

THE EMPOWERMENT PARADOX: RHETORICS OF LYME DISEASE AND THE FUTURE  
OF CHRONIC ILLNESS

Sarah Ann Singer

A dissertation submitted to the faculty at the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the Department of English and Comparative Literature.

Chapel Hill  
2019

Approved by:

Daniel Anderson

Mara Buchbinder

Jane Danielewicz

Jordynn Jack

Todd Taylor

© 2019  
Sarah Ann Singer  
ALL RIGHTS RESERVED

## ABSTRACT

Sarah Ann Singer: “The Empowerment Paradox: Rhetorics of Lyme Disease and the Future of Chronic Illness”

(Under the direction of Jane Danielewicz and Jordynn Jack)

In the current age, patients and their healthcare providers must navigate the digital deluge of contradictory claims about sickness, health, and healing in print and online. Some would argue that access to more data is better, whether it is generated by clinical trials or online discussion boards. However, for those who deal with chronic and contested health conditions like Lyme Disease, the most common and rapidly spreading tick-borne infection in the United States, more data means more problems. My dissertation, *The Empowerment Paradox: Rhetorics of Lyme Disease and the Future of Chronic Illness*, argues that patient empowerment efforts do not merely help patients to access reliable health information nor find compassionate healthcare providers. Instead, corporations, clinicians, and other stakeholders use empowerment rhetoric unethically to persuade patients to share their health data, seek out specialists who charge astronomical fees, and perform extensive labor in a quest to find the “right” healthcare information. These underhanded persuasive efforts lead to a problem I call the empowerment paradox: widely accepted rhetorical moves often considered empowering—such as teaching patients to research their medical conditions online, prompting patients to share information about their illnesses on social media networks, and using digital platforms to advocate for patient-centered healthcare practices—may be disempowering and harmful.

In the broadest sense, my dissertation reveals how patients are subjected to the empowerment paradox, which means that they must navigate the conflicting, unofficial, and

unauthoritative data circulating in our digital information economy, in search of a cure. There is much at stake. Patients are desperate to help themselves, and they do gain significant rhetorical and health literacy, yet their expertise does not lead to better health outcomes. Worse yet, chronically ill people are being used and abused for their money and health data. Using Lyme Disease as a case study, each dissertation chapter illustrates how devastating the empowerment paradox can be for patients. To show how the empowerment paradox works, I rhetorically analyze online sites of patient empowerment and interviews with twenty-three Lyme Disease patients.

To my grandmothers, the best teachers I know—

Dena Share

Fay Singer

Norma Stueckler, in loving memory

## ACKNOWLEDGEMENTS

There are many people to thank, so I'll make a list.

- My dissertation committee: Thank you, Jane and Jordynn, for reading countless drafts, for making accommodations, for meeting me exactly where I was, and for never giving up on me. Thank you for talking me out of research rabbit holes, co-authoring papers with me, and teaching me how to be a teacher, mentor, and colleague. Thanks also to Dan Anderson and Todd Taylor for your ideas, energy, and enthusiasm. And thanks especially to Mara Buchbinder, who committed to mentoring me even though I was coming from an English Department and guided me through the interview process. I am so very lucky to be your student.
- My medical team: Bree Kalb, Jimmy Mali, Louise Metz, Kate Mitchell, Laura Terry, and Kathleen Transue.
- My interview participants. Thank you for sharing your stories with me.
- My writing partner and research assistant, Oriole Singer-DeSantis (see fig.1). She is responsible for any errant semi-colons and/or capitalizations that appear in this document.
- My family: My parents, Marla and Ken Singer, for inspiring me to pursue work that brings me joy and supporting me financially during the process. I could not have done it without you. Thanks also to my brothers, Daniel and Seth Singer, for their design help, coding support, GIS insight, pesto, and Appalachian Trail photos/captions. My maternal grandparents, Dena and Howie Share, spoiled me with food, love, research materials, and

*Say Yes to the Dress* episodes; I couldn't have done it without your support. My paternal grandparents, Fay and Sam Singer, spoiled me with trips to warm destinations, deli food, and by paying my student fees; your generosity and care were critical to my success. I am also grateful to my aunts, uncles, and cousins, particularly to Shelly Singer Alexander (for introducing me to Women's Studies), Linda Share (for all of the massages), and Dr. Yaron Dayani (for asking about my dissertation at every family event).

- My UNC support team: My forever mentors, Emi Stuemke, Alex Funt, and Jason Loan, who led the ever-evolving #TeamRhetoric, which during my time at UNC, has included them and Oren Abeles, Matt Duncan, Tyler Easterbrook, Jen Edwell, Tiffany Friedman, Chelsea Milborne, and Carly Schnitzler. You are all amazing. I'm also grateful for my other UNC colleagues, especially Melissa Geil, Michael Gutierrez, Susan Irons, Hilary Lithgow, John McGowan, Chris Meineke, Courtney Rivard, Jeanine Simmons, Allison Smith, and my favorite IAH officemate, the late Jean Chandler.
- My cross-institutional support team: Sue Briggs, Jane Donawerth, Jessica Enoch, Debby Rosenfelt, and Catherine Schuler.
- The Carolina Digital Humanities Institute, who sponsored my dissertation fellowship in summer 2017.
- The Frankel Family, who sponsored my dissertation fellowship in spring 2018.
- My friends near and far: Elizabeth Clark, Michael Clark, Erin Collins, Mark Collins, Arie Cohen, Elle Everhart, Mali Krantz, Jamie Lee, Nicole Riccio, Jennifer Schiller, and especially Kimmie Farris, Tiffany Friedman, and Carlie Wetzel. Thank you for reading my work, brainstorming ideas, buying me drinks, visiting me, and letting me wear pajamas to social events.

This project was literally and metaphorically messy—stacks of books sitting forever on the kitchen table, half-drunk mugs of tea covering the desk, laundry and papers everywhere. My partner in everything, Nick DeSantis, continues to love me exactly as I am, as I evolve in sickness and health. The Queen and I owe everything to you. Thank you, thank you, thank you.



Fig. 1: Oriole the Cat and I are ecstatic to be #PhDONE! Photo by author, 2019.



## TABLE OF CONTENTS

<b>LIST OF FIGURES .....</b>	<b>XII</b>
<b>INTRODUCTION.....</b>	<b>1</b>
PATIENT EMPOWERMENT: A HISTORICAL VIEW .....	4
LYME DISEASE .....	7
RHETORIC OF HEALTH, SCIENCE, MEDICINE, AND TECHNOLOGY .....	10
DISABILITY STUDIES .....	12
RESEARCH METHODS.....	14
<i>Semi-Structured Interviews</i> .....	15
<i>Coding and Data Sorting</i> .....	20
<i>Data Analysis</i> .....	21
CHAPTER OUTLINES.....	21
<b>CHAPTER 2: HEALTHCARE PROVIDERS’ CLINICAL WEBSITES .....</b>	<b>24</b>
THE CDC LYME DISEASE WEBSITE.....	25
HEALTHCARE PROVIDERS’ CLINICAL WEBSITES: A RHETORICAL GENRE.....	27
CASE STUDY .....	29
<i>Establish Credibility</i> .....	30
<i>Value and Validate Patients’ Stories</i> .....	36
<i>Construct Alternate Narratives of Lyme Disease</i> .....	40
CONCLUSION .....	46

<b>CHAPTER 3: HEALTH INFORMATION SHARING WEBSITES.....</b>	<b>49</b>
USER-CENTERED TECHNOLOGY VS. USER-CENTERED RHETORIC .....	53
ABOUT MYLYMEDATA.....	56
<i>Patient vs. Power</i> .....	58
<i>Individual vs. Community</i> .....	63
<i>Simplicity vs. Complexity</i> .....	68
CONCLUSION .....	74
<b>CHAPTER 4: CLINICAL LYME LITERACY .....</b>	<b>79</b>
CONNECTING FUNCTIONAL LITERACY WITH HEALTH LITERACY.....	82
FRAMING “CLINICAL LYME LITERACY” .....	84
<i>Overview: Interview Participants</i> .....	87
<i>Empirical: “realizing our bodies are whole things”</i> .....	91
<i>Experiential: “[H]e sat and he listened to everything I said”</i> .....	97
<i>Embodied: “Why don’t you step in my body and then you’ll have a different thought?”</i> ..	100
CONCLUSION .....	103
<b>CODA.....</b>	<b>106</b>
FUTURE RESEARCH .....	106
<i>Cultivating Social Networks</i> .....	107
<i>Inventing Information-Sorting Practices</i> .....	110
<i>Developing Alternative Testing Protocols</i> .....	112
IMPLICATIONS.....	114
<i>Digital Research Ethics</i> .....	115

