormancy and return to an active state once antibiotic treatment ceases (Alban, Johnson, and Nelson 2000, Sharma et al. 2015). These articles are celebrated by chronic Lyme advocates and sufferers and themselves may later be incorporated into critical reviews that claim these findings lack clinical import (Lantos, Auwaerter, and Wormser 2014, Feder et al. 2007). In this way, these articles feed back into literature that seeks to delegitimize chronic Lyme through systematic reviews of evidence in support of it. From these first two categories (medical article on early Lyme and reviews on chronic Lyme), I have chosen notable articles based the number of times they have been cited and in one case the preeminence of the journal which published the article.18 The two articles addressing the illness narratives and experiences of people with chronic Lyme disease appear to be the only two of their kind present in the literature.

“The Clinical Assessment, Treatment, and Prevention of Lyme Disease, Human Granulocytic Anaplasmosis, and Babesiosis: Clinical Practice Guidelines” by

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18 For these citation counts, I used the Web of Science citation index. Impact factors were pulled from Google searches. Citation counts indicate how influential an article is by showing how many other articles reference it, and the journal impact factor similarly shows how many citations articles in that journal receive, over the number of articles published total. (Nature, widely considered one of the most eminent scientific journals in the life sciences, has an impact factor of 38.138 currently, for reference.)
the Infectious Diseases Society of America, published in 2006, devotes 5 pages of 45 total to addressing “Post-Lyme disease syndrome, posttreatment chronic Lyme disease, and chronic Lyme disease” (Wormser et al. 2006) The text is a set of extensive guidelines for the diagnosis, treatment, and prevention of Lyme disease, intended to be read and used by doctors canonically. Out of the 13 authors of the guidelines, one is a woman. Per their website, the IDSA was founded in 1963 and “represents physicians, scientists and other health care professionals who specialize in infectious diseases. IDSA’s purpose is to improve the health of individuals, communities, and society by promoting excellence in patient care, education, research, public health, and prevention relating to infectious diseases” (IDSA 2017).

The chronic-Lyme-specific section makes no explicit mention of gender and only one oblique reference to the social context of chronic Lyme. The comment, “few additional details were provided by the authors as to the characteristics of the patient population” of a study which used a contentious method to detect B. burgdorferi in chronic Lyme disease patients may simply mean something like clinical history as the “characteristics of the patient population” (Wormser et al. 2006). The content of the guidelines is understandably technical; half of it is devoted to “Evidence to support treatment recommendations” which maintains that the IDSA’s understanding and definition of Lyme disease as a short-term, readily treatable infection. Presumably they do not view the accuracy of various diagnostic tests as related to the gender of sufferers of chronic Lyme disease, which they put in scare quotes. The authors do, however, make note of subjectivity within these diagnostic criteria, saying “the appearance of cellular debris may be confused with spirochetes,” indicating the belief
that objective knowledge is available to the observer of the microscope, if they have the appropriate skill.

“The Biological and Social Phenomenon of Lyme Disease” is a 1993 article in Science by Alan Barbour (a co-discoverer of Lyme disease) and Durland Fish (Barbour and Fish 1993). The article has been cited 374 times and the impact factor for Science in 1993 was 21.074 and is now 34.661. It addresses biological, epidemiological, and clinical characteristics of Lyme disease, and devotes a section to “Dilemmas in Diagnosis and Case Management.” This section does not explicitly mention gender, either, but does discuss the controversy around chronic manifestations of Lyme disease. The authors appear skeptical of chronic Lyme’s existence, referencing clinically similar conditions and the fallibility of serological tests in diagnosis. There are many conditions which can mimic Lyme disease in both its early and late stages, but they write that “factors such as the premorbid personality and a tendency to somatization may determine the length of convalescence and the response to postinfection fatigue and joint aches” (Barbour and Fish 1993). This sentiment clearly demonstrates the prevailing belief among doctors that patient personalities contribute to the experience of illness, placing blame in the hands and psyches of patients. In this case, the meaning that gets attached to chronic cases of Lyme disease is that is only a disease of malingerers and somaticizers. As Gilman writes in Disease and Representation, many of our anxieties around illness stem from the loss of self-control it can bring, but this loss may already be present in a personality predisposed to malingering, on Barbour and Fish’s account. This statement also reproduces key ideas about biomedicalization by subtly shifting
medical responsibility for healing onto the sick individual, construing health as a moral obligation to maintain. The paper also, however, rejects biomedicalization’s focus on chronic conditions by framing Lyme disease as a rigidly short-term infection subject to biomedical intervention only through antibiotic therapy.

The last document from the “medical literature on chronic Lyme disease” category is “A Critical Appraisal of ‘Chronic Lyme Disease’” by Feder and colleagues from The New England Journal of Medicine. It was published in 2007 and many of the authors contributed to the discovery of Lyme disease or are coauthors on the IDSA Lyme Disease guidelines. The article was cited 206 times per Web of Science and the journal’s most recent (2015) impact factor is 59.558. This article is understandably critical of the veracity of chronic Lyme as a disease category (it’s in the title), and depicts the conflict as one between doctors who are using empirically produced, objective evidence against the knowledge of Lyme-literate physicians and chronic Lyme sufferers and advocates which they portray as circumstantial (dependent on which doctors are willing to accept a chronic Lyme diagnosis and treat the patient accordingly), unscientific, and dangerous (for the risks that extended antibiotic therapy poses). The authors write of one category of chronic Lyme patients who have another disease such as chronic fatigue or multiple sclerosis: “they have received either a misdiagnosis or a diagnosis…that they are reluctant to accept and have sought an alternative diagnosis from a physician willing to treat them for chronic Lyme disease” This contrasts with the “well-defined clinical criteria and validated laboratory studies” which ought to be used for diagnosis. The authors contend that good, objective medical knowledge is working against the tide of
inaccurate diagnoses either by patients using embodied knowledge of their condition or physicians using their patient’s illness narratives in diagnosis against the clinical facts. The medical knowledge the authors rely on is presented as coming from no perspective; they assess studies they consider faulty on aperspectival grounds, using knowledge from immunology and microbiology, not the emotional or personal knowledge of their patients’ cases that the “self-designated ‘Lyme literate physicians’” may be using in their diagnoses of chronic Lyme disease (Feder et al. 2007, 1422). There is no mention of gender in the article.

All three of these papers seen together resemble a prevailing thought style from Fleck’s work *Genesis and Development of a Scientific Fact*. Some of the authors are shared between texts and all have an intellectual stake in how Lyme disease is defined. Communities of scientists are what Fleck calls “thought collectives” and he argues that ideas circulate so effectively within them that they become closed off to alternative theories and research programs. The way diseases are defined by thought collectives determine how facts and discoveries are produced around the disease, and the mainstream medical response to chronic Lyme disease is one characterized by uniform criticism of the disease entity’s lack of “objective” support. This closed system “[resists] contradiction and revision” from its narrow viewpoint in objective measures of diagnostic and treatment options. That these doctors are unwilling to consider the standpoint of experience in their guidelines for and reviews of Lyme and chronic Lyme literature shows their commitment to a prevailing thought style around chronic Lyme disease characterized by skepticism and adherence to clinical findings.
The other kind of academic literature on chronic Lyme disease are sociological studies of the disease without regard to its etiological reality. These instead seek to study and characterize the experience of CLD, specifically as a controversial condition plagued with uncertainty. I could find only two such articles of this kind, and their recent publication dates lead me to believe this is a new area for qualitative research.

“Experiences of patients identifying with chronic Lyme disease in the healthcare system: a qualitative study” by Ali and colleagues was published in BMC (BioMed Central) Family Practice in 2014. BMC is a for-profit, open-source publication company that publishes on biological and medical topics. Web of Science says it has been cited 4 times. This study was qualitative and phenomenological and looked at 12 adults who self-identified as having chronic Lyme disease. Because the article was not aiming to investigate the clinical legitimacy or reality of CLD, participants did not have to be formally diagnosed with the disease. The interviews with participants were analyzed for emerging topics and themes around “beliefs/understanding, personal history/narrative, consequences/limitations, management, and influences on care” (Ali et al. 2014). The authors found four major themes emerging from “participants’ descriptions of their experiences and perceptions: 1) changes in health status and the social impact of chronic Lyme disease, 2) doubts about recovery and the future, 3) contrasting doctor-patient
relationships, 4) and the use of unconventional therapies to treat chronic Lyme disease” (Ali et al. 2014).19

All the themes the researchers uncovered depict chronic Lyme disease as a condition that can be understood through Kleinman’s framework of interpretive medicine based in patient experiences and the narratives they construct. The participants showed that CLD has a “remarkable” impact on “social relationships, and activities of daily living, as well as perceptions of mortality and debility” (Ali et al. 2014). This study is sympathetic to the experience of chronic illness in line with Kleinman’s recognition of the particularly debilitating features of chronic illnesses that may be poorly explained and understood by modern biomedicine. Chronic Lyme disease has a biomedical explanation, but it is hotly contested and divides doctors between those who accept it and those who posit the kind of explanation biomedicine does not have room for: an idiopathic mystery that could simply be psychological. The themes gleaned from the researchers’ interviews speak to Kleinman’s model of illness narratives grounded in social and experiential reality. A critical feature of CLD for the participants is its impact on their social life that this drastic change in health status has wrought; this is a tacit endorsement of privileging patient narratives in treating CLD. This study does not explicitly analyze gender as such in its analysis of the experience of chronic Lyme disease. Nine out of 12 participants are female, and quotes from participants were labeled so that gender was apparent for each one, but not explicitly acknowledged (unlike Rebman et al., see below). The authors also note

19Interestingly, these closely resemble many of the themes I encountered analyzing the discourse surrounding celebrities with chronic Lyme disease, see page 76.
that the interviews were conducted by two men. All participants were white and eight out of 12 were employed part- or full-time. This acknowledgement of social kinds without analysis or further investigation perhaps shows the limits the researchers were under in attempting to pioneer a social study of chronic Lyme disease, and they acknowledge that their sample does not resemble the typical gender breakdown of Lyme disease (which has a male predominance of 53%) but do not address the female predominance of chronic Lyme or other chronic conditions (Ali et al. 2014).

The other study I found, “Living in Limbo: Contested Narratives of Patients with Chronic Symptoms Following Lyme Disease” was published in 2017 in Qualitative Health Research. This peer-reviewed medical journal is published by SAGE Publications. Rebman and colleagues investigated the experience of 29 participants who had chronic symptoms following a more typical short-term Lyme infection (instead of the category of chronic Lyme disease, which does not have to follow a typical Lyme infection), called post-treatment Lyme disease syndrome or PTLDS. “Thematic narrative analysis” of semistructured interviews yielded “three predominant themes: (a) Physical and social limitations lead to a “new normal” characterized by fundamental shifts of ways of being in the world, (b) disease-specific factors contribute to symptom and illness invisibility that affects social support in nuanced ways, and (c) pervasive medical uncertainty regarding PTLDS/CLD promotes an increased sense of personal responsibility for care” (Rebman et al. 2015). These themes overlap with those of Ali et al.’s study, specifically regarding the social experience of PTLDS/CLD and a lack of uniform medical authority and certainty on the disease.
The authors reproduce concerns Leslie Jamison identifies concerning empathy over poorly understood and legitimated illnesses, as well as similar ideas from Kleinman as the Ali et al. paper above. When the theme of “invisibility and social support” is discussed in this paper, the authors are engaging in the identification of invisible features of both the medical and social status of PTLD/CLD as central and integral to the overall experience of the illness. This invisibility was crucially tied to social support from the disease, and though the authors are silent on how clinicians or family members ought to perform or show this support, the acknowledgement of its importance to sufferers speaks to the legitimacy that belief and support give to the experience of PTLD/CLD.