<i>Pedagogy</i> .....	115
<b>APPENDIX</b> .....	<b>119</b>
<b>WORKS CITED</b> .....	<b>121</b>

## LIST OF FIGURES

Figure 1 – Oriole the Cat.....	viii
Figure 2 – CDC Lyme Disease Website.....	27
Figure 3 – Dr. Steven G. Meress’s website homepage.....	31
Figure 4 – Susan Neuber’s Office Policies & Fees page.....	36
Figure 5 – Susan Neuber’s list of “Lyme Disease” facts.....	45
Figure 6 – <i>MyLymeData</i> homepage.....	49
Figure 7 – “Count Me In!” button on the “About MyLymeData” page.....	64
Figure 8 – “Can 1 Have Power” video slide.....	65
Figure 9 – Explanation of Big Data on the “About MLD page”.....	69
Figure 10 –Twenty-Four Month Follow Up Survey.....	70
Figure 11 – <i>MyLymeData</i> FAQ page.....	73
Figure 12 – “Disability” question in the <i>MyLymeData</i> survey.....	75

## INTRODUCTION

There is no clear consensus on the definition of patient empowerment, yet it is considered to be a fundamental means of improving health outcomes. Generally, patient empowerment is “defined as a process of behaviour change, with a focus on how to help patients become more knowledgeable and take control over their bodies, disease and treatment” in which patients are “activating” themselves to become “more knowledgeable about, satisfied with, and committed to their treatment regimens” (Aujoulat et al. 1229). Many other terms align with and complement the goals of patient empowerment, including patient-centered care, patient-powered, patient engagement, self-management, patient-centered outcomes, patient activism, and shared decision making (Castro et al.). Patient empowerment research primarily occurs in the health sciences. In these fields, researchers use surveys, qualitative interviews, and other assessment tools to determine if patients feel prepared to make healthcare choices, follow medication protocols, and shift their lifestyles to better accommodate health conditions.

This project extends the critical work that examines patient empowerment rhetorically—that is, how patient empowerment discourse, images, data, narratives, and other tools are used to persuade diverse stakeholders, such as patients, healthcare providers, researchers, and advocates, to produce certain social actions. Generally, rhetoricians of health and medicine argue that empowerment is fundamentally positive. However, following Rebecca Dingo’s (2014) work on empowerment and global development, this project will identify rhetorics of patient empowerment in the context of chronic disease, examining who they help, how they help, and

how they are circulated and repurposed for a variety of uses—some more nefarious than others. Using Lyme Disease as a case study, I will demonstrate how these persuasive efforts lead to a problem that I call the empowerment paradox: widely accepted rhetorical moves often considered empowering—such as teaching patients to research their medical conditions online, prompting patients to share information about their illnesses on social media networks, and using digital platforms to advocate for patient-centered healthcare practices—may be disempowering in some ways. By analyzing a range of popular and scholarly websites, health information sharing platforms, and interviews with Lyme Disease patients, I suggest that non-academically validated websites provide critical information for patients, sharing health data may be more harmful than helpful, and gaining health literacy may prevent patients from getting healthy.

In this chapter, I will begin by offering a brief history of the patient empowerment movement (1930s-2010s), which has provided the basis for the empowerment paradox. Once dismissed as mere “patients,” healthcare activists began engaging consumerist discourses as a way to advocate for better care. However, insurance companies and other major economic stakeholders also took up this rhetoric, which framed ill people as the persons responsible for making effective healthcare decisions instead of physicians or medical institutions. As more people became impacted by chronic diseases, ill people were forced to negotiate between claiming a suffering “patient” and agented “consumer” identity. By 2000, more than 70,000 websites provided health information and more than 18 million U.S. adults looked online to find health-related information (Cline and Haynes 672). However, it seemed that suffering patients remained at the mercy of sexist, classist clinicians, while agented consumers—seemingly—had the power to select and/or purchase the most effective healthcare providers and treatments.

Extending this work, I will consider how health literacy has become a critical agent of empowerment for twenty-first century patients. Tracing this history will help me build a case for focusing on Lyme Disease, the most common and rapidly spreading tick-borne infection in the United States. I contend that online sources created by lay people, such as websites, forums, social media platforms, and health information sharing tools, are products of the remaining “patient”/healthcare “consumer” divide. In the case of Lyme Disease, these online sources have emerged in response to the contestation around Lyme Disease diagnosis, treatment, and prognosis. As I will demonstrate, ill people, especially those who are suffering from a chronic condition with ambiguous symptoms, are forced to play the roles of suffering “patient” *and* activist “consumer” in an effort to get well. The idea that ill people are forced to embody two competing roles exemplifies the empowerment paradox: patients must be simultaneously sick enough to prove that they are worthy of expensive and risky treatments but well enough to research and seek out those treatments. This dynamic connects with broader shifts in healthcare, which has transitioned to focusing on patients as individuals who may be best served by individualized care and, ultimately, personalized genomic medicine. Unfortunately, playing both roles does not often result in improved health, which is the ultimate irony of the empowerment paradox. My research suggests that Lyme Disease patients rarely recover fully; rather, they are bound to a lifetime of continuously seeking new treatments, providers, and health information.

Then, I will situate this project within the context of recent research in rhetorics of health, medicine, science, and technology, as well as disability studies. I consider how this study aligns with current trends in the field, including conducting mixed-method, interdisciplinary research, focusing on digital sources, and centering on what Ashley Kelly and Carolyn Miller call “parascientific genres.” Although peer-reviewed scientific journal articles tend to be the most

important data sources for scientists and other scholars, these resources have failed people with Lyme Disease, who are forced to triangulate a range of public and professional sources in order to find the most up-to-date and practical information. This challenging rhetorical situation, in which ill people must play “patient” *and* “consumer” while seeking guidance from validated *and* self-appointed experts, has framed this project’s research methods, which are detailed in the next section.

### **Patient Empowerment: A Historical View**

In a recent article, “The Patient as Consumer: Empowerment or Commodification?,” bioethicists Melissa M. Goldstein and Daniel G. Bowers (2015) note that the Latin root of “patient” means “to suffer,” while the Latin root of consumer means “to use” (162). Rhetorics of consumerism were first connected to healthcare discourse in the New Deal Era (Lee 142). Historian Nancy Tomes argues that, contrary to popular belief, “patient activists” were the first people to “embrace” the controversial term, “health-care consumers,” in the 1960s-1970s (*History* 84). They were in search of a “liberating alternative to a traditional doctor-patient relationship they believed to be hopelessly mired in paternalism” (84). As such, the term “health-care consumer” has functioned as a “synonym for patient” since the 1980s and connotes the “growing market orientation” of medicine the U.S. (Tomes, *History*, 83).

Tomes claims that our twenty-first century focus on the patient empowerment movement “rests on a faith that well-informed patients can help curb our dysfunctional medical culture,” and that patients are forced to serve as “watchdog[s]” who identify emergent issues in our “changing medical economy” (Tomes, *Remaking* 8). Some patients feel that their carefully cultivated healthcare “behaviors,” such as “doctor shopping,” reading scientific and medical journal articles, and “feeling emboldened to challenge both medical opinion and bureaucratic



decision making,” help them feel more in control and make confident healthcare decisions (Tomes, *Remaking* 1). However, anthropologist Annemarie Mol claims that the idea of an empowered patient—an ill person equipped to make the right choices about their healthcare—is itself a red herring because most patients “lack the material resources required to choose,” and in most healthcare situations, there are no good choices (7). To refer to patients as consumers assumes that they wish to “enter the market to buy products that they find attractive” rather than seeking help to ease suffering (32). Goldstein and Bowers consider this critique as well, noting that the emphasis on “personal responsibility and knowledge” is not only used to help patients get well, but also to “slow the rate of skyrocketing health care expenditures” (163).

Rhetoricians, too, have become invested in studying empowerment discourses. Rebecca Dingo, for example, shows the links between policy arguments from different transnational governing bodies, showing how some of the same language and topoi are used to empower women in some circumstances while disempowering them in others. In her book, Dingo demonstrates that the language of empowerment is taken up in multiple contexts, many of which ignore the systemic issues that create gender inequalities and instead place the burden of success on individual women. Similarly, Tasha Dubriwny also examines rhetorics of empowerment and focuses on gendered narratives in healthcare contexts. She considers case studies of breast cancer and prophylactic mastectomies, postpartum depression, and the Gardasil vaccine to argue that female patients are rendered “vulnerable empowered subjects” in our current healthcare marketplace (3). Her research suggests that the “postfeminist narratives” around these health topics reaffirm traditional gender roles, particularly for white, upper-middle class women (3).