Regarding the medical uncertainty that participants experienced and its resultant effect on their sense of personal responsibility, the authors reference Swoboda and Nettleton’s findings about the prevalence of doubt and uncertainty in contested illnesses (Swoboda 2006, Nettleton 2006). In their findings surrounding this medical uncertainty, the authors highlight one woman’s story of having her illness questioned at a dinner party. An infectious disease specialist was seated next to her and showed frank disbelief when she explained the PICC line in her arm was for antibiotic treatment of chronic Lyme disease (Rebman et al. 2015). Jamison discusses one advocate’s (for Morgellons, the arguably more contested disease entity she writes about) stance towards such medical authority over one’s own illness as “delusions of doctors,” the delusion being that a doctor could know someone’s body better than they themselves do. Kleinman writes about medical meanings of illness arising out of normative conceptions of the body, and how contested and poorly understood
diseases push against these conceptions, leading to disease states doctors cannot or are unwilling to make sense of. Rebman et al. write that “it was challenging [for some participants] to content with the realization that the context of PTLDS/CLD was not as straightforward as other illnesses” (Rebman et al. 2015, 541).

This paper does not explicitly discuss gender in PTLDS/CLD, perhaps for the same reason I posit Ali et al. do not, that the researchers faced limits in their pioneering social study of this disease. In many quotes, the gender of the research participant is explicitly named, but this is inconsistent throughout the paper. The sample was 52% women, and so more closely resembles the gender breakdown of regular Lyme disease. When quotes are labeled for gender, interesting features of what is said emerge. A woman is quoted talking about belief in the sincerity of her illness and physical state as it relates to emotional support she received, then next a man is quoted talking about belief in the context of his fellow-daredevil friend calling him a coward for his inability to be physically active. Another man reported feeling that he should “tough it up, you’re a guy” in response to his illness, while a woman was questioned about the legitimacy of her treatment in the dinner party story above (Rebman et al. 2015, 540). While these two papers do not construct a theory of gender around chronic Lyme disease, they are non-neutral documents regarding gendered issues of objectivity, believability, and illness narrative in the experience of being ill. These facts do not allow me to make a totalizing conclusion regarding the place of gender in chronic Lyme, but we know from Smith, Harding, and Haraway that objectivity and believability in empirical science have been historically masculine ideals, with the standpoint of women and experiential embodied
knowledges (often coded feminine) excluded from what was considered good, objective science. Many of the participants in this study, male and female, have embodied knowledge of their illness from their symptoms and struggles with treatment, knowledge that is able to be called into account, in Haraway’s words, because it is not hiding its situatedness (Haraway 1988).

These papers also begin to frame chronic Lyme disease as a biomedicalized entity through the themes identified in sufferers’ accounts. The emphasis on one’s health status dramatically changing one’s life and social world instantiates biomedicalization’s totalizing focus on health maintenance as a new social virtue. The medical uncertainty surrounding chronic Lyme in these two articles leads to the feeling of personal responsibility over one’s health and healing, also a hallmark of biomedicalization. Lastly, the emphasis on alternative therapies to treat chronic Lyme disease is representative of another feature of biomedicalization, wherein what were previously viewed as competing knowledge systems against Western biomedicine are co-opted into Western biomedicine for their economic viability as a result of increasingly widespread consumer interest.

2.2.2 Lay Advocate Media

There is a substantial contingent of lay advocates for chronic Lyme disease who produce diverse media for their cause. It consists in documentaries, newsletters, magazine and newspaper articles (as well as academic articles by scientists who believe in CLD), blogs, and online message boards where people write about their experiences and struggles with the disease and keep updated on scientific research into the behavior of *Borrelia burgdorferi*. From this rich source of information on
how lay actors construct meanings around the disease and gender, I have chosen to
examine a select few pieces of media I feel are indicative of the broader lay advocate
discourse around chronic Lyme.

The “Chronic Lyme Disease” page on LymeDisease.org, a prominent
advocate website, presents the organization’s view on the nature of Lyme disease and
its chronic potential, using biomedical and epidemiological facts (many of which are
unsurprisingly in dispute) about the disease to construct a picture of epistemic
certainty about CLD. Authorship is unclear in many parts of LymeDisease.org; many
newsletter articles (available to members through a paywall) seem to be written by
“LymeTimes Editor,” though several are written by doctors. The website itself gets
between 100 and 300 thousand visitors a month, based on data from SimilarWeb, an
online software that reports website traffic (SimilarWeb 2017).

This article makes no mention of gender and attempts to use facts to construct
an unassailably biomedical picture of chronic Lyme disease, including statistics about
the quality of life CLD sufferers experience and graphical visualizations of this data.
The discussion of how debilitating chronic Lyme disease can be features prominently
in this article, after an initial description of the organization’s position on the
symptomology, proper treatment, and even mortality rate, the rest of the article
concerns the quality of life and level of debilitation that sufferers experience. These
facts paint an alarming picture of CLD; the article says “patients’ quality of life was
consistently worse than that of control populations and equivalent to that of patients
with congestive heart failure. Pain levels were similar to those of post-surgical
patients, and fatigue was on par with that seen in multiple sclerosis”
This fact, from “four NIH-sponsored retreatment trials” is in dispute however, with mainstream medical opinion arguing it has been interpreted incorrectly by advocates. In “A Critical Appraisal of Chronic Lyme Disease” the authors write that it was an eligibility criterion for admittance into these trials that symptoms “must be severe enough to interfere with the patient’s ability to function,” and that with this criterion the investigators actually had “great difficulty” filling the trials, leading them to involve more sites and extend the enrollment periods of all studies (Feder et al. 2007, 1426). While the biomedical reality is in dispute, LymeDisease.org nevertheless attempts to use facts to paint a picture of the reality and legitimacy of the experience of chronic Lyme disease.

**Symptom Severity**

75% of chronic Lyme patients experience severe or very severe symptoms. 63% describe two or more symptoms as severe or very severe.

![Symptom Severity Graph](image)

*Figure 1: Graph displaying the severity of various symptoms experienced by chronic Lyme sufferers. Image from LymeDisease.org*
A guest blog post from January 19th, 2017 on one of LymeDisease.org’s several blogs, “Touched by Lyme” details one woman’s struggle to be believed and supported in her chronic Lyme disease because of her own cavalier attitude towards her illness. The author, Shira Gusfield, is writing a guest post on Dorothy Kupcha Leland’s blog, which attempts “to explore the personal side of Lyme disease and how it affects individuals and families,” among other goals like keeping people informed and creating community around Lyme disease (Touched by Lyme).

Gusfield writes that she struggles to present herself as legitimately ill and this limits the potential support and sympathy she receives from family and friends, support (and belief) she desperately needs to overcome her illness. She says she makes light of her illness by joking with people that she goes to the doctor all the time because she is the “sickest healthy person you’ve ever met,” but she knows this leads people to believe she is simply a hypochondriac (Gusfield 2017). She believes she makes jokes because she has struggled to accept herself as legitimately ill, a struggle Wendell documents extensively in The Rejected Body. Wendell writes that the cognitive and social authority of medicine devalues the experience of people with controversial or poorly understood illnesses, especially when their symptoms are largely subjective (Gusfield says she knows she looks healthy) (Wendell 1996). This medical authority delegitimizes patient suffering and alienates patients from support networks who cannot understand or empathize with illnesses outside of biomedical jurisdiction. Gusfield wants to “train people to take [her] seriously” to gain the support she needs to overcome her illness. Gusfield’s status as a woman in this is also consequential, and Jamison’s exploration of gender in contested illnesses shows this
well. Jamison writes that women are especially vulnerable to the stigma associated with these illnesses, and believability is of course connected to gender and one’s standpoint as explained by Smith, Harding and Haraway. Biomedicalization has created the context for Gusfield’s blog post on a popular chronic Lyme advocacy website, as the identity group of “chronic Lyme sufferers” is a new (in the last few decades) category for individuals to organize politically and educationally around. The author is serving as an advocate for the legitimacy of chronic Lyme while constructing an identity that incorporates the illness.

The last piece of lay media I will analyze is the 2008 documentary *Under Our Skin*, directed by Andy Abrahams Wilson, which covers the experience of several chronic Lyme sufferers as well as the medical and insurance “conspiracy” against the disease that seeks to silence and delicense doctors who treat chronic Lyme with long-term antibiotic regimens and other controversial approaches (Wilson 2008). This documentary won “Best Documentary” at several film festivals and was a semifinalist for “Best Documentary Feature” at the Academy Awards. It has been reviewed in publications such as the *New York Times* and *Vanity Fair*. This documentary presents chronic Lyme disease as a criminally ignored condition that doctors and insurance companies are attempting to hide because the latter do not want to pay for extensive treatments inherent to the chronic condition and the former either do not wish to get involved in the situation of taking on chronically ill patients or simply do not believe Lyme disease can be chronic. The film covers issues of suffering and believability alongside the political struggle chronic Lyme patients face against what they view as
medical neglect. It also presents gender in non-neutral ways in relation to chronic Lyme.

Figure 2: movie poster for Under Our Skin, featuring a woman's face half-submerged, with strikingly green eyes. Image from underourskin.com

A significant part of the film consists in various sufferers giving testimony about their experience with the disease; there is Jordan, the former park ranger whose Lyme disease lasted years when doctors wouldn’t treat his tick bite because he lived in California, a non-endemic region, and Mandy (presented always alongside her husband Sean) who similarly struggled with diagnosis because she lived in Florida, Elise, who lives in an endemic area but struggles with childbearing after contracting Lyme disease, and Dana, who is on tour with U2 and finds redemption through her Lyme literate doctor and a new boyfriend after tour ends.

One place where Lyme sufferers of all genders feature prominently is in parts of the film where many unnamed Lyme sufferers or their family members all speak in
short clips on themes like how many doctors they have seen, how much money they have spent on treatments, and what various debilitating symptoms they have experienced. Men and women are presented simultaneously and in roughly equal numbers with the effect of implying that Lyme disease affects a broad range of people (many races are also represented). The film achieves this through the concise and consistently universal statements drawn from these people, showing a unified front of Lyme disease sufferers without nuance between their stories. When more nuanced and intimate portraits of sufferers are depicted, gendered narratives inevitably emerge.

The first in-depth subject in the documentary is Jordan the park ranger, who is almost always recorded talking about the empirical reality of chronic Lyme disease. His is a struggle for truth, as he presents scientific facts and his disappointment in the failure of the medical system to recognize the scope and severity of what he sees as an epidemic in the US and worldwide. As he talks at one point, graphs play across the screen, showing the incidence of Lyme disease in comparison to other infectious diseases, and its geographic spread across the continent. He talks about the ecological changes bringing about this epidemic, and his position as a knower in all of this is tied into his former career as a park ranger and current career as a writer about Lyme disease. When he talks about the emotional dimension of his experience with the disease, he expresses the extreme sentiment that if it weren’t for his family and children, he would have killed himself rather than struggle through his illness.

Towards the end of the movie, baseball player Ben Petrick talks about his experience with Lyme disease that was misdiagnosed as Parkinson’s, leading him to
retire from the Colorado Rockies until he was diagnosed with Lyme disease and began treatment. In this case the experience of illness is presented as interfering with a man’s livelihood and career.

Women are presented throughout the movie differentially to the male subjects. Susan Wendell writes that a disabled woman may be “redundantly fulfilling cultural expectations of her,” and this seems to be the case in the experience of Mandy, a woman in Florida who has chronic Lyme disease and begins antibiotic treatment in the course of the film (Wendell 1996, 62). She is depicted frequently alongside her doting husband, Sean, who is seen supporting her in her weakened, debilitated state as she moves around their house and to doctors’ appointments across state lines. The film documents their wedding and Sean’s insistence that he will stand by Mandy for their entire lives and as long as it takes for her to recover. The wedding is meant to be poignant; as the camera zooms in on the couple as they exchange vows and say “in sickness and in health” we are meant to grasp the reality this phrase has in the couple’s life already. We see the loss of control Mandy has throughout her illness and when treatment is particularly debilitating (antibiotics can often produce adverse reactions even as they treat)\textsuperscript{20} as terrifying. The low-quality home footage Mandy and Sean record of her twitching uncontrollably or lying in uncomfortable looking positions underscores the grim reality the couple face. Sander Gilman writes about the act of seeing disease as constituted culturally as much as biologically, and we can see disease being visually constructed through Mandy and Sean along these lines.

\textsuperscript{20} Called the Jarisch-Herxheimer Reaction, this occurs when certain kinds of pathogens release toxins as they are killed. See "The Jarisch–Herxheimer reaction". Lancet. 1 (8007): 340–1. February 1977
(Gilman 1988). At one point when she is beginning treatment, we see Mandy filming herself administering antibiotics through her PICC line as she sits in her wheelchair, telling us she wants to film this even though Sean refuses to do it for her, so that people can see. Presumably what people will see is her experience of suffering, and this visibility offers legitimation of her suffering.

The experience of suffering also features in the storyline of Dana, an apparently independent (in contrast to Mandy’s union with Sean) woman who uses her work as a tour manager for U2 to distract from her growing pain and debilitation from Lyme disease, and finds redemption in treatment and a relationship. Dana, too, references the invisibility of suffering this disease has wrought; her opening lines in the film are “pain, pain, pain, relentless pain. No one would believe it” before she recounts a story of asking her friend how she looked, their reply that she looked great, and her response “you cannot imagine the pain I am in right now.” She is able to keep in control of her illness until tour is over, attributing this to the need to simply keep going for her job, and then moves to Seattle to see a Lyme literate doctor, Dr. Dietrich Klinghardt, who also practices alternative medicine in treating Lyme, an important element of biomedicalization. Dr. Klinghardt, who believes that electromagnetic waves cause autism, details on his website the various alternative therapies he uses in treating Lyme disease to reduce toxicity, such as avoiding electromagnetic waves and noise and light pollution when sleeping (Klinghardt 2017). She says she “met a lovely gentleman” and expresses her happiness at not having “to go it alone anymore” with her illness and treatment.
Elise is another woman whose experience with Lyme disease is inflected significantly by her experience as a woman and mother. After becoming ill with Lyme disease, she experienced multiple miscarriages that she says were confirmed to be from Lyme infection of the fetus and placenta. This partially perspectival knowledge is contrasted with interspersed testimony from Dr. Gary Wormser, a notable critic of chronic Lyme disease and co-author of the IDSA treatment guidelines as well as the critical review of CLD discussed above, saying that there have been absolutely no documented cases of transmission of Lyme disease in utero. Elise’s experience nonetheless contradicts this, and her pregnancy and eventual birth of her son (who is healthy but tests positive for Lyme disease) are marked by profound anxiety about Lyme disease. Elise, too, is seen finding redemption in carrying her son to term, though she is measured in her optimism when filmed a year later discussing his positive serological tests.

Elise, Dana, and Mandy all demonstrate the anxiety around control that illnesses engender in us culturally. Dana struggles to control her professional life in the face of her increasing debility, eventually profoundly reshaping her life as she moves to find treatment and finds a boyfriend in the process. Elise feels the loss of control over her reproductive life that Lyme has created, and manages to recover some control and successfully carry a child to term, but is unable to escape the shadow of Lyme completely, as her son apparently has Lyme antibodies, though he remains asymptomatic at the time of filming.

These lay accounts of Lyme disease appear to differentially construct gender around the illness, despite an apparent interest in remaining gender neutral, and
therefore biomedically legitimate by representing the experience of men and women with chronic Lyme disease equally, in line with the gender breakdown of Lyme disease accepted by mainstream medicine and medical authorities. More nuanced portrayals of the experience of CLD cannot but reveal the intrinsic gendering of the disease, as has occurred with many controversial diseases in Western culture. We see women experience a struggle for control over one’s life and body in the face of invisibility of suffering and lack of belief in one’s illness as legitimate in contrast to the objective reality seemingly presented by men in these accounts. Also present is the instantiation of biomedicine’s production of novel individual and collective identities through technoscientific facts. The facts around chronic Lyme disease are in dispute, and technological features of diagnosis and treatment provide the basis for disagreement, such as the ability of PCR to detect true positives for infection, or the validity of administering IV antibiotics through a PICC line. The subjects of the film and author of the blog post discussed are organizing themselves as activists and educators around chronic Lyme disease, without assent from mainstream medical authority and often with mostly personal experience as their epistemic basis for their claims about Lyme disease’s chronic nature.

2.2.3 Mainstream Media

A comment in “A Critical Appraisal of ‘Chronic Lyme Disease’” about the media (as well as news articles about Lyme disease that friends and relatives frequently sent me while I was doing this project) lead me to investigate the discourse being produced by mainstream media outlets regarding chronic Lyme disease. In “A Critical Appraisal,” the authors write that “the media frequently disregard complex
scientific data in favor of testimonials about patients suffering from purported chronic Lyme disease and may even question the competence of clinicians who are reluctant to diagnose chronic Lyme disease” (Feder et al. 2007). I wanted to look at some prominent media accounts of chronic Lyme disease and see if this was true. I chose the articles I did for the prominence of the publications they appear in and their focus on the chronic potential of Lyme disease as well as the science behind the chronic Lyme controversy.

“The Lyme Wars” appears in the New Yorker’s July 1, 2013 issue and was written by Michael Specter, a writer who has written about “AIDS, T.B., and malaria in the developing world, as well as…agricultural biotechnology, avian influenza, the world’s diminishing freshwater resources, and synthetic biology” (Specter 2013). The long-form article covers the case of Kaleigh Ahern, who had late-stage Lyme disease years after being bitten by a tick at age 12, as well as the clinical, epidemiological, and ecological circumstances of Lyme in the US and recent (for 2013) research into its potential to be chronic. Ahern lived in upstate New York, an endemic area for Lyme, but was not tested or prophylactically treated for Lyme after being bitten by a tick. She didn’t develop severe enough symptoms for her to take notice until years later when she was in college and suffered crippling “anxiety, depression, and insomnia” as well as headaches, muscle pain, and brain fog (Specter 2013). Once she was diagnosed with Lyme disease through positive serological tests, she was only given three weeks of antibiotics, which her mother fought to have extended another three weeks. She failed to get better after this and had to take time off college. She said of this time: “I would have episodes where I would just lie on the ground
writhing. And my parents could do nothing but watch. I wish they had taken videos and put them online, so people would know.” Again, we see loss of control depicted as one of the most terrifying manifestations of illness, while visibility is presented as a legitimating force.

Ahern eventually turns to alternative medicine and starts to recover. Specter writes “She knows that her approach to Lyme disease is controversial and acknowledges that the improvements might be due to her dietary regimen or to Rife treatments [an electromagnetic device that emits radio waves which supposedly target bacteria] or to a placebo effect. She doesn’t mind; after enduring such pain, she has found that fine points don’t matter” (Specter 2013). Kleinman’s consideration of the patient experience of suffering as often the most significant part of the overall experience of illness illuminates Ahern’s stance toward this. Unable to recover through standard biomedical interventions, the alternative therapies she uses better accommodate the suffering she has experienced from Lyme disease. These alternative therapies also represent chronic Lyme as biomedicalized, as alternative approaches to healing have become increasingly mainstream under biomedicalization because of their economic viability in medical care.

The other Lyme sufferer Specter interviews and writes about is David Roth, a managing director at an New York City investment group, who hopes to use science to end the Lyme controversy. He does not indulge “dark conspiracies” about Lyme originating in a government research lab on Plum Island or a gag order on New York Times coverage of Lyme (Specter 2013). Roth is presented in contrast to Ahern’s experience of embodied suffering despite biomedical knowledge as a rational thinker
in pursuit of objective truth. Specter writes that “for Lyme activists to be taken seriously, they will have to be led more by people like Roth than by those who foster dark conspiracies,” but soon writes that Kaleigh Ahern is one such well-informed activist for Lyme; she wrote her undergraduate thesis on tick molting behavior to better understand the ecology of the disease and hopes to further study diagnostic tests for it in graduate school (Specter 2013).

That Roth is an adult man and Ahern is first presented as a young girl, then a young woman, is noteworthy. The depiction of gender in this article is not clearly defined; Ahern’s story is presented as an embodied experience of illness yet she is also able to achieve some sort of expert status about her illness alongside the depiction of David Roth as a rational, objective advocate.

In an article on the “Well” blog of the New York Times Jane E. Brody writes about chronic Lyme disease and its medical controversy through the experience of one woman. I chose this article because it appeared in (a blog of) the New York Times and dealt with chronic Lyme specifically. Brody writes that chronic Lyme can mentally and physically debilitate people, leaving them without medically established recourse, an immediate affirmation of the view chronic Lyme sufferers and advocates take of their own illness (Brody 2013). The article opens with the case of Mary Rasenberger, a 51-year-old New York lawyer who experienced mysterious, debilitating symptoms for 10 years before being diagnosed with chronic Lyme by a Lyme-literate doctor. She was told her fatigue was from depression. One doctor, an infectious disease specialist from Maryland, speaking about chronic Lyme patients in general, is quoted as saying “These are high-functioning people—couch potatoes
don’t get Lyme disease. They are not crazy, and the doctors who treat them are not evil. They are desperate people trying to get better, and well-intentioned doctors who are trying to help them” (Brody 2013). This article is presenting chronic Lyme as legitimate, not through objective scientific evidence (the author acknowledges the disputed claims around the disease and the studies for and against chronic Lyme) but through the lens of experience. Rasenberger and Aucott, the Maryland infectious disease doctor, are both relying on their experience to construct their views of Lyme disease, though Aucott uses medical knowledge additionally. The doctors Brody quotes in her article both call for more research to help resolve these clinical controversies, but the article itself readily accepts Rasenberger’s account of her illness as fact, despite evidence against long-term antibiotic treatment of Lyme disease.

The last mainstream media article comes from the Chicago Tribune’s investigative reporting team and is titled “Chronic Lyme disease: A dubious diagnosis.” Understandably, it is highly critical of the veracity of claims that Lyme disease can be a long-term infection (Callahan and Tsouderos 2010). The writers explain the controversy as both political and scientific, and say that science favors a narrower view of Lyme infection and short-term antibiotic treatments, while pro-chronic Lyme advocacy organizations and nonprofits are achieving significant success in the political arena, as many states have passed laws preventing doctors from being investigated for their Lyme treatment practices.

The article opens on Dr. Bernard Raxlen, whom we later learn is a psychiatrist, not an infectious disease specialist, attending a gala to “Unmask a Cure”
for Lyme disease, which the writers point out already has a cure. The writers inform us that while Raxlen attends the tony gala, he is also under investigation for the fourth time in 10 years for his treatment practices of chronic Lyme disease. The authors do not take chronic Lyme disease to be believable considering the scientific evidence and majority scientific opinion against it, but do consider the landscape of social views of health today conducive to the proliferation of alternative therapies and “dubious medicine” as people are suspicious of the power doctors and pharmaceutical companies wield, and the assumed tangled economics of medicine (Callahan and Tsouderos 2010).