Health literacy, defined by the U.S. Department of Health and Human Services as “the degree to which individuals have the capacity to obtain, process, and understand basic health

information and services needed to make appropriate health decisions,” is now a critical component of patient empowerment. Like women enacting their empowerment by taking out micro-loans and starting family businesses, high levels of health literacy are assumed to be a marker of patient empowerment. In fact, the World Health Organization (WHO) claims that “health literacy is critical to empowerment” (“Track 2”). Perhaps this is because health literate patients have a better potential to improve their health outcomes—for example, they know how to read a nutrition label to determine how many carbohydrates are in one serving of ice-cream and they know what potential side effects might be caused by their medications. This information might prevent them from experiencing a blood sugar spike or suffering temporary or permanent harm from a new medication, which is a good thing. However, health literacy is a rhetorically complex skillset that can harm patients with a range of chronic and acute conditions. Patient empowerment rhetoric is also taken up across contexts, and primarily the burden of success is placed on patients themselves, even though they may not truly be agents who can be empowered.

Of the various contested illnesses, I chose to study Lyme Disease because its rhetoric best elucidates the empowerment paradox. To this end, I build on Dingo’s research method of “networking arguments” in my examination of patient empowerment discourses and Lyme Disease. First, “networking arguments” necessitates bringing together texts (broadly defined) from different contexts and seeing how they work together. In the case of Lyme Disease, it would be almost meaningless to study how discourse operates solely in CDC-produced documents about Lyme Disease *or* patient community-produced documents about Lyme Disease; it is only when studying them together that new exigencies and unexpected rhetorical ecologies are revealed. In this particular case, for example, although the term “Lyme Literate” circulates in

both online patient forums and medical journals, it is used in contradictory ways. The power of networking arguments, Dingo suggests, is that they allow us to “begin to effectively disentangle the commonplaces of public policy from their taken-for-granted meanings and show how they are not a single totalizing discourse but many interwoven strands of arguments” (25), which ultimately opens up public policy as a “space of negotiation” (26). Networking arguments around Lyme Disease illuminate the burden placed on vulnerable patients, who may seem to be well-equipped to manage their health problems, but are, instead, drowning in a sea of competing information. And no matter how health literate these patients become, they remain ill and suffering, and the burden of finding a cure is overwhelming.

### **Lyme Disease**

Lyme Disease has been studied for almost forty years, but debates have emerged around its name, diagnosis, treatment, and prognosis. Lyme Disease comes from *borrelia burdorferi*, a bacterium transmitted to humans when they are bitten by infected deer ticks. Initially, ill people might notice a bull’s-eye rash (a red splotch surrounded by a red ring), a stiff neck, and flu-like symptoms, such as nausea and body aches. Theoretically, Lyme Disease is simple to diagnose and treat, and recovery should begin as soon as it is treated. A diagnosis is made when a medical provider identifies a bull’s-eye rash on a patient’s body and/or when patients test positive via two blood tests. According to the most recent clinical guidelines, infected individuals who are diagnosed quickly after their initial infection and treated with antibiotics for fourteen to twenty-one days are expected to recover completely (Wormser et al.). Research suggests that it is most commonly found in boys ages five to nine and more than 90% of cases are found in just fourteen states (“Lyme Disease”).

However, 10-20% of sufferers reportedly struggle with persistent symptoms, and it can take patients years to receive a proper diagnosis, which makes treatment less effective (Johnson, Aylward, and Stricker). These patients report symptoms as diverse and ambiguous as chronic fatigue, widespread body pain, “brain fog,” intermittent headaches, and visual disturbances, which are largely considered invisible and subjective (Rebman et al. 534). Because the symptoms are so ambiguous, patients are often misdiagnosed with the flu. When the symptoms do not subside, Fibromyalgia or Myalgia Encephalitis/Chronic Fatigue Syndrome. When Lyme Disease goes untreated, patients are likely to acquire these debilitating long-term symptoms (Rebman, Soloski, and Aucott 346). There is no consensus in the medical community about how to diagnose or treat post-Lyme Disease symptoms. As medical anthropologist Mara Buchbinder notes, diagnosis may be “the fundamental explanatory act in medicine” (9), and patients seeking a Lyme Disease diagnosis must often rely on “rhetorical resources” to prove their suffering and negotiate treatment plans (Segal, *Health* 75). Kimberly Emmons reminds us that a rhetorical illness “would have very little rhetorical force if it did not exist as a condition that causes real suffering in the world” and thus “expand[s] beyond the doctor’s office and into everyday life” (7).

The increasing number of patients with persistent symptoms, along with three influential publications, have triggered distrust between Lyme Disease patients, healthcare providers, and other stakeholders. An investigation by the Attorney General of Connecticut found that the 2006 diagnosis and treatment guidelines, developed by the Infectious Diseases Society of America (IDSA), had “significant flaws” in their “development process” (Johnson and Stricker 1). This information was published in a widely circulated press release, which was discussed in both peer-reviewed articles and editorials in scholarly journals. A 2013 press release from the CDC,

which revealed that the rate of Lyme Disease diagnosis was more than ten times what the CDC originally believed, further increased suspicion. Although the CDC has long studied the rate of Lyme Disease infection, this revelation suggested that their data collection methods were flawed and emphasized that Lyme Disease is an increasingly devastating health problem in the United States. Critiques escalated again in 2016 when researchers from the Mayo Clinic discovered a new species of bacteria that causes Lyme Disease, redefining it as “a multisystem tick-borne disease of wide public health significance” (Pritt et al. n.p.). This definition is significant because it acknowledges that Lyme Disease can impact a range of systems in the human body and suggests that it should be treated seriously—as much more than a simple infection. This new research raised additional questions about the diagnosis of Lyme Disease, since patients with this new strand “presented with differing clinical presentations.”

The idea that Lyme Disease can cause long-term symptoms and suffering has shifted in recent years from a concept circulated in alternative online patient communities to an accepted concern for mainstream patients, public figures, and researchers alike. The debates over Lyme Disease terminology and etiology—now commonly referred to as the “Lyme Wars”—have created an exchange between public and expert audiences that impacts suffering patients’ and healthcare professionals’ lives in three fundamental ways:

1. Thousands of patients are forced to trust their embodied experiences of suffering and conduct their own research in search of effective Lyme Disease treatment;
2. Much to their chagrin, health, medicine, and science professionals are forced to respond to rhetorically savvy patients who ask controversial questions, contest test results, and “doctor shop” to find practitioners who will listen to them and flex outside of the strict 2006 IDSA Lyme Disease treatment guidelines; and

3. Healthcare providers have designated themselves as Lyme Disease experts and created personal websites to advertise their services, which attract patients who have been failed by traditional western biomedicine.

In Judy Segal's words, all of this means that patients, healthcare providers, advocates, and other stakeholders are constantly negotiating the "shape-shifting" territory of authoritative knowledge about Lyme Disease ("Internet" 352).

### **Rhetoric of Health, Science, Medicine, and Technology**

I situate this project within scholarship on the rhetorics of health, medicine, science, and technology. In particular, many scholars have turned their attention to digital sites and spaces because most Americans look online to find health information (Fox and Duggan, *Health Online 2013*). This "shape shifting" territory owes much of its energy to the affordances of digital communication. Rhetoricians have long been interested in the linguistic, visual, stylistic, and other choices made in/about health, medicine, science, and technology, and the move to denaturalize and demythologize empowerment rhetoric aligns with current trends in the field. Recent studies have examined diverse topics such as the rhetorics of breast cancer (Finer; Segal, *Health*), autism (Jack, *Autism*; Yergeau), hormones (Koerber, *From*), and pregnancy (Owens; Seigel). Lori Beth de Hertogh's study of an online natural birth community, Kim Hensely Owens's study of digital birth plans, and Cristy Beemer's study of an online breast cancer community are recent examples of this work. As Beemer writes, examining women's rhetoric in online spaces "contributes to our examination of feminist rhetorical theory in practice" (121).

As Amy Reed's recent literature review suggests, most rhetoric of health and medicine scholarship is critical and considers how these disciplines function as "powerful, productive site[s] of ideological construction" (17). Reed argues that rhetoricians should use the tools of

rhetoric to do what people within these fields cannot: question established hierarchies, demystify organizational processes, and analyze how expertise is conferred and conveyed across genres. Accordingly, Melonçon and Frost have recently noted that rhetoricians should leverage their skills to “help improve patient-centered language and practices across a multitude of media and document types” (7) and figure out “how user experience intersects with patient centered-care” (12). These are excellent goals for rhetoricians of health and medicine and will extend the reach of this research beyond the silos of academic departments and into the public, where it may be able to be used for the greater good. If rhetoric of health and medicine scholars can show patients how the language, images, spaces, and relationships within the healthcare system function persuasively, patients may be able to leverage these tools to access different treatments and better healthcare. Patients may feel more embodied authority, emboldened to ask more effective questions, or better yet, ask questions in the first place. For example, if rhetoricians of health and medicine can teach patients about the politics of the language used by their healthcare providers, patients may be able to communicate better with their providers, who may be able to understand their acute and chronic problems more effectively, and as a result select more effective treatments for them.