The only in-depth depiction of a chronic Lyme patient in the article is Kimberly Frank, a mother of four with a busy work life and two foster children whose life is significantly slowed by chronic Lyme disease. The writers explain that she believes Lyme was created by the US government at the Plum Island Animal Disease Center, a conspiracy theory that seems to damage her credibility as a rational thinker in the eyes of the reporters and presumably the audience of the article. Her suffering (and that of two of her children, who she says also have Lyme) is rendered uninteresting and unimportant next to her controversial and fringe beliefs about the origin of this suffering. In many ways, Frank’s story engenders cultural anxieties about the loss of control illness signifies, as described by Gilman, and the reporters of the story reinforce this anxiety in how they choose to depict Frank. She is first introduced as a high-powered business woman taking care of her many children and foster children before, then once she obtains a diagnosis of chronic Lyme disease for her crippling fatigue and musculoskeletal symptoms she is depicted as a source of
counterfactual and absurd medical claims. In this, she is also adopting a standpoint from her experience with chronic Lyme and with doctors who diagnose and treat it, similar to the situated knowledges Haraway describes.

There is however, an acknowledgement of the importance of personal suffering in generating empathy and belief towards chronic Lyme disease. The reporters discuss the political battle over chronic Lyme’s diagnosis and treatment, describing the author of a post on a popular Lyme advocacy blog telling people to use their personal stories as political tools for chronic Lyme’s legitimacy. She wrote “in a competition between posting the IDSA guidelines or your Lyme story…it is going to be you that they choose to read about” (Callahan and Tsouderos 2010). This intersects with notions of the believability of lived experience in the face of scientific/medical facts discussed by Wendell and Kleinman and makes a case for the power of personal experience over the considerable power scientific meanings hold in our culture. It is Wendell and Kleinman’s arguments taken to their logical conclusion, with experience winning out finally over medical authority. The prize here is political legitimacy, however, and not the epistemological legitimacy Kleinman and Wendell support.

This article presents chronic Lyme disease as politically biomedicalized but scientifically outside the jurisdiction of biomedicine, as chronic Lyme is not accepted by mainstream medicine, and as the authors argue, not well supported by medical or scientific evidence. Advocates have had success, however, in turning chronic Lyme into the legitimate biomedicalized entity they envision it as through political action that configures chronic Lyme disease as a condition whose treatment can be
individually determined between doctors and patients, as shown by state laws permitting this.

2.3 Conclusion

In this chapter, we see struggles over the believability of chronic Lyme’s symptoms play out in medical literature, lay activist media, and mainstream media accounts of chronic Lyme disease. These accounts are divided, some more starkly and some representing ambivalence towards both sides of the issue. Gender features significantly in these accounts, as actors either attempt to hide it in support of a gender-neutral, biomedical vision of chronic Lyme, or use it as a tool of empathy, believability, reliability, and objectivity in accounts featuring the personal standpoints of gendered actors around chronic Lyme. We can also see biomedicalization working in these accounts to create an image of chronic Lyme disease that is rooted in the technoscientific transformations and new collective identities created out of biomedicalization.
Chapter 3: Chronic Lyme in Celebrity Discourse

3.1 Introduction

Chapter three turns to media representations of chronic Lyme disease as it appears in celebrity discourse and culture, including reality television, memoir, documentary, and interview. Various female celebrities have not only come out publicly about their struggles with chronic Lyme disease (explicitly or implicitly identified as such), but have allied themselves with advocacy for the condition. The impact female celebrities have had on how meanings of the disease are shaped shouldn’t be underestimated, as celebrities have previously played an important role in meaning-making around diseases, such as Rock Hudson and Magic Johnson with HIV/AIDS (Treichler 1999). Using the three frameworks developed in chapter 1, the questions I ask are: (1) How do celebrities shape the meaning(s) of Lyme disease, (2) How does gender operate in this pop culture context to make Lyme disease legible, and (3) How does the aesthetic and affective representation of Lyme disease enacted through these forms specifically alter meanings of the disease as such? The position of celebrity in American culture shapes relationships to knowledge and ideals of empiricism, as celebrities act as cultural gatekeepers and authorities on subjects, making them legible and consumable for larger audiences. Culturally, celebrities are in a position of enormous power to shape meanings of illness, and subjectively they are relatable and thus make the suffering felt by many Lyme sufferers legible to broader audiences who are not personally affected by Lyme disease.

In this chapter I analyze the discourse celebrities produce out of their experiences with chronic Lyme disease through social media, reality TV,
documentary, and memoir. From this discourse emerged six major themes: public advocacy, invisibility of suffering, multitudes of doctors and therapeutic interventions, healing in percentages, Lyme as a “silent killer,” and comparisons to HIV/AIDS. Gender operates largely implicitly throughout the discourse, and its most notable manifestation is in the fact that the most visible and widely-known celebrities talking about chronic Lyme are women.

3.2 Celebrity Culture and The Power of Celebrity

This section provides a brief theoretical background on the concept of celebrity from a cultural, critical, and historical perspective. To analyze the discourse on chronic Lyme being produced around and by celebrities I wanted to first answer two questions: 1) What is celebrity? and 2) How does celebrity function in pop culture, that is, what happens when celebrities speak, in this case about Lyme disease? To do so, I turned to sociological and theoretical investigations of the phenomenon of celebrity, primarily focused on American culture.

There is agreement that celebrity has been around as long as Western culture has existed, and has been continually shaped by new technologies that enable new attention-garnering strategies in the fame discourse (Gamson 1994). One of these technologies was mass media, which enabled people to know those beyond their immediate surroundings, when previously they might only have an abstract conception of figures like the king, for example (Monaco 1978). Celebrities may have initially been people well-known for their accomplishments, like writers and thinkers, but later this fell out of the qualifications for celebrity; it became enough “to be known for being well known” (Monaco 1978, 7). This apparent shallowness now
forms a significant part of what we consider celebrity culture, with its entertainment news, pageant-like awards shows, and media focus on fluffy, human interest content. Celebrity goes beyond these aesthetic and affective manifestations within our culture, however. Celebrities are not just notable for being prominent, they wield a certain kind of cultural power. Gamson writes that “celebrity is a primary contemporary means to power, privilege, and mobility” (Gamson 1994, 186) and similarly, Marshall describes celebrities as the “cluster of individuals [who] are given greater presence and a wider scope of activity and agency than are those who make up the rest of the population” (Marshall 1997, ix).

This brings up the question of celebrities’ power over their own statements, which form part of celebrity discourse and move into other discourses when celebrities speak on issues beyond their own lives and careers. At the heart of this is the obvious manufactured-ness of celebrity culture, which is driven by publicists wholly beyond the scope of the manufactured fictions celebrities inhabit in their film and television roles. The celebrities themselves may be produced by publicists, when a “shrewd agent discovers a market and manufactures a celebrity product to suit it” (Gamson 1994). As Gamson iterates the problem: “if celebrities are artificial creations, why should an audience remain attached and lavish attention on their fabricated lives? How can stars be both true and false?” (Gamson 1994, 48). Marshall answers this question through a critical theoretical account of how “the celebrity structures meaning, crystallizes ideological positions, and works to provide a sense and coherence to a culture.” First, “celebrity status…confers…a certain discursive power: within society, the celebrity is a voice above others, a voice that is channeled
into the media systems as being legitimately significant” (Marshall 1997, x). This is not a coherent locus of power, however, because while celebrities are celebrated, they also represent false value in our culture for the frivolity or meaninglessness of their work as celebrities. An important aspect of celebrities’ discursive power for the analysis that follows is their status as individual subjects. Marshall writes:

In a cultural sense, the celebrity is one form of resolution of the role and position of the individual and his or her potential in modern society. The power of celebrity, then, is to represent the active construction of identity in the social world. Studying the celebrity offers the reader of culture a privileged view of the representative forms of modern subjectivity that pass through the celebrity as discourses. (Marshall 1997)

Further, Marshall draws on Richard Dyer’s work *Heavenly Bodies: Film Stars and Society* to talk about a few specific meanings of celebrity: ²¹

1. The celebrity is the epitome of the individual for identification and idealization in society.

2. The celebrity is not wholly determined by the culture industries and is therefore somewhat created and constructed by the audience’s reading of dominant cultural representations. Gramsci’s conception of hegemony best expresses this reworking of the dominant ideological images into social categories of class, gender, age, and so on.

3. The celebrity is a commodity, and therefore expresses a form of valorization of the individual and personality that is coherent with capitalism and the associated consumer culture. (Marshall 1997)

There are also specific features of television as a medium that construct celebrity subjects differentially to film or music, for example. Television is marked by intimacy, especially in the talk show format, wherein hosts directly address the

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audience. Talk shows attempt to produce topical stories to boost their own significance and maintain an audience, while also “mak[ing] coherent the interpretation of marginal phenomena brought onto the show” and “construct[ing] the ethical field in which the marginal/ized cultural activity can be positioned” (Marshall 1997).

In conclusion, celebrities “embody the collective in the individual, which identified their cultural signs as powerful” and serve as “the public representation of individuality in contemporary culture, where their movements…are significant” (Marshall 1997, 241, 242).

3.3 Themes in the Celebrity Discourse of Chronic Lyme Disease

3.3.1 Public Advocacy

In a 2016 article published on Jezebel, a women’s media blog with a feminist stance, Stassa Edwards argues that celebrities who come forward about their experiences with chronic Lyme disease are “[rendering] the disease real; they make it visible” (Edwards 2016). There are powerful cultural effects of celebrity visibility on issues; people find celebrities relatable and often feel personal connections with them, so seeing celebrities talk publicly about this controversial disease entity gives credibility to the disease and its sufferers. As Marshall writes above, celebrities are “given greater presence and a wider scope of activity and agency” than the rest of us (ix). Celebrities triumphing the cause of Chronic Lyme disease serves as advocacy, creating visibility and awareness for Chronic Lyme by playing on notions of medical and scientific objectivity, cultural meanings of the disease, and the embodied suffering these celebrities enact when they publicly discuss Lyme disease. This
subsection, “Public Advocacy,” documents several celebrities who serve as advocates for chronic Lyme disease, framing the discourse under my three theoretical arguments: criticisms to objectivity, cultural meanings of illness, and the legitimacy of the embodied experience of suffering, a structure all remaining subsections follow.

**Criticisms to Objectivity**

Yolanda Hadid appears on the Bravo TV show The Real Housewives of Beverly Hills (or RHOBH) and uses her platform to discuss her struggle with Chronic Lyme disease. She speaks openly about the pain she feels daily and the struggle to be recognized as legitimately sick. Hadid documents this struggle in her storyline on the show, in her cast-member blog on Bravo’s website, and on her personal Instagram page, which is full of photos of her receiving a panoply of medical treatments as well as images featuring text and statistics on Chronic Lyme, often from the International Lyme and Associated Diseases Society, a pro-chronic Lyme advocacy organization which funds research on the disease. She makes frequent use of hashtags to maintain a stance on the disease and her intentions in being public with her illness, such as #SearchingForACure, #FindACure #AffordableForAll and #LymeDiseaseAwareness. She has portrayed herself as boldly seeking a cure through countless doctors across the world and countless medical treatments, so that she can share this with others who are suffering. She has said that if Lyme disease wasn’t so controversial she would choose to be more private about her disease, but instead she “wants to shine a light on a disease that so many know so little about” (Hadid 2015a).