Rhetoricians have long prioritized studying empirical scientific knowledge (Bazerman; Berkenkotter; Wickman), scholars are building on recent research in the health/medical humanities (Charon; Couser; Vonnegut) and shifting their focus to other forms of knowledge that broader publics find compelling. Health/medical humanities scholars stress listening to patient stories, developing empathy, and studying patients’ bodily knowledge, and thus they study non-specialist genres such as illness narratives. Accordingly, much of the recent scholarship in rhetorics of health, science, medicine, and technology focuses on what Ashley Kelly and Carolyn

Miller call “parascientific genres” for information. Kelly and Miller define “parascientific genres” as types of writing and communication that are “concerned with the collection, arrangement, or application of scientific knowledge in contexts formally external to but somehow involved with the scientific community” (231). From a patient perspective, uncertainty within the “privileged genre” of the peer-reviewed journal article suggests that empirical scientific knowledge is insufficient for understanding Lyme Disease or Lyme Disease patients (Jack, *Science* 8). Parascientific genres, such as social media posts, health databases like 23andMe, and healthcare providers’ clinical websites, often integrate empirical scientific knowledge with informal data from living with, diagnosing, and/or treating Lyme Disease.

Although scholars tend to be wary of parascientific genres, patients rely on them to find health information, especially in cases like Lyme Disease, where there is no biomedical consensus about how to diagnose or treat it. Accordingly, this project examines a range of scientific genres, but due to their importance in the Lyme Disease community, prioritizes parascientific genres.

### **Disability Studies**

Some scholars argue that disability rhetoric and health and medical rhetoric are at ideological odds. Much of the work by disability rhetoricians critiques the medical models of disability and helps scholars and the public understand disability as a socio-cultural phenomenon exacerbated by exclusive built environments. This project is articulated around one of Simi Linton’s goals for the future of disability studies: to analyze metaphors and other persuasive devices “in an array of cultural products to understand their meanings and functions, and to subvert their power” (125). This goal is also related to those of “post-identity” disability studies, as described by Lennard J. Davis in the fourth edition of *The Disability Studies Reader*. Davis



notes that we are entering an epoch of “post-identity,” in which disability studies will help us think through new complexities like “questions of interdependency and independence as well as issues around the construction or materiality of gender, the body, and sexuality” (xiii). I consider how issues of inter-dependency and dis/ability are reframed in the context of Lyme Disease, patient empowerment, and health literacy. My research suggests that empowerment is not simply about developing an individual’s health literacy skills, for instance, but—instead—developing community networks for evaluating and sharing information.

My work also contributes to growing body of scholarship on “unhealthy disability.” In her foundational article in feminist disability studies, Susan Wendell names and distinguishes between the “healthy disabled” and “unhealthy disabled” to challenge perceptions about who “counts” as a disabled person. Disability studies—inside and outside of rhetoric—has most often prioritized the perspectives of the so-called “healthy disabled”: people whose disabilities are generally static and require routinized accommodations; people who are “permanently and predictably impaired” (21). Research in rhetorical studies has primarily focused on blindness and deafness. Although we cannot possibly engage the experience of living with low, limited, or no vision as merely one universal experience, for instance, many of these individuals are able to collectivize and organize around this identity. But for people who fall into the “unhealthy” disabled category, it is harder. “Unhealthy disabled” individuals may have significant fluctuations in their conditions and may “pass” (voluntarily or involuntarily) as abled; as such, and especially because many of them lack a singular diagnosis, their disabilities may go unrecognized and they lack an illness- or disability-based group with which they can identify (29). Wendell argues that “unhealthy disabled” people are “held responsible for their disabilities,” and that the general public believes that, if they better cared for themselves, they

could ease or eliminate their disability (29). “Unhealthy disabled” individuals, then, are burdened with the responsibility for their own care and lack the recognition necessary for seeking accommodations.

Following Wendell, Kafer argues that the medical model of disability, which “frames atypical bodies and minds as deviant, pathological, and defective, best understood and addressed in medical terms,” mischaracterizes disability as merely an individual problem (5). Instead, she offers a political/relational model of disability, which situates disability in “built environments and social patterns that exclude or stigmatize particular kinds of bodies, minds, and ways of being” (6). Kafer’s model prompts scholars to ask questions about who “counts” as disabled and “presents disability less as diagnostic category and more as collective affinity (12-13). Most notably, Kafer argues that we must account for “unhealthy disabled” individuals even though they do not typically consider themselves “disabled.” Kafer suggests that the lack of recognition of unhealthy disabilities means that “unhealthy disabled” individuals cannot access institutional resources that societies have put in place to help individuals with disabilities, such as workplace accommodations. And even if chronically ill people require disability accommodations, they may consider themselves disabled only partially or some of the time. As such, “unhealthy disabled” individuals are better accounted for in Kafer’s model, which does not rely on ill or disabled people identifying with “a discrete group of particular people with certain similar essential qualities” (10).

### **Research Methods**

I integrate rhetorical analysis and interviews in this project, following Amy Koerber’s “multifaceted methodological approach” to studying rhetorics of infant feeding, which interweaves textual analysis studies and ethnographic studies (*From* 147). The following sections

detail the interviews that I conducted, beginning with the recruitment process and ending with my modes of data analysis.

### *Semi-Structured Interviews*

Between January and March 2018, I conducted twenty-three interviews with Lyme Disease patients. I primarily recruited via an advertisement on the all-university listserv at my institution, which was sent to approximately ten thousand students, faculty, and university staff members. I also emailed every person in the UNC Department of English and Comparative Literature, in addition to other friends and colleagues in the North Carolina area, and some of those people forwarded my recruitment flyer to their friends and colleagues as well as posted it in their online social networks. Additionally, I hung flyers at local hospital outpatient clinics, coffee shops, and restaurants in Chapel Hill, Durham, and Raleigh, NC. Most significantly, a local clinician forwarded my study information to a North Carolina Lyme Disease support group, which has active chapters across the state, and ultimately two-thirds of my participants came from this pool.

To participate in my study, participants needed to have been diagnosed with Lyme Disease by a healthcare professional, experienced Lyme Disease-related health problems for one year or longer, be comfortable speaking in English, and be over the age of eighteen. Thirty-three people contacted me about the study between January 3, 2018 and February 27, 2018, after which I ended my formal recruitment efforts. Ten participants either did not respond to follow-up phone calls or became too ill to be interviewed. In turn, I interviewed twenty-three people about their experiences with Lyme Disease. I conducted fourteen interviews in-person and nine over the phone. Most participants considered chronic Lyme Disease to be their current diagnosis, while one identified more with Chronic Fatigue Syndrome (and the associated support

communities), another felt like he had mostly recovered and did not identify with a diagnosis, and one revealed that chronic Lyme had been a false diagnosis and that she was, instead, experiencing a histamine allergy. All of my participants were legal adults at the time of the interview, although three had experienced the majority of their illness during their childhood and/or young adult years.

I chose to recruit and interview participants from North Carolina for a number of other reasons. North Carolina is a politically significant location for studying Lyme Disease. The CDC argues that most Lyme Disease cases are limited to fourteen U.S. states, thus suggesting that Lyme Disease is not native to North Carolina. In turn, many participants cited the difficulty of finding traditional biomedical healthcare providers to treat their Lyme Disease in North Carolina, since many providers simply did not believe that Lyme Disease existed here—and even though many of them had moved to North Carolina from Lyme-endemic states such as New York and Pennsylvania. One participant believed that she had acquired Lyme Disease in Germany while studying abroad. However, other study participants noted that they had rarely—if ever—left the state of North Carolina. Additionally, I lived in North Carolina at the time of the interviews. Living in the same state as my participants meant that I was familiar with some aspects of the local Lyme Disease culture (such as popular providers in the area and active support groups) and made it easier for me to travel to meet them in person, which was critical for getting a full sense of their story.

Although I hoped to meet each participant in person at a mutually convenient time and location, circumstances sometimes made this impossible. For example, a few of my participants became increasingly ill as our interview date approached, so I rescheduled them for phone interviews to preserve their (and my) health. Another time, an unexpected snowstorm forced me

to revert to a phone interview, while at one or two other times, I began feeling ill and reverted to phone interviews in an attempt to preserve my own well-being. And in a few cases, interview participants simply lived too remotely for me to meet them or their jobs prevented them from meeting me at a mutually convenient time, and I conducted phone interviews with them at their request.

For participants who were able to meet me in person, I tried to make the interview as convenient as possible, which meant meeting them near their homes or work locations. In all, I drove 471 miles roundtrip to conduct interviews, going as far east as North Raleigh and Apex and as far west as Clemmons, NC. I met participants in the morning, in the afternoon, during the week, and on weekends. I generally conducted only one interview per day, but I did a few two-a-days, in which I did one phone interview and one in-person interview. At the start of each interview—upon meeting each participant—I introduced myself and offered to buy the participant a beverage from the eatery at which we were meeting (if applicable). All but one participant refused, and one even insisted on paying for my beverage, citing my “poor graduate student” status. To help establish a friendly environment, I often began by mentioning something about the eatery or the weather and telling the participant a little bit about myself and my project. Since a number of my participants had earned master’s or doctoral degrees, they had questions about the type of program in which I was enrolled and how an English Ph.D. project could be focused on Lyme Disease.

I recorded all in-person interviews on my iPhone 6s using the “voice memos” application. I used Audacity and a professional recorder borrowed from the university library to record my first few phone interviews; the sound quality was generally poor. Later, I learned that I could record phone calls using Google Voice, and I conducted the last few phone interviews this way

with great success. Since I established a Google Voice account and an established phone number that I was already using for study recruitment, I easily adapted to using Google Voice for recording and storing my phone interview data. I first called my phone interview participants at the assigned time and discussed the consent form over the phone. Upon getting their verbal consent, I asked them to call me back, at which time I would turn on the Google Voice recorder and began asking my interview questions.

I tried to be direct about what I was looking for in the project, and per IRB guidelines, read the project goals to the participants directly from the IRB-approved consent form. However, at least at first, I must not have done a sufficient job of explaining the project to them, because most participants had additional questions about what the project was for and how their data would be used. One participant in particular was very concerned about whether or not identifiable data would be stored on a university server. Most others, however, mentioned that they did want their data to be private, and in fact, asked if I would share their data with any Lyme specialists or other providers whom I interviewed or with whom I came into contact.

I did not immediately reveal that I had Lyme Disease to any of the participants. However, at some point, often at the beginning of the interview, most participants asked why I was choosing to research Lyme Disease. When that happened, I revealed that I had been diagnosed with Lyme Disease in 2009. Often toward the end of the interviews, participants asked me multiple questions about my experiences with Lyme Disease: How was I feeling? Which doctors had I seen? Who supports me in my illness? And perhaps most significantly, what doctors, medications, and/or recommendations had other participants shared? One participant even emailed me after her interview to ask if I had gotten any additional doctor recommendations. When it felt appropriate, I answered plainly and offered a short version of my narrative: that I

don't remember getting a tick bite, but I became ill with H1N1 ("Swine Flu") in September 2009, from which I never fully recovered, and after multiple rounds of testing, I was eventually diagnosed with Lyme Disease in November 2009. I noted that, throughout the years, I have since been diagnosed with other chronic health conditions, which I believe are related to my initial Lyme Disease infection.

I conducted the interviews using a semi-structured set of interview questions. In the first few interviews, I generally followed the list of questions and asked every single question at the beginning, and if there was a time constraint, selected a few from the end to ask; my selections depended on the content of the rest of the interview and my evolving set of codes and themes. Sometimes I combined two questions from my list or phrased a question from my list differently in order to elicit particular information that I felt I had not gotten during the earlier parts of the interview.

However, as the interview process went on, I began presenting participants with a few options about how we might proceed. I would begin by noting that I had a list of questions, and then I would try to ask for the participant's preference: Would they like me to go down my list? Would they like to just start telling their story however they wished? Would they like to warm up with a few questions about background information? Some participants asked that I ask every single question, citing their desire to help me as much as possible with my project. At the end of the interview, these participants often asked if they'd forgotten to include any information or if they could do anything else to help me. In what I feel were some of the most successful interviews, I asked the participants to first tell me a little bit about themselves either "as a human" or "apart from the fact that they have Lyme Disease," which gave me some necessary context that they might not have included otherwise. Most participants used these introductory

narratives to launch into their stories of diagnosis, treatment, suffering, and frustration. In the interviews in which I did not directly go down my list of questions, participants seemed to naturally launch into a chronological story about their illness. However, sometimes they bounced back and forth between diagnoses and time periods; many participants had had two or more bouts of Lyme Disease, and sometimes I had to ask clarifying questions to ensure that I understood what they were talking about.

### *Coding and Data Sorting*

During the interviews, I took extensive notes by hand (generally 2-10 pages). Sometimes, as I was talking with participants, I would circle or put a star next to certain words or moments as I noticed interesting issues or key themes emerge. After each interview, I uploaded the recording to my flash drive, where I stored all of the data. I began transcribing some of the interviews shortly after I conducted them. Originally, I planned to transcribe interviews right after I conducted them in order to prevent a pile-up at the end of the process. However, as I got more and more participant interest in the study, I sometimes conducted 4-7 interviews per week and thus fell behind on transcribing interviews.

After I conducted all of my interviews, I began the coding and transcribing processes. I coded the interviews as I transcribed them, building on a list of questions and themes I generated while conducting interviews. One of the first things I noticed was that participants—when I asked them directly—did not have much to say about their Lyme Disease research processes or health literacy. I often asked multiple follow-up questions, phrased differently, in hopes of getting participants to talk about this process, and I had little success. After consulting with Dr. Mara Buchbinder, Dr. Jane Danielewicz, and Dr. Jordynn Jack, I decided to let that theme go and allow others to emerge. As I continued the interviews, I tried to let the participants have more



freedom to dictate the flow and pace, and when I allowed for this flexibility, participants began bringing up health literacy, their research processes, and issues of authority and legitimacy on their own, often requiring few or no additional questions from me.

### *Data Analysis*

First, I glanced through the handwritten notes I took during the interviews and generated an initial list of themes. Following Virginia Woolf's essay, *On Being Ill*, I thought of the themes as short meditations on different topics (such as "on the process of diagnosis," "on health literacy", "on listening doctors"). Then, I closely read through the notes I took during each interview and wrote memos about each theme (if applicable). I included key quotations that I jotted down, in addition to references to anecdotes and my overall impression of what the participant said about the theme in the interview. Through this process, I generated additional themes/codes and added to them. After I completed this phase, I began transcribing the interviews more fully. At first, I planned to simply scan for incisive quotations about Lyme Literacy and health literacy, but I decided that I would be better prepared to use the data in future articles (and perhaps my future book) if I performed "spot transcriptions" (which included a note about what was happening and relevant quotations in every 30 second section of each interview). Throughout this process, I generated even more codes.

The results of these interviews appear most directly in Chapter 4, but they also inform my analyses in Chapters 2 and 3. All names used are pseudonyms. I offer a brief description of the interview participants at the beginning of Chapter 4.

### **Chapter Outlines**

In the remainder of this project, I examine parascientific genres, including a health information sharing site and multiple healthcare provider's clinical websites, alongside

interviews with Lyme Disease patients, to show how the empowerment paradox works in practice.

Chapter 2 describes how patients have taken to sharing their health histories on internet databases like *MyLymeData*, given the rise of rare and chronic disease, invention of personalized genomic medicine, and increasing lack of research funding. I adopt Robert Johnson's theory of user-centered technology to examine MLD, a health information sharing website for Lyme Disease patients and their families. The creators of MLD argue that collecting, aggregating, and publishing data from people with Lyme Disease will help current patients make healthcare decisions and help scientists find a cure faster. I examine how MLD forwards three dominant, user-centered discourses—patient vs. power; individual vs. community; and simplicity vs. complexity—in its aim to capture patients' data. Ultimately, these databases serve the biotechnology companies who purchase access to users' data instead of the ill people who contribute their data. My analysis suggests that the aggregation of data erases the texture of individuals' stories and presents another example of how patient empowerment has been misappropriated.

Chapter 3 compares the official information about Lyme Disease from the Centers for Disease Control and Prevention (CDC) website to four Lyme Disease healthcare providers' clinical websites. I argue that healthcare providers' clinical websites appear to empower patients by establishing the credibility of "Lyme Literate" doctors, valuing and validating patients' stories of suffering, and forwarding alternative narratives that better explain patients' experiences with Lyme Disease. But despite these advantages, clinical websites might also harm patients because they stress radical, unproven, and/or expensive treatment methods and encourage patients to undergo controversial medical tests.

Chapter 4 defines two kinds of “Lyme Literacy”: “Patient Lyme Literacy” and “Clinical Lyme Literacy.” The term “Lyme Literacy,” a derivative of health literacy, spans popular and professional publications, but there is not an agreed-upon definition nor a comprehensive understanding of how it works in practice. This chapter draws on data derived from qualitative interviews I conducted with twenty-three Lyme Disease patients. I consider how health literacy operates as a rhetorical tool that can afford authority, agency, and improved health outcomes while also disempowering patients. I provide a case study of “Clinical Lyme Literacy” to argue for a broader definition of health literacy that extends beyond the typical deficit model.