Hadid’s is an example of a celebrity advocating awareness and compassion for Chronic Lyme disease and its sufferers, and using her position as a reality star to
accomplish this. She is also, however, dealing in ideas of scientific and medical objectivity that she understands as central to chronic Lyme’s controversial nature. She talks in one blog post on the Bravo website about traveling the world to find a cure, because “a lot of great medicines and ancient therapies are blocked by the FDA” and paints this (often luxurious looking travel and treatments) as recognizing “the value of diverse points of view in medicine.” In the same post, she further criticizes the American public health and mainstream medical response to Lyme disease, saying “there is medical data on Lyme and spirochete infections going all the way back to 1908, but yet we still don’t have proper diagnostic testing, a vaccine, or a cure for Lyme disease while we are living in the United States of America, the most extraordinary country in the world.” Hadid is invoking American exceptionalism to criticize what American scientific and medical research has been able to accomplish towards treating and preventing Lyme disease. Her statement that there is no “proper diagnostic testing…or a cure for Lyme disease” is contestable, as serological diagnostic testing does exist for the disease, but is often accompanied with other concrete indicators such as the erythema migrans rash or the presence of a tick bite. The CDC would also say that often, and especially when caught early enough, Lyme is in fact easily treatable with antibiotics. These are two vastly different conceptions of Lyme disease, however, between Hadid and the CDC/mainstream medical thought. This relates to Dorothy Smith’s idea of traditional notions of objectivity excluding the standpoint of experience; we can say that in Hadid’s experience there is definitively no effective test, vaccine, or cure for Lyme disease. Harding offers the notion of strong objectivity, which situates scientific knowledge within its social context, while
Haraway advances a similar view of situated knowledges, which are able to attain objectivity specifically through their embodiment, so that they are able “to be called into account.” So Hadid’s statement, though at odds with traditional medical understandings of Lyme disease, is objectively true for her experience and understanding of Lyme (Haraway 1988, 583). The notion of a prevailing thought style from Fleck is also present in her statement that there is medical data on “Lyme and spirochete infections going all the way back to 1908.” Though this medical data existed, it existed in the European medical literature specifically concerning dermatology, so was largely invisible to American doctors. The Yale team of rheumatologists also were using a prevailing thought style to classify the emerging disease they saw in Lyme, Connecticut. Until every doctor dealing with Lyme disease agreed that they were looking at a spirochete infection, prevailing thought styles kept disparate conceptions of the disease apart and kept some researchers pursuing dead ends, such as a viral etiology for the disease, because they were simply embedded in their own research, “[resisting] contradiction and revision” (Fleck 1979, 27).

Later on, in a blog post detailing her speech at the Global Lyme Alliance (a pro-chronic Lyme disease organization) gala, Hadid criticizes some of the medical care she has received, saying “soon I learned that doctors were quick to treat my symptoms but unable to identify the cause of this multi-faceted disease” (Hadid 2016c). This distrust in mainstream medical practice is echoed in many statements by chronic Lyme sufferers and advocates. It expresses a belief that medicine is focused on the wrong areas, such as treating symptoms, and that when identifying the true cause of disease is prioritized, better treatment will follow. The issue with this idea is
that with chronic Lyme disease, diagnosis is based on subjective symptoms with very few external tests or signs for doctors to rely on in their treatments.

Singer Avril Lavigne expresses similar sentiments to Hadid in an emotional interview with Good Morning America on her struggle with Lyme disease. She never explicitly calls it chronic Lyme disease, but the language she uses describes a long-term, controversial medical condition more than a straightforward short-term Lyme infection. Lavigne had to “[put] her career, her life, and even her world tour on hold” when she became sick, and she describes being misdiagnosed by doctors as depressed and simply being encouraged to get out of bed or try playing the piano. After blood tests failed to provide a diagnosis, she “became her own health advocate” and saw specialists, who she says “can diagnose through symptoms” (Lavigne 2015). This emphasis on the validity and reliability of symptoms serves to legitimate chronic Lyme diagnosis, which has been criticized for its highly subjective diagnostic criteria. Lavigne characterizes specialization (and therefore expertise) as means to give insight into the diagnostic picture of Lyme disease when blood tests are not sufficient to do this.

Lavigne is using her platform not only to raise awareness for chronic Lyme disease and advocate its legitimacy (when asked to give a message to other sufferers, she says to “not let people tell you you’re crazy”), but also to criticize the medical knowledge that is working to produce an authoritative meaning of the disease. She describes seeing “literally the top doctors” and calls their ineffectual diagnoses and attempts at treatment “so stupid.” She refers to doctors who believe in and treat chronic Lyme disease as “specialists,” a word which emphasizes their particular
situatiedness and the expertise this brings, rather than their controversial position or the possibly fringe nature of their views (Lavigne 2015).

Ally Hilfiger, the daughter of Tommy Hilfiger and one-time reality star of MTV’s *Rich Girls*, also discusses medical and scientific objectivity in her memoir about Lyme disease. The book, *Bite Me: How Lyme Disease Stole My Childhood, Made Me Crazy, and Almost Killed Me*, details her years-long struggle against various Lyme symptoms that eventually land her in a psychiatric ward. The format of the book is a medical mystery, wherein she recounts each new symptom and its effect on her life with the benefit of hindsight, and eventually is diagnosed (with the help of her psychiatrist) with Lyme disease and embarks on another years-long struggle to be cured. The book takes a spiritual approach to medicine and healing, and Hilfiger emphasizes the ways in which she views her sickness as a spiritual emergency, wherein she sees spiritual salvation as a path through illness. When discussing the medical community and its response to Lyme disease, Hilfiger identifies an inherent bias: that doctors are unwilling or afraid to diagnose chronic Lyme disease because the symptoms can be multifarious and the disease itself is controversial. This reflects the cognitive and social authority of medicine to dictate reality that seeks to ignore diseases which pose problems in treatment described by Wendell, as well as Fleck’s idea of a thought collective working against the acceptance/legitimation of chronic Lyme disease. She is grateful for the doctors that have been willing to diagnose and treat her, and stresses the scientific, empirical nature of the work these doctors do, writing how “a doctor scientifically sees in your blood that there is actually something going on” to diagnose Lyme disease (Hilfiger 2016, 189). As Aronowitz
writes, this is a common contradiction within lay communities centered around Lyme advocacy; “they depict value-neutral science as the ultimate arbiter of legitimacy while attacking the hegemony of contemporary medicine” (77). This could stem from a desire to present one’s experience as legitimate through its basis in objective, empirical knowledge-making. Hilfiger also recounts visiting numerous doctors, including both accepting and dismissive ones (Hilfiger 2016, 12). 22

Finally, one particularly bizarre case of celebrities involving themselves in medical epistemology surrounding Lyme disease is Chrystal Hefner, Playboy model and the wife of Hugh Hefner, posting to Instagram about her Lyme diagnosis and exhorting others to get tested if they have “EVER GONE HIKING.” Hefner specifically recommends using the lab IgeneX, saying it is the best lab for Lyme testing, and then lists many of the non-specific symptoms of chronic Lyme disease that could indicate infection. She says “having just one of these could mean you have Lyme” and further asserts that, as Lyme disease is related to syphilis (both are spirochete infections whose etiological agent share a taxonomic family) it “can be sexually transmitted and passed from mother to child during pregnancy.” Hefner is making some bold medical claims, most of which are not widely accepted, and is doing so in a way that benefits one company in particular. IgeneX has been criticized and investigated for the accuracy of its tests, and is thought by some to be too liberal at diagnosing Lyme disease from blood and other body samples (Hurley and Santora 2005).

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22 This emphasis on the number of doctors one must visit in searching for a cure for Lyme disease is also something Yolanda Hadid mentions repeatedly, and is discussed later in this chapter. See page 99.
Cultural Meanings of Illness

Celebrities also use their advocacy for Lyme disease to create cultural meanings of the disease. Celebrity visibility creates a particular image of Lyme disease for the viewing public to then digest. Celebrities have often made complicated, controversial, or simply less well-known issues accessible and digestible to broad audiences. Treichler discusses how this occurred during the AIDS epidemic when first Rock Hudson and then Magic Johnson went public about their HIV positive status. These revelations completely turned the cultural tides of the public perception of HIV/AIDS, because despite the revelation that Rock Hudson was gay, he was still seen as an All-American, morally supportable figure who showed people that anyone at all could be HIV positive or have AIDS, not just strangers in posh coastal cities whose lifestyles seemed wholly distinct from that of the average American. Magic Johnson’s announcement that he was HIV positive brought HIV/AIDS awareness further into the mainstream, making the public aware of HIV/AIDS as more than just a “gay disease” (Treichler 73, 85).

Many of the celebrities engaging in chronic Lyme advocacy explicitly state this wish to bring visibility to Lyme disease so that it may be recognized as more legitimate and that those suffering from it will receive medical care and empathy. In Instagram posts as well as on her RHBOH blog Yolanda Hadid has stated that she doesn’t “intend to host a pity party by sharing [her] pain and struggles” instead, she says “by sharing, I think I help open minds to what invisible chronic disease looks like” (Hadid 2016a). She writes “when I first got diagnosed with chronic Lyme disease and learned about the stigma around it, I chose to share and bring awareness
to this ignored disease whose surrounding controversy feels like such an unfair and shameful affair.” Ally Hilfiger expresses the wish that sharing the story of her struggle with Lyme disease will help others to feel less isolated. It is ironic that these two express this sentiment while simultaneously listing the countless treatments and doctors they have had access to in their journeys toward healing. Lavigne, too, mentions seeing “the top doctors,” all of whom were unable to properly diagnose her.

In all cases, these celebrities are sharing their stories in order to educate and ostensibly help others in their position, but it should not go unacknowledged how unique their position actually is, due to their financial privilege. Celebrities are still cultural representatives of the individual, however, even when they do not resemble most of America, and so celebrity advocates of chronic Lyme are showing the public possible subject positions in the chronic Lyme discourse (Marshall 1997).

Kathleen Hanna addresses her struggle with Lyme disease in a documentary about her life and career, *The Punk Singer*. She details how difficult it was for her to admit her ability to use her body for her career was compromised by her sickness. Hanna makes a comparison between feminism and Lyme disease, discussing how being outspoken about either can lead to opposition or simply being written off for caring about something deemed outside popular interest. She says: “when a man tells the truth, it’s the truth. And when, as a woman, I go to tell the truth, I feel like I have to negotiate the way I’ll be perceived” (Anderson 2013). She asserts that suspicion exists around “a woman’s truth”; the possibility that one is exaggerating. She relates this to Lyme disease by saying “I don’t care if people don’t think late-stage Lyme’s disease exists, because I have it, and other people have it, and we help each other.
And we know it exists….my problem is…when people get in the way of people who are sick getting better, because they don’t understand it” (Anderson 2013). This relates to the “standpoint of experience” discussed by Smith in *Conceptual Practices of Power*, as Hanna occupies this standpoint alongside fellow Lyme sufferers, even in the face of medical suspicion and doubt. That the standpoint of experience is connected to womanhood does not escape Hanna either, and she acknowledges and fights against this subordinate epistemic position. Hanna also understands the cultural situation of the kind of Lyme disease she has, late-stage Lyme disease, as one of controversy and often disbelief, and she knows that its legitimacy has been questioned in the same way that the legitimacy of women’s thoughts and feelings is called into question by our society and cultural values. Though late-stage Lyme disease is distinct from chronic Lyme disease in medical literature, it still entails a significant experiential burden on sufferers, and is also harder to diagnose than early Lyme infection. It is not free from the power of metaphor that Sontag argues against, and Hannah knows that some of the symbolic meanings attached to late-stage and chronic Lyme are that it is fake and that its sufferers are lying and just want an excuse to avoid hard parts of life such as work. Late-stage Lyme disease can also represent our fear that disease may strike anywhere and this fear contributes to the disbelief that Hanna has experienced, as people do not want to believe it possible for such a debilitating disease to strike out of the blue and drastically alter one’s life (Gilman 1988).