My dissertation concludes with a discussion of directions for future research. I suggest that future research might be done on Patient Lyme Literacy, and I offer preliminary data from my interviews as a starting point. Building on Chapters 3 and 4, I consider the ethical challenges of working with data from human subjects, especially when it is derived from public/private digital spaces. I also propose a new term—“wildcard sources”—to describe healthcare providers’ clinical websites and other parascientific genres that I discuss in Chapter 2. Drawing on recent scholarship about teaching information literacy in the composition classroom, I reaffirm the challenges of teaching students to examine ambiguous, non-academically validated sources. I suggest that instructors provide rhetorical context and consider integrating these sources into their classes instead of simply eschewing them for more traditionally scholarly sources.

## CHAPTER 2: HEALTHCARE PROVIDERS' CLINICAL WEBSITES

In 2008, Judy Segal argued that Internet health websites were a paradigm-changing form of written communication. Segal suggested that all Internet health users, whether they were searching for solutions to urgent medical needs or gathering more information about chronic conditions, must learn to “tell a good source from a bad one” (“Internet” 353). For Segal, this meant determining which sources were grounded in “good science,” and thus could articulate an authoritative perspective on scientific and medical issues. Like most other academic researchers, Segal implied that “good science” comes from scientific empirical knowledge: data from double-blind clinical trials, which are conducted by biomedical researchers and published in peer-reviewed journal articles. As such, in her study she examined a range of health-related websites, some of which she deemed “quite authoritative,” such as the U.S. Centers for Disease Control and Prevention (CDC) website, others which she deemed “less so,” such as [Morethanmedication.com](#), a health and lifestyle website run by the drug company Pfizer (355).

By 2019, Segal’s assumption that Internet health users search for and are persuaded by “good science” no longer holds. Increasing numbers of patients suffer from ambiguous health problems that defy biomedical diagnosis and treatment. My interviews suggest that, in the case of Lyme Disease, patients’ notions of “good science” become destabilized when they become chronically ill from a supposedly acute condition. In the age of Health 2.0, rhetoricians must reinvestigate the definition and ethos of “good science” from the Internet health seeker’s perspective, and moreover, the idea that “good science” is persuasive in every Internet health

encounter. Scholars might ask: What counts as “good science” and to whom? How is rhetoric used to frame different types of knowledge as authoritative? How do different types of authoritative knowledge work together to persuade Internet health users to take specific social actions?

In this chapter, I analyze the CDC’s Lyme Disease website alongside four Lyme Disease healthcare providers’ clinical websites to illuminate one key facet of the empowerment paradox. As I will demonstrate, patients are forced to choose between two undesirable directions: to seek care from a traditional healthcare provider who does not believe in Chronic Lyme symptoms, or to seek care from a radical healthcare provider who charges exorbitant fees and may administer untested, harmful treatments. Patients often remain ill regardless of their decision—despite their best efforts. In what follows, I provide background information about the rhetorical situation out of which healthcare providers’ clinical websites developed and how they respond to the CDC website. Next, I rhetorically analyze the websites. I contend that healthcare providers’ clinical websites perform at least three specific social actions as they: 1) establish credibility; 2) value and validate patients’ stories of suffering; and 3) create alternative narratives about Lyme Disease that better explain patients’ experiences. I conclude by considering how the range of websites illuminate how the empowerment paradox works in practice.

### **The CDC Lyme Disease Website**

Although there are many Internet health resources that primarily rely on scientific empirical knowledge, these resources may not adequately fit Lyme Disease patients’ needs. For instance, the CDC website eschews the complex, sometimes traumatic health issues that Lyme Disease patients experience, which prompts them to disregard the website and its data entirely. Scholars can recognize that these rhetorical choices reflect aspects of the CDC’s core mission, values, and “Pledge to the American People,” which include “protect[ing] America from health,

safety and security threats, both foreign and in the U.S.” and “[p]romoting healthy and safe behaviors, communities and environment[s]” (“Mission, Role, and Pledge”). On the other hand, we can also recognize how this kind of website does not meet all of its Lyme Disease patients’ dynamic needs.

The CDC site rhetorically places the focus on the disease itself and on prevention, not on people who have it. On the homepage, viewers immediately notice one image—a series of four ticks increasing in size, situated on top of a coin for scale—and a block of explanatory text (see fig. 2). The paragraph of text, which is only eight sentences long, provides a summary of Lyme Disease. In these brief sentences, it discusses what causes Lyme Disease as well as its symptoms, diagnosis, tests, treatment, and prevention. Embedded hyperlinks encourage readers to click on additional pages to get more information about certain topics.

But the paragraph is rather sterile. Although it acknowledges that Lyme Disease can “spread to joints, the heart, and the nervous system,” when it is “left untreated,” it emphasizes that “[m]ost cases of Lyme disease can be treated successfully with a few weeks of antibiotics,” which implicitly dismisses the increasing number of chronic cases (“Lyme Disease”). The paragraph also focuses on prevention, steps of which include “using insect repellent, removing ticks promptly, applying pesticides, and reducing tick habitat,” which puts the onus on future sufferers to avoid and correctly remove ticks instead of on healthcare providers to administer adequate treatments.

Consequently, this combination of rhetorical choices focuses more on providing general information about Lyme Disease rather than alleviating human suffering for those who have Chronic Lyme. Although there are brief references to Chronic Lyme, the term “Chronic Lyme” does not appear on the page, and information about persistent symptoms is buried within a block

of miscellaneous information. In this way, the CDC website exemplifies the empowerment paradox: even though the website appears to be thorough, patients are forced to search for buried information and supplement the CDC's information with data from other sources. The CDC's poor information design is part of the empowerment paradox: patients are forced to locate and analyze confusing health information without guidance from healthcare providers.

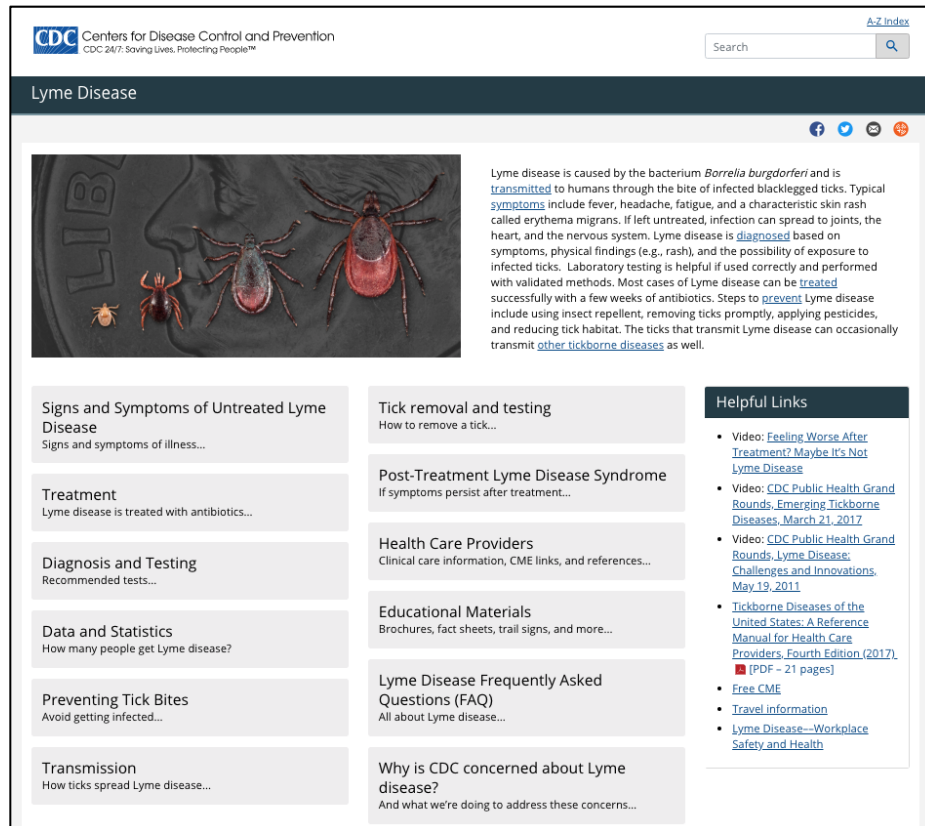


Fig. 2: CDC Lyme Disease Website, 21 December 2018, <https://www.cdc.gov/lyme/index.html>. Screenshot by author.