Avril Lavigne takes a moment from her TV interview to address those who are also suffering from Lyme disease, telling them that they shouldn’t accept being
told they are crazy. The language and context of her interview also serve the larger purpose of raising general awareness for Lyme disease, and especially Lavigne’s version of chronic Lyme disease. The anchors of the show and the one specifically conducting the interview talk to her and about her in a way that enforces the cultural message she is sending, through their sympathetic expressions and sentiments of solidarity or admiration for her struggle. The fact that this interview is on Good Morning America in the first place shows that the producers of the show and those who run the network view her message as one worth sharing, either for the pathos involved in seeing a public figure tearfully share personal information about a lived experience, or for the message (delivered through a relatable public figure) that a disease affecting thousands of Americans may be underdiagnosed or misunderstood. The talk show format is described by Marshall as one marked by intimacy as well as the interpretation of various marginal phenomena, in this case a debilitating and controversial illness, by the host who “constructs the ethical field” in which to position this phenomenon (Marshall 1997). The hosts here are positioning Lavigne sympathetically and encouraging the audience to empathize with her struggle.

*The Embodied Experience of Suffering*

Celebrities who advocate visibility and awareness for chronic Lyme disease are doing so on the understanding that their suffering can inspire compassion and empathy within the public and their fans in a way that random strangers cannot. They represent an important possible form of subjectivity in modern society (Marshall 1997). It is not just that celebrities have larger, more visible platforms for sharing such messages, but they also inspire identification through the way their personalities
are used in the media. All the celebrities I have mentioned are either reality stars or singers, and so are manufacturing what appears to be a genuine persona for the public to consume, leaving a transparent conduit between the public and the celebrity.

Further, as Marshall writes, the celebrity is “somewhat created and constructed by the audience’s reading of dominant cultural representation,” indicating a reciprocal creation of celebrities and their advocacy for chronic Lyme as the celebrity is constructed by audiences as a woman speaking publicly about a contested illness while the public advocacy is occurring (Marshall 1997).

Yolanda Hadid has mentioned that she wishes to use her platform to inspire sympathy and understanding for those suffering from Lyme disease. One caption on an Instagram post about her chronic Lyme struggle reads “you may be tired of hearing about it but I am tired of living it” (Hadid 2013–6). In her blog posts on the Bravo website she often speaks of the immensity of the suffering she has experienced since becoming sick, but always follows this with an assertion of her “undeniable spirit” and often the statement that “God often uses our deepest pain as the launching pad of our greatest calling” (Hadid 2015b). When she states she is not trying to host a pity party but instead “open minds to what invisible chronic disease looks like” she is expressing a wish for her suffering to be less contained and more public so that others can be believed about their illness. This follows Klienman’s interpretation that the experience of suffering is often one of the most pressing parts of someone’s experience of illness, as Hadid brings her suffering to the forefront with her public advocacy.
Avril Lavigne’s interview on her Lyme disease also serves to underscore and legitimate the suffering she has experienced due to her illness. When she tearfully speaks of it being “literally the worst time of [her] life” she is sharing a conception of Lyme disease as something that can ruin lives, or at least put them “on hold.” That she is doing this on morning network television broadcasts this idea and makes it consumable to millions of potential viewers, rendering her suffering and embodied experience of Lyme disease visible on a greater scale due to her celebrity. Ally Hilfiger, too, uses her greater visibility to show how life-altering the experience of Lyme disease is. She writes that “the main difficulty Lyme sufferers face [is] not being taken seriously, or being accused of exaggerating our suffering” and about learning through “past-life regression healing” that she “needed to share [her] experience with others who suffer from Lyme so they don’t have to feel so isolated in their struggles. [She] knew that that was the only way [she] was going to get and stay better” (Hilfiger 2016).

The epistemological, cultural, and experiential dimensions to celebrity public advocacy for chronic Lyme are biomedicalized in several key ways. These celebrities are taking the “public and private performances” of health under biomedicalization to a logical extreme by performing their illness for mass audiences, whether through reality TV, social media, or memoir. These celebrities are also aware of the moral imperative to remain healthy in Western culture, and use their advocacy for chronic Lyme to push back against this by legitimating their own suffering and that of others with CLD. Through this advocacy and activism, they also see themselves as participants in the production of medical knowledge of chronic Lyme; making claims
about how it should be diagnosed and treated and criticizing medical practices they view as inaccurate or harmful. Lastly, Hefner’s Instagram advocacy enacts the very transformations Clarke et al. argue are constitutive of biomedicalization in recommending the lab IgeneX for anyone worried about their Lyme status. This lab uses molecular and some genetic techniques, not all of which have medical consensus regarding their validity, to detect *B. burgdorferi* and possible co-infecting pathogens in patient blood. This directly reflects the biomedicalized emphasis on molecular technologies and genomization, as the controversial PCR test attempts to isolate pathogen DNA in blood or urine, despite CDC warnings that this test has not been validated or peer-reviewed (CDC 2005).

3.3.2 The Invisibility of Suffering

Another common theme espoused by celebrities related to chronic Lyme is the invisibility of suffering one experiences with this disease. Yolanda Hadid constantly refers to Lyme as an invisible disability or an invisible illness, and reminds us that every one of us is “fighting a battle you know nothing about.” Avril Lavigne, when asked to give a message to fellow sufferers says “Lyme disease is real” and to “not let people tell you you’re crazy.”

Criticisms to Objectivity

The symptoms of chronic Lyme disease lend themselves to this invisibility because they are highly variable and, critically, subjective. This aspect of chronic Lyme disease makes it easy for medical epistemology to overlook the disease, as it does not have clear boundaries or universally agreed-upon diagnostic standards. The function celebrities serve here is to then create visibility through acknowledgement of
Lyme disease’s reality and devastating effects. The subjective nature of its symptoms is completely at odds with the “prevailing thought style” from Fleck present in the history of infectious disease research, where outward manifestations of illness have been critical to diagnosing and understanding the mechanisms of these diseases. Psychiatry, however, is a field that has always thrived on ambiguous cases with unclear etiologies and occasionally complex patterns of symptoms. Psychiatric diagnoses are often present in the periphery of chronic Lyme cases because the symptoms may resemble mental illnesses and are “invisible” (outside of behavioral and affective manifestations) to a doctor attempting a diagnosis. We can see this in Lavigne’s exhortation to Lyme patients to not accept being told they are “crazy” and her rejection of the diagnosis of depression from her symptoms. Ally Hilfiger’s case of Lyme disease even landed her in a psychiatric hospital for a whole set of reasons, including psychiatric manifestations of her illness like paranoia and panic attacks. Wendell writes about the medical urge to classify poorly-understood conditions as psychiatric or psychosomatic to maintain medicine’s “myth of control” over the body. If doctors cannot easily find a physical explanation for suffering, they assume there cannot be one at all and declare the problem mental or emotional.

**Cultural Meanings of Illness**

Invisibility is yet another metaphoric meaning that has been attached to chronic Lyme disease to the detriment of sufferers. The excess signification of chronic Lyme’s cultural “invisibility” serves to keep the disease out of mainstream

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thought, but celebrities sharing their experiences reverse this effect, making the disease visible at a cultural level that would not be possible without their work on this. Marshall writes that celebrities have discursive power to be “a voice above others, a voice that is channeled into the media systems as being legitimately significant,” allowing them to counteract cultural meanings of chronic Lyme disease as invisible (Marshall 1997). I have also seen this occur in my experiences sharing the subject of this thesis (in other words, through my experiential knowledge of chronic Lyme). I live in the Northeast, where Lyme disease is extremely well known, and am also from Texas, where it is far less common and therefore more obscure on a personal level. In both places, people to whom I have told the subject of my work will invariably bring up various celebrities with chronic Lyme disease, most often Yolanda Hadid. She and other celebrities seem to form a significant part of people’s understanding of the disease, regardless of whether they also have personal experience with it.

*The Embodied Experience of Suffering*

Critical to Hadid’s understanding of her Lyme disease is the acknowledgement that her suffering is largely invisible, despite its severity. She says it is hard to understand someone “looking good and feeling like death” and repeatedly calls Lyme disease “invisible,” but Hadid also seems to know that her words have the power to render this pain visible in ways her body cannot.

The invisibility of chronic Lyme suffering according to the celebrities who discuss their experiences with the disease is one of the factors that makes the disease so painful on an experiential, embodied level. When celebrities discuss this as a
source of pain in their own experiences with Lyme disease, they are making the invisible suffering of others with chronic Lyme disease visible in the cultural imaginary. Celebrities have more cultural power than most non-famous people, and this power can work to combat the invisibility of suffering experienced by themselves and others with chronic Lyme disease (Gamson 1994). Celebrities are able to work to change this invisibility in their own lives/public followings when they speak explicitly about it. It serves to legitimize their own experience of illness which may look minor from the outside but experientially has been highly impactful, mirroring Kleinman’s interpretation of the experience of suffering in chronic illness at critical to an accurate understanding of the illness (Kleinman 1988).

3.3.3 Multitudes of Doctors and Therapeutic Interventions

Another common element to celebrity illness narratives is the sheer amount of medical attention they receive in battling chronic Lyme disease. They list figures for how many doctors they have seen, how many different countries they have visited, how many months of certain treatments they have received, and frequently document the involved, often strange treatments they have received in their journeys to wellness. A significant part of the medical care celebrities discuss are alternative therapies like those described in Ali and colleagues’ study of patient experiences of chronic Lyme disease, a critical feature of biomedicalization (Ali et al. 2014).

Yolanda Hadid sends a message of humanitarianism in her search for a cure; as she documents her various treatments on her Instagram account, she repeatedly uses hashtags such as #DeterminedToFindACure, #AffordableForAll. The idea of a cure affordable for all is perhaps antithetical to the sheer number of treatments she
has received from a similarly high number of doctors. Many of these treatments appear luxurious, such as cryotherapy, in which the whole body is immersed in a freezing chamber meant to reduce inflammation and stimulate the immune system. Part of Hadid’s treatment plan also involves extensive diet modifications and occasional juice cleanses which are intended to detoxify the body, as well as reduce inflammation. Often accompanying her posts on whatever foods, juices, and supplements she is consuming is the hashtag #HealthIsYourWealth, which is perhaps ironic, considering how wealthy she appears.

_Criticisms to Objectivity_

From a medical epistemology perspective, this practice circumvents and even destabilizes the hegemonic power western medicine has over medical knowledge-making in the US and Europe by utilizing and valuing alternative approaches to healing and using celebrity platforms to broadcast this, raising the visibility and public awareness of these treatments. These include cryotherapy, traditional Chinese medicine, special diets modulated for the “six major genotypes” humans supposedly have, detox diets, and homeopathic treatments (Hilfiger 2016, Hadid 2013-6).

_Cultural Meanings of Illness_

What is also at work here is continuation of the history of upper class women inhabiting a sick role. In the Victorian period, women of the upper classes were constantly subject to medical attention for parts of life we would consider normal and recoverable today, from pregnancy to grief to emotional states labeled “hysteria.” Doctors saw this cultural fixation of wealthy women’s health as an opportunity to
make money at a time when there were some 173 doctors for every 100,000 number of people in 1900 (compared to 50 per 100,000 today), and would use frequent house calls and treatments to line their pockets, as well as satisfy the wishes of husbands wanting a better means to control their wives (Ehrenreich and English 1973). Doctor’s orders of bedrest serve this purpose well, and though none of the celebrity women today advocating chronic Lyme awareness seems to be explicitly under the patriarchal control of her husband, they are able to inhabit their sick role (with the multifarious treatments and extensive time in bed) due to their financial privilege and high status in society.

*The Embodied Experience of Suffering*

These treatments also contribute to an overall picture of embodied illness and suffering by acting as the physical manifestation of chronic Lyme disease, while the symptoms remain invisible. These treatments render visible the suffering felt by celebrity advocates of chronic Lyme, and allow these women to inhabit a sick role. Kathleen Hanna discusses this sick role that she never wanted to inhabit because of her feminism and reputation as a strong, self-sufficient woman. She says about the breakup of Le Tigre that she lied, attributing it to the band reaching its creative limit, rather than accept that her body was no longer capable of working as a touring musician (Anderson 2013). Hadid’s sick role is less clear-cut than that of Hanna. In Instagram posts from her time battling Lyme disease and its relapses, she poses demurely under blankets and on couches and in beds, wearing elegant (or at least comfortable-looking) leisure wear and little makeup. She looks wholesome and hopeful as she receives various treatments through an IV inserted in her arm (Hadid
2013-6). Hadid is enacting a biomedicalized version of Lyme disease wherein it is her moral responsibility to care for her health, as well as embodying the increasing focus of medicine towards managing chronic conditions rather than treating acute ones (Clarke 2014).