### Healthcare Providers' Clinical Websites: A Rhetorical Genre

Alternatively, healthcare providers use rhetorical strategies that place the focus on patients. Undoubtedly, healthcare providers' clinical websites serve to advertise their healthcare services. However, because clinicians have a certain professional ethos—a combination of traditional scientific training and hands-on experiences with helping patients—their websites

serve multiple purposes for Lyme Disease patients. Healthcare providers' clinical websites, thus, bridge the public/professional divide through a combination of generic features, including personal testimonies, interpretations of scholarly research, plain language descriptions of complex diseases, reference lists, frequently asked question sections, and descriptions of provider qualifications.

Healthcare providers' clinical websites are accessible to anyone who can use the Internet and are crafted to meet a Lyme Disease patient's complicated needs: to access competing scientific literature about Lyme Disease, to get care from qualified providers, to access different kinds of potentially effective treatment, to learn about the latest Lyme Disease research, and perhaps most importantly, to have their experiences of suffering acknowledged and "heard," since there is no definite cure. In this way, healthcare providers' clinical websites have become a platform for articulating perspectives about how contested health conditions should be categorized, defined, diagnosed, and treated. For patients whose needs remain unmet by the CDC Lyme Disease website and other similar scientific genres, healthcare providers' clinical websites are an integral source for information.

My research suggests that healthcare providers' clinical websites have become platforms for articulating perspectives about how contested health conditions should be categorized, defined, diagnosed, and treated. Most healthcare providers coming from a western medical tradition believe that data from clinical trials is the primary form of authoritative knowledge. But patients with conditions like Lyme Disease, who feel that traditional healthcare providers have dismissed their suffering, disregarded their symptoms, and/or dodged questions about the efficacy of clinical trials, may stop believing that this data is authoritative. Accordingly, these patients seek out alternative resources—especially healthcare providers' clinical websites—



which offer different types of credible knowledge, affirm their suffering and stories, and articulate different narratives about Lyme Disease. On the CDC website and others like it, there is plentiful procedural scientific information about tick removal and lists of antibiotics used to treat Lyme Disease. However, there are no cures nor solutions. For Lyme Disease patients who are suffering from persistent symptoms, reading about the experiences of other patients can help them generate ideas and feel less alone. Since Lyme Disease is so difficult to treat, this may prove to be even more important than the typically important scientific information, since reading personal stories may give patients ideas for new treatments, suggestions for good healthcare providers, and overall recommendations for living with Lyme Disease.

### **Case Study**

I came upon the genre of healthcare provider's names while reviewing discussion threads about Lyme Disease on [www.healthboards.com](http://www.healthboards.com) and [www.reddit.com](http://www.reddit.com). From there, I Googled the healthcare providers' names and came upon their clinical websites. As I followed the conversations about recommended Lyme Disease healthcare providers, it became clear that there are two types: 1) providers who advertise that they treat Lyme Disease, and 2) providers who treat Lyme Disease patients but do not advertise these services. This distinction is significant. Because Lyme Disease is such a controversial condition and healthcare providers offer a range of treatments within and beyond clinical guidelines, it is risky for healthcare professionals to publicly promote themselves as Lyme Disease healthcare providers.

I have limited my case study to four healthcare providers' clinical websites that were mentioned multiple times on these discussion boards and in which the provider self-identifies as a Lyme Disease specialist or promotes their ability to treat Lyme Disease. Specifically, I examine the clinical websites for Dr. Steven G. Meress, internal medicine doctor; Dr. Jane Marke, psychiatrist; Dr. Joseph G. Jemsek, infectious disease specialist; and Ms. Susan Neuber,

nurse practitioner. The following analysis will show how these healthcare providers' clinical websites establish credibility, value and validate patients' stories of suffering, and construct alternative narratives that better explain patients' experiences with Lyme Disease.

### *Establish Credibility*

Unlike the CDC website, which assumes credibility because it is grounded in scientific empirical knowledge, healthcare providers' clinical websites make a concerted effort to establish credibility. Even if websites like the CDC can inform patients about the symptoms, tests, and health outcomes for Lyme Disease, they do not help patients take actionable steps, such as selecting a specialist to consult or creating a list of questions to ask a healthcare provider. To establish credibility, healthcare providers emphasize their combination of academic and experiential training and how it has equipped them to provide personalized care for patients' unique Lyme Disease symptoms. As such, the providers discuss their qualifications multiple times and on multiple pages of their websites.

Dr. Steven G. Meress, for example, provides personal biographical information on the "About," "Meet Our Staff," and "Frequently Asked Questions" pages of his clinical website. Before readers are introduced to Meress, they see a bold subtitle on his homepage: "We treat the cause of the disease, not just the symptoms. Each patient is an individual with a specific illness and will respond to a treatment differently than others" ("Home"). The phrase "each patient is an individual" is the beginning of a powerful syllogism. It reinforces the idea that that "patient" is not merely an object or recipient in a healthcare transaction, but a unique human who requires specialized care. This shift in agency can be considered another aspect of the empowerment paradox: since there is great variability in how Lyme Disease manifests, patients are responsible for seeking out healthcare providers who can offer individualized, specialized treatments.

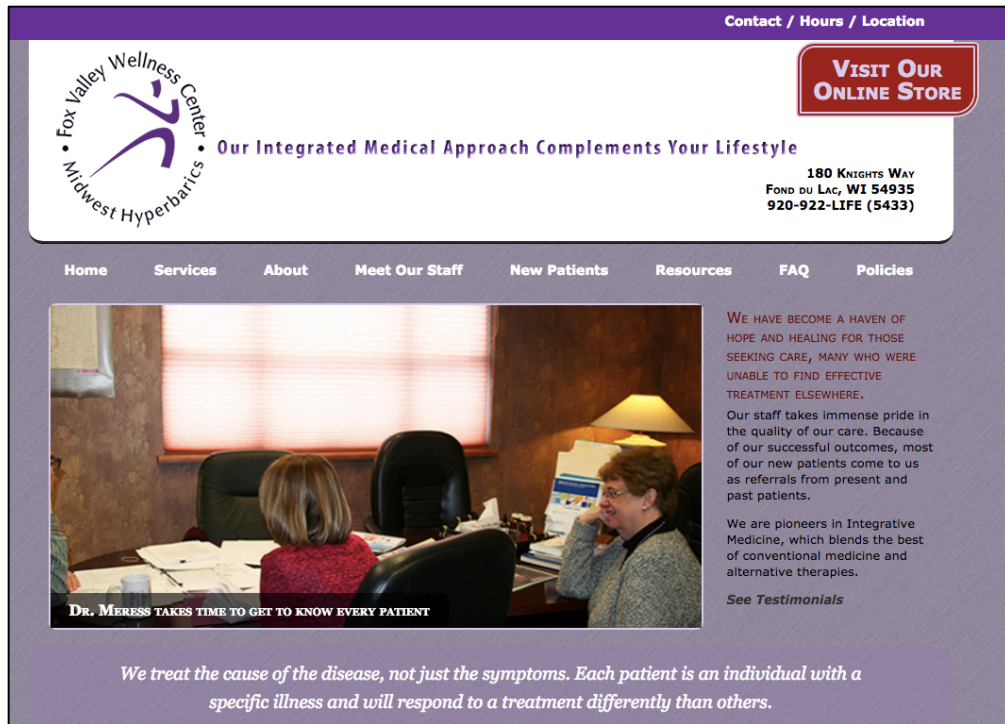


Fig. 3: Dr. Steven G. Meress’s website homepage, 11 February 2019, <https://foxvalleywellness.com/>. Screenshot by author.

This personal focus primes readers to learn more about Meress and his colleagues’ qualifications, which provide evidence for their ability to provide this kind of individualized care. Readers are first introduced to Dr. Meress in a section called “Our Doctors” at the bottom of the homepage, which provides synopses of the provider information detailed on the “Meet Our Staff” page. The first provider listed is Dr. Steven G. Meress, whose name is modified with three licensures: MD (doctor of medicine), FACP (Fellow of the American College of Physicians), and ABHM (American Board of Hospital Medicine). By including all three of these traditional academic degrees and honors, Dr. Meress positions himself as a doctor with extensive western medical training. The brief biography included on the front page reaffirms this training; it reads, “Dr. Meress has been board certified in Internal Medicine and Holistic Medicine with experience in Emergency Medicine, Primary Care, Wellness and Longevity techniques.” By

drawing on both his board certification—an integral academic credential—as well as his “experience” in four different areas, Meress demonstrates his multiple competencies, rhetorically reassuring patients that his wealth of training has prepared him to help them get better.