Figure 3: an Instagram post showing Yolanda Hadid receiving an unnamed treatment for chronic Lyme disease. She is wearing no makeup and neutral-toned, yet stylishly youthful clothing. She throws the camera a friendly peace sign. The caption reads “Exhausted but determined to uncover the mystery of chronic Lyme disease...” Image from Hadid’s Instagram.

These complicated treatments work to biomedicalize chronic Lyme disease, as celebrities use genomic and molecular technologies to treat a condition many doctors believe is treatable with straightforward antibiotic interventions. Because early-stage Lyme infection is bacterial, it has not formed a part of advances to technology and medicine that have reshaped the medical field relative to genetic conditions or the notions of risk and prevention. Lyme disease risk and prevention efforts involve avoiding being bitten by a tick, not the major lifestyle or diet changes constitutive of biomedicalization. Celebrities are showing what a multifaceted, biomedical approach
to chronic Lyme treatment looks like, through Hilfiger’s doctor who prescribes her a certain diet based on her “genotype” and the many alternative therapies, including homeopathic and traditional Chinese medicine, used to treat the condition. Hadid and Hilfiger can thus present themselves as moral subjects for pursuing health through managing their chronic conditions.

3.3.4 Healing in Percentages

An interesting element shared by many celebrities advocating chronic Lyme awareness is their use of percentages to describe their illness or healing process. This quantification is pervasive in many Lyme narratives, and especially prominent in talking about chronic Lyme disease, which many of these celebrities say is not curable, but only manageable with the proper care (and lifestyle). Yolanda Hadid mentions in a blog post that she “was only able to get about a 60% recovery” preceding a serious relapse of her symptoms, and in a later blog post mentions that her doctor has told her “50% of healing is in the emotional and spiritual body” (Hadid 2015b). Ally Hilfiger uses this idea in her memoir as well, saying she is not 100% recovered, and “will never be cured from Lyme disease” (Hilfiger 2016, 276). Avril Lavigne takes a different stance within this pattern and tells Good Morning America that she “will make a 100% recovery” now that she is receiving treatment for Lyme disease (Lavigne 2015). This use of percentages also forms a part of the “public and private performances” of health constitutive of biomedicalization, and therefore represents another aspect of celebrities biomedicalizing chronic Lyme disease around the new identity category created with the medical entity chronic Lyme disease.

Criticisms to Objectivity
It is perhaps not noteworthy that people use percentages to talk about their health; this is a measure that is widely understood and makes an often abstract, nebulous process (becoming sick or healing) quantifiable and more easily understandable. What is noteworthy, I believe, is the pervasiveness and consistency with which celebrities deploy this tactic to talk about their health. This use of numbers and percentages could be an appeal to a positivist, objective standard of medicine that uses reliable measures of sickness or healing and in doing so remains authoritative. This kind of authoritative knowledge claim over one’s own body and health is understandable with chronic Lyme disease, where this knowledge is often denied or disbelieved in sufferers by their doctors or the mainstream medical community at large. Percentages might simply be one in a number of legitimizing techniques (including appeals to blood and PCR tests, listing number of doctors seen, and various treatments undergone) that celebrity chronic Lyme sufferers use to make their experiences visible and understandable to their audiences.

**Cultural Meanings of Illness**

Celebrities can also use the cultural meanings attached to the figure of the percentage in their statements about Lyme disease. They may be making chronic Lyme disease appear more technical by using mathematical ratios, but they also may be making their experiences more legible to their audiences. Avril Lavigne’s use of a “100% recovery” allows her message of hope and healing to have a positive, positivist ring; she is not just recovering, she will *fully* recover. Hadid’s “60% recovery” prior to relapsing makes it clear and authoritative how far she came and how much she has left to go in healing. Perhaps she decided the level of recovery,
perhaps she was told by her doctor, but either way we can understand her health better through this figure. The signification and meaning that get attached to chronic Lyme disease when percentages of healing appear in the discourse are morally and mythically neutral in contrast to the kinds of cultural meanings Sontag argues against in diseases like cancer and tuberculosis, and in meanings of chronic Lyme as a disease of liars and malingerers. The use of percentages perhaps keeps the illness from reflecting on the character of the sufferer, relegating the sickness to the quantifiable zone where biomedicine operates.

**The Embodied Experience of Suffering**

The role of illness narrative is important in explaining the use of percentages in celebrity accounts of chronic Lyme. One’s own experiences and knowledge of illness form an important part of the overall knowledge possible in the experience of having a disease. In Arthur Frank’s account of the role narrative plays in illness, the most socially and personally desirable narrative an illness can have is the restitution narrative (Frank 2013). In this, someone becomes ill, seeks treatment, and finds restitution in their journey from sick to well. This contrasts sharply with the chaos narrative typical to chronic illnesses, where one’s sickness resists clear treatment or healing and uncertainty marks the experience of illness. Healing in percentages enables these celebrities to construct restitution narratives out of the chaos chronic Lyme disease has wreaked in their lives. While chronic (or even late-stage) Lyme disease is not an easily diagnosable and treatable condition and is therefore more

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24 The former has been considered an illness of repressed, emotionally negative people while the latter was considered a romantic affliction of sensitive, passionate people (Sontag 2002).
amenable to a chaos narrative, especially for its controversial status and the multiplicity of medical opinions surrounding it, celebrities describing their trajectory towards wellness with the clear, concrete, mathematical description that percentages offer creates order out of chaos.

3.3.5 Lyme as a “Silent Killer”

A persistent theme in celebrity discourse surrounding chronic Lyme disease is its ability to ruin lives, with some going so far as to call it deadly. In her speech at the Global Lyme Alliance gala, Yolanda Hadid makes explicit reference to the “debilitated lives” that “millions of people affected by this invisible disease…live because of this silent killer” (Hadid 2016c). In other blog posts, she again refers to Lyme disease in this way, describing her body as “invaded by this silent killer called Lyme disease” (Hadid 2016b). On Instagram, she mentions that Lyme disease often makes people appear healthy yet feel like dying on the inside. Avril Lavigne called her experiences with Lyme disease pre-treatment “literally the worst time of [her] life” (Lavigne 2015). Ally Hilfiger wrote “Lyme kills…by inches and minutes, and while it takes its time trying to kill you, it settles for making your life painfully miserable” (Hilfiger 2016, 241). This sentiment is a powerful notion, and one out of line with mainstream medical opinion on Lyme disease. The CDC officially recognizes seven deaths due to Lyme carditis, a rare condition where Lyme bacteria infect the heart tissue (CDC 2016c). I believe that when celebrities talk about Lyme being deadly, however, they are speaking in much more abstract terms. Some Lyme advocacy organizations do believe Lyme to be more deadly than the CDC reports, with the Lyme Disease Association reporting 36 deaths from Lyme from 2002-2007.
These numbers however, do not reflect the devastation reported by Lyme sufferers. This speaks to a different understanding of “deadly,” one more in line with “debilitating” and yet seriously claiming suffering on the level of loss of life.

_Criticisms to Objectivity_

When celebrity Lyme sufferers make sense of their disease as something deadly, literally or figuratively, they are basing this in their experience. It is easy to reject the standpoint of experience, especially when it is coming from women and their knowledge, as Dorothy Smith writes. The idea of Lyme ending/ruining lives is produced by Lyme sufferers themselves, coming from within their own self-understanding. In this it is not hiding its situatedness or attempting to perform objectivity as coming from no discernable perspective, like the weak objectivity described by Harding. Like Haraway’s situated objectivity, it is responsive to being called into account because the subject position of those making the claim “Lyme is a silent killer” is clear. They are also using their subjective position to advance this knowledge; Hadid at one time writes that she cannot “turn her back and walk away [from raising awareness for Lyme sufferers] and the debilitated lives they live because of this silent killer” (Hadid 2016c).

_Cultural Meanings of Illness_

Culturally, representation is critical to the experience and social significance an illness entails for its sufferers, and labeling an illness a “silent killer” brings heavy signification to bear on it. Celebrities may be attempting to perform this work of
creating signification in the cultural meanings of Lyme disease by representing their experience as analogous to dying and their suffering as on par with losing one’s life. This legitimates chronic Lyme disease through altering its cultural meaning to be far graver than the disease realistically is.

**The Embodied Experience of Suffering**

Calling chronic Lyme disease a “silent killer” serves to legitimize the pain and suffering experienced by chronic Lyme patients in the face of the widespread doubt and uncertainty surrounding the condition. Leslie Jamison talks about the need to render suffering visible in two essays, *Devil’s Bait* and *Grand Unified Theory of Female Pain*. Either in the case of Morgellons wherein patients are desperately seeking medical legitimacy and the epistemic legitimacy to make claims over their own illness or in the case of an inherent pain to femaleness that demands visibility even without explanation, Jamison argues for the right to make this pain visible, noteworthy, and legitimate. Chronic Lyme disease may not be literally deadly, but the experience of its sufferers is such that it is experientially deadly.

**3.3.6 Comparisons to HIV/AIDS**

One of the most striking and perhaps worrying aspects of this idea of chronic Lyme as a “silent killer” are comparisons to HIV/AIDS made by celebrity chronic Lyme advocates. Ally Hilfiger, before the statement quoted above, wrote “Lyme disease in the United States is spreading much quicker than AIDS did in the 1980s—the CDC estimates that there are at least 300,000 new cases each year” (Hilfiger 2016, 241). Yolanda Hadid also made a comparison between the two diseases in a blog post, saying “hundreds of thousands of gay men were shamed into believing
HIV was their disease only. Now, 30 years later, we all know the truth, don’t we?” In writing about celebrities and chronic Lyme for Jezebel, Stassa Edwards, too notes this frequent comparison. She writes:

The comparisons between Chronic Lyme, the Tuskegee experiment and HIV/AIDS denialism are potent and misguided. They speak to an undeniable history of vile government malfeasance and play on a deep distrust of government that crosses political ideologies. Yet they conflate chronic Lyme patients, who are overwhelmingly white women who ostensibly can afford treatment not covered by insurance, with historically disenfranchised groups. There is, perhaps, great irony in demographic groups who’ve historically had the greatest access to health care claiming that a medical system designed for them is still impossibly broken.

Beyond that, the comparison glosses over the real consequence of both syphilis and AIDS: death. Lyme rarely results in death. From 1985 to 2013, the CDC reported seven deaths from Lyme carditis, which occurs when the bacteria enters the heart tissue. It’s a rare (but the most deadly) condition reported in one percent of Lyme patients. Yet many of those who suffer from chronic Lyme say that their day-to-day quality of life is so miserable that they’ve become passive to the thought of death. While accepting an award from the Global Lyme Alliance in 2015, Foster described “the deepest core of hopelessness inside of me.” (Edwards 2016)

_Criticisms to Objectivity_

Edwards is describing how chronic Lyme straddles a boundary between life and death while failing to convincingly exist alongside more literally deadly conditions. Ontologically, this elision of chronic Lyme and HIV/AIDS may set the two up as equally serious, using the biomedical success story of HIV’s discovery and the development of successful treatments for HIV/AIDS to lend credibility to the currently murky and uncertain status of chronic Lyme. If HIV/AIDS struggled for medical recognition yet ultimately overcame its controversial status as a gay disease, why can’t we take this lesson from history and apply it to chronic Lyme? As Edwards says, this is misguided in that celebrity chronic Lyme sufferers claim to be socially
marginalized for their disease when they appear to in fact have an excess of social privilege, despite their status as women in a patriarchal society.

*Cultural Meanings of Illness*

Culturally, this comparison also would seem to legitimize chronic Lyme. As Treichler writes of the relationship between language and reality, the signification that becomes associated with illnesses forms a critical part of the illness as cultural object. In this case, the signification that has already been attached to HIV/AIDS can be tacked on to a separate disease, carrying the weight and connotations of stigma, epidemic, and mortality that HIV/AIDS carries. Celebrity chronic Lyme sufferers are not simply fashioning chronic Lyme disease into a biomedical illness, they are undertaking work to alter the representation of CLD towards a position graver than just some suburban infection spread in bucolic woods.

*The Embodied Experience of Suffering*

Experientially, HIV/AIDS comparisons alter the shape of illness narratives celebrities create, positioning celebrities alongside AIDS activists who fought for more research and better access to clinical trials in the early stages of the epidemic (and in the process creating the restitution narratives described by Frank). Equating chronic Lyme to a deadly disease like AIDS is a part of the illness narratives celebrities are constructing in a highly visible, public manner. As such, the experience of chronic Lyme can take on graver implications and importance in the lives of celebrity sufferers and their audiences. Yolanda Hadid and Ally Hilfiger both see a strong religious/spiritual element to their illnesses, describing their trials as a religious
test from God or spiritual crisis, respectively. Jamison would argue that there is 
legitimacy to this embodied understanding of chronic Lyme, even if it is not true that 
chronic Lyme has much at all in common with HIV/AIDS.

Aligning chronic Lyme disease with HIV/AIDS is yet another means through 
which celebrity discourse can biomedicalize the former condition, capitalizing on the 
successful biomedicalization of the latter. HIV/AIDS activism in the 80s and 90s 
marked a time when identity politics intersected with medical authority and 
knowledge production, and new individual and collective identities were produced 
out of this. Celebrity chronic Lyme sufferers may be attempting to perform a similar 
identity enactment through the public performance of their illness.

3.4 Conclusion

Celebrity discourse in this chapter shows six key themes related to chronic 
Lyme disease: public advocacy, invisibility of suffering, multitudes of doctors and 
therapeutic interventions, healing in percentages, Lyme as a “silent killer,” and 
comparisons to HIV/AIDS. Through these themes, a biomedicalized picture of 
chronic Lyme emerges as celebrities sort through the medical epistemology and 
criticisms to objectivity, cultural meanings, and personal experience of suffering with 
chronic Lyme disease. They are doing so within a larger cultural context, marked not 
only by celebrity culture but also a medical system based on science that subordinates 
women as knowing subjects, and a cultural and individual/experiential landscape that 
reflects this.
Conclusion

Chronic Lyme disease is not a fixed entity. It is medically, culturally, and experientially heterogenous, contested, and continually reconstructed. The discourse of chronic Lyme is being produced in American culture by disparate actors who at times appear diametrically opposed; on one side, medical authority denies the possibility for Lyme disease to be chronic while the other side, composed of lay advocates and select doctors, vehemently argues that it is. The media appear at times sympathetic to chronic Lyme disease, though not unilaterally, while many celebrities have taken on advocate roles, arguing for the disease’s validity. This discourse is taking place across many forms, from film to television, to online and print media, while social media seems to represent a more recent site of discourse production.

There are no concrete meanings produced out of discourses, rather, possible meanings can be pinned to certain elements of the discourse circumstantially and based on what is possible or logical to conclude within the discourse. This means I cannot simply explain what chronic Lyme is or means and why it is controversial out of the discourse I analyze in this thesis. Instead, I can suggest meanings that might make sense within the discourse I lay out in chapters 2 and 3.

At the outset of this thesis, I asked the question “Is chronic Lyme biomedicalized?” The work of advocate media analyzed in chapter 2 and celebrity discourse analyzed in chapter 3 shows various ways this is the case. Chronic Lyme differs from Lyme disease in its dependence on molecular and genetic/genomic technologies for diagnosis and treatment. While mainstream understandings of Lyme disease as an easily diagnosed and treated infection suggest risk assessment based on
geographical and exposure criteria and antibiotic therapy as treatment, chronic Lyme opens technoscientific avenues in both treatment and diagnosis through genetic techniques such as PCR to detect infection and alternative therapeutic interventions such as cryotherapy. Celebrities do a significant portion of the cultural work to depict chronic Lyme as biomedicalized, speaking publicly about the value of a biomedicalized approach to chronic Lyme. Chronic Lyme sufferers, celebrity and otherwise, also use their platforms and the rapid dissemination of information made possible by the internet to create new individual and collective identities around their disease, a hallmark of biomedicalization.

Within my theoretical framework under the heading *criticisms to objectivity* I asked “to what extent is this controversy a medical, scientific dispute over how knowledge surrounding disease is produced in our biomedical era?” Chapter 2 reveals that the medical facts around chronic Lyme are very much in dispute, even with peer-reviewed literature produced on both sides of the debate. This debate has multiple valences as well. It is partially a debate between groups using the same epistemological standards for their knowledge claims as scientists and doctors work on both sides to justify or negate chronic Lyme, but the pro-chronic Lyme camp also seem to base claims in alternative epistemologies that emerge out of criticisms to traditional notions of objectivity. Doctors and patients are using the standpoint of experience in their medical claims and, drawing on Smith, Harding, and Haraway, I suggest this is valid, objective stance. Another endorsement of chronic Lyme’s epistemological validity is the resemblance its skeptics and critics share with the prevailing thought styles from Fleck. Their shared viewpoint supports the work they
do (and many of the scientists producing work critical to chronic Lyme co-author papers and clinical guidelines together) and resists change from alternative viewpoints. In Fleck’s framework, alternative understandings of Lyme disease are excluded not for their (epistemological) inferiority but for their exteriority to the prevailing through style which says that Lyme is an easily treatable, short-term infection.

Chapter 3 shows celebrities participating in the medical dispute over Lyme’s reality by criticizing the epistemology behind mainstream understandings of Lyme disease. Celebrities express mistrust in mainstream medical approaches to diagnosing and treating Lyme disease, themselves identifying the thought collective/prevailing thought style in infectious disease medicine that ignores chronic Lyme. Celebrity discourse also brings situated knowledges to bear on the debate as celebrities use their own experience to legitimate alternative approaches to diagnosis and treatment of chronic Lyme.

When thinking about cultural meanings of illness, I asked the question “how does the nature of Lyme disease as both a scientific fact and a cultural artifact influence how it is conceived of by the medical community, lay advocates, and celebrities?” In chapter 2, discursive representations of chronic Lyme show it to be a powerful cultural object for its ability to debilitate sufferers and inspire disbelief from medical authority. Advocate and mainstream media accounts attempt to shift meanings of Lyme away from a serious but easily treatable infection towards a major life event and growing epidemic being criminally ignored. In chapter 3, celebrities accomplish this meaning shift through comparisons to HIV/AIDS that situate Lyme
in the historical context of other marginalized, governmentally neglected epidemics, and in the medical context of a debilitating, deadly infectious disease. Advocates and celebrities do political work to change conceptions of chronic Lyme disease as both a cultural and scientific object. They are aware of the political power they hold to shape cultural meanings of the illness through how it is represented, and this representation relies on the embodied experience of suffering to effect political transformations in the chronic Lyme discourse.

On the issue of the embodied experience of suffering, I asked “what is at stake in valuing and privileging someone’s lived experience of illness and suffering, even when there is doubt and uncertainty about the nature of their disease?” I have found this experiential aspect of chronic Lyme disease to not only be highly impactful at the level of individual people and patients but also in assigning cultural meanings and even epistemic validity to the disease. Interrogating the personal experience of suffering thus recursively informs my other two frameworks. In chapter 2, sociological research on chronic Lyme identifies the experience of suffering as critical to patient’s overall experience of their illness, and lay advocate accounts reinforce this. Lay advocates are also aware that their personal narratives and embodied experiences of chronic Lyme disease are convincing cultural objects when compared to drier, technical facts found in medical literature. Advocates can then use this to their advantage in achieving political goals.

Chapter 3 shows celebrities similarly using their embodied knowledge and personal narratives of chronic Lyme to alter cultural meanings and objective interpretations of chronic Lyme disease. Celebrities make their suffering visible
through speaking publicly about chronic Lyme and in discussing their treatments and recoveries, which serves to change cultural meanings of chronic Lyme as well as contribute knowledge from their alternative epistemic standpoint.

So, is the discourse surrounding chronic Lyme patriarchal? My three frameworks also each intersect with gender to produce the chronic Lyme discourse. Women have historically been excluded from traditional notions of objectivity as their experiences were seen as contingent and unreliable, and in the chronic Lyme discourse the standpoint of experience if often similarly gendered. Women appear as subordinate knowers while men can authoritatively make claims about the disease. Culturally, meanings of gender and illness intersect to reinforce the inevitability of chronic Lyme as a women’s illness. As an ambiguous, controversial disease entity chronic Lyme is positioned to differentially affect women from men, as women (especially upper class women) are expected to fulfill a sick role. Experientially, suffering intersects with the experience of femaleness, and in the case of chronic Lyme, the advocate, celebrity, and mainstream media representations of the disease show a clear preponderance towards women communicating their narratives of suffering through chronic Lyme.

One implication of this thesis that has been hinted at but insufficiently explored is that chronic Lyme and its controversy are a condition of postmodernity. This idea is supported by the work of Harding on the gendered underpinnings of modernity as a break from a traditional past towards reason and rationality, as well as Shildrick on the postmodern ability of our bodies to fail us in unexpected and unruly ways, and Frank’s contention that the chaos narratives frequently accompanying
chronic, unexplained medical conditions are counter to modernity’s goals of “remedy, progress, and professionalism,” instead “[revealing] vulnerability, futility, and impotence” (Frank 2013). Modernity has medicalized Lyme disease through epidemiology and the development of antibiotic therapy, but perhaps postmodernity can best offer avenues of legitimation for the multivalent, fractured entity of chronic Lyme disease. The postmodern contention that science cannot provide true, epistemically valid knowledge allows a conception of chronic Lyme disease as fragmented, disjointed, and heterogeneously constituted without recourse to any “grand narrative” of knowledge (Lyotard 1984). If science doesn’t enable true statements about the world, as Lyotard writes “science…is incapable of legitimating other language games…[and] is incapable of legitimating itself,” then we cannot trust the scientific narrative handed to us of Lyme disease as a short-term bacterial infection (Lyotard 1984). Instead, the multiplicity of “language games” the disease operates in (medical, cultural, experiential contexts, etc) all can contribute equally to an understanding of chronic Lyme. If medicalization represents a modernization project of reason and rationality, biomedicalization could figure the chaotic, decentered loci of knowledges dispersed throughout medicine and culture. Future research on the nature of chronic Lyme disease could explore the implications of understanding the disease as a fundamentally postmodern entity.

The discourse around chronic Lyme disease is not fixed; it is constantly evolving out of new research and political and public moves around the disease. Celebrities have emerged in recent years as major producers of this discourse and continue to constitute the public face of chronic Lyme for many people. Numerous
calls for further research to complete the clinical picture of chronic Lyme lead me to think that this research could push more mainstream medical acceptance of chronic Lyme as the pathogenesis of the causative bacterium is increasingly elucidated. Further research could also serve to differentiate chronic Lyme from its numerous lookalike conditions such as chronic fatigue syndrome. However, these are empirical explanations for the chronic Lyme controversy, and as such cannot capture or explain the cultural and experiential dimensions to the disease. It is only in the discourse that we can understand what chronic Lyme disease really is.
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