Since the website’s internal pages are listed from left to right, readers most likely then encounter the “About” page, which describes both the founding of Dr. Meress’s clinic and his academic and experiential training (“About Fox Valley Wellness Center.”). Here, Meress provides a more comprehensive career narrative, telling readers that he earned a B.S. from University of Wisconsin, Madison, and then an M.D. from St. George University in Grenada. For some patients, a medical degree from an international university may signal a lack of expertise or competence. However, Meress quickly moves on to mention that he completed a residency program at the University of Wisconsin-Marshfield Clinic and worked as a staff physician and Chief of Emergency Medicine, which further emphasize his academic training. From there, Meress discusses how he earned a board certification in Holistic Medicine in 2009 and claims that he is “one of the foremost ‘Lyme-literate’ physicians in the country, treating well over 2000 patients with Lyme Disease and is a member of the International Lyme and Associated Diseases Society.” Since there is not a medical specialization in “Lyme-literacy” nor a national survey of the top “Lyme-literate” providers, Meress leverages this factoid to appear especially qualified to treat Lyme Disease patients. By mentioning that he has treated more than two thousand patients, Meress further emphasizes that, coupled with his academic training, he is prepared to put new patients on a path to healing. Later in this section, Meress also mentions his trips to Barbados, St. Vincent, and Grenada, which allowed him to “experience Third World medicine,” which was administered “for little to no cost and with much less technology” (“About Fox Valley Wellness Center”). Although American patients tend to view medical training in non-U.S./Canadian

countries as less rigorous and therefore less credible, Meress attempts to frame his international work experience and medical education in Grenada as relevant “experience” that exposed him to new—and potentially better—ways of helping people and, implicitly, prepared him to effectively treat Lyme Disease.

Ms. Susan Neuber, a nurse practitioner who specializes in treating Lyme Disease, does not refer to herself as “Lyme-literate” like Meress, but she leverages her educational and experiential training to provide evidence of her ability to treat unique cases. Prospective patients can learn about Neuber from the “About Susan” page. In a mere 209 words divided into two paragraphs, Neuber begins her biography by saying that she has worked in medicine “for a lifetime.” As evidence, she mentions her current experiences serving as a hospitalist, hospice healthcare provider, and researcher, and past experiences as a paramedic and in the fields of pediatrics, cardiology, and home care. Prospective patients would likely be impressed by her range of experiences, which would make them feel confident that she could draw on her variety of competencies to help them heal. Neuber’s biography then moves into cataloging her academic degrees: her “*first*” B.S. in Biology, her “*second*” B.S. in Nursing, her M.S. in Science, and her A.S. in Paramedical Science (emphasis added). She follows with additional cataloging of certifications and licensing information. Although this information would be more easily readable if it were presented in a bulleted list, Neuber chooses to pack it into a single paragraph. This design makes the information somewhat overwhelming to process, but perhaps that is her intent: she is overwhelmingly qualified to help struggling patients cope with Lyme Disease.

Neuber then discusses the experiential training that has prepared her to treat Lyme Disease. She first notes that she has “worked closely alongside Dr. Bernard Raxlen” and then that she “has also received *additional* Lyme training with Dr. Charles Ray Jones and *further*

Lyme education from Dr. Joseph Burrascano” (emphasis added). Neuber’s continued use of framing language is a means of amplification. Although Raxlen, Jones, and Burrascano may not be household names, prospective patients who are familiar with the Lyme Disease controversy would know that these clinicians have long asserted that Lyme Disease can be chronic and advocated for long-term antibiotic treatment. This, too, is part of the empowerment paradox: if patients are unfamiliar with these healthcare providers, they are expected to Google them and learn about their training and perspectives. Perhaps Neuber chooses to list all three doctors to prove that she has plenty of experience treating Lyme Disease even though she is not a medical doctor. In any case, she uses these experiences to demonstrate her belief that Lyme Disease is a complex illness that requires significant expertise to treat.

Interestingly, Neuber names her most significant qualification last: in her words, “her own battle with the illness.” Neuber writes, in the third person, “She suffered immensely for years, putting her life on hold, while trying to find a diagnosis for her symptoms. Susan was ultimately treated for three tick-borne diseases. She is excited to provide hope and treatment to others in a truly understanding environment” (“About Susan”). By sharing her own story, Neuber validates the ways that prospective patients have likely suffered over the years and suggests that she understands the suffering not only from a medical perspective, but from a human one as well.

To further underscore their desire to provide personalized treatment, Lyme Disease healthcare providers set up unusually long appointments with each patient and only accept cash payments. If providers do not need to file for insurance reimbursement, they do not have to tailor their care to prioritize reimbursable services. In short: when providers require patients to pay cash, the providers always get paid. Neuber’s appointments range in price and the cost is determined “based on individual complexity and time” (“Office Policies and Fees”). Patients are

expected to pay for appointments in cash as soon as healthcare services are rendered. On her “Office Policies” form, which must be signed by patients prior to their first appointment, Neuber notes, “Not only do fees reflect the time spent with you in our office, but also the time spent on your behalf between office visits.” The empowerment paradox emerges here as well: patients are forced to compensate healthcare providers for (what is framed as) additional time and attention. However, as part of their regular work, healthcare providers should be spending time helping patients between appointments. Neuber, then, includes a list of examples, such as “reviewing reports, making and receiving telephone calls from other healthcare providers, insurance companies, pharmacies, laboratories, and home care agencies.” By pricing appointments differently and adjusting appointment times to accommodate patients, Neuber highlights the care she takes to treat patients’ unique problems.

The screenshot shows the website for the Lyme Center of New England, featuring a navigation menu with links to Home, About Susan, Forms, Office Policies & Fees, Links, and Contact. The main content area is titled "Office Policies & Fees" and includes a photograph of a deer in a field. The text explains that fees are based on individual complexity and time, ranging from \$225.00 to \$550.00 per appointment. It also states that the center does not bill insurance but provides statements and receipts for submission to the patient's insurance provider. A sidebar on the right contains a "LOCATION AND HOURS" section with the address: 573 Mendon Rd. (Route 122) Suite 3, Cumberland, RI 02864. It includes a map showing the location and office hours: by appointment only, with some weekends available. The contact number is 401-334-LYME (5963).

Fig. 4: Susan Neuber’s “Office Policies & Fees” page. N.d., <http://www.lymecenterne.com/policies.html>. Screenshot by author.

Similarly, Meress's "Frequently Asked Questions" page states that the "initial consultation" will be "approximately two hours and include an extensive medical evaluation," along with a "detailed nutritional assessment and vitamin and supplement education" and "[t]raditional blood tests." By conducting traditional western medical and holistic evaluations, Meress reaffirms how his academic medical training has been enhanced by his experiences working with patients, who he claims benefit from a wide variety of tests and interventions. All of these individualized services come at a high cost: in this "cash-based facility," prospective patients must put down a "new patient deposit" of \$254.00 to book an appointment ("Our Policies").

#### *Value and Validate Patients' Stories*

Healthcare providers' clinical websites leverage patients' stories to convince prospective patients that someone will listen to them, and by paying close attention, figure out ways to ease their suffering. These stories are framed as "testimonies." By definition, a testimony can be "any form of evidence or proof," but it is generally thought to be "[p]ersonal or documentary evidence or attestation *in support of* a fact or statement" (OED Online). To be sure, healthcare providers' clinical websites leverage these testimonies to convince prospective patients that someone will listen to them, and that by paying close attention, they will figure out innovative ways to ease suffering. Yet Catherine Schryer et al. argue that testimonies are essential (and ultimately very valuable and persuasive) when the so-called "gold standard" of scientific research—"the hypothesis-driven experiment"—has failed (218). Although many of the testimonies included on Lyme Disease healthcare providers' clinical websites venerate the healthcare provider, others speak to the broader complexities of dealing with a contested, chronic illness and the nature of the care healthcare providers are able to offer.



Dr. Joseph G. Jemsek, an infectious disease specialist who has treated patients with both HIV/AIDS and Lyme Disease, includes many testimonials on his clinical website. At the bottom of the front page is a testimonial from “Wallis B.” from Montgomery County, Pennsylvania, emphasized by its placement in a large gray box. “Wallis” is arguably a gender-neutral name, so readers have the opportunity to imagine a patient like them—whoever they are—benefitting from the Jemsek team’s care. Perhaps more important, though, is Wallis’s role: a mother or father of an ill daughter. Wallis writes, “Dr. Jemsek was the answer to our prayers, and my daughter’s results under his treatment have been nothing short of miraculous. He has saved my daughter’s life” (“Home”). In his or her testimony, Wallis uses terms such as “prayers,” “miraculous,” and “saved,” which can be interpreted in multiple ways. First, Wallis’s testimony names Dr. Jemsek as a god-like figure who rescued his or her daughter from a disease that could not be cured using any other means. Second, and accordingly, Wallis’s testimony suggests that Lyme Disease patients can only be healed with help from the divine or earthly manifestations of the divine. This is a powerful argument for Dr. Jemsek’s ethos as a healthcare provider: he is all-powerful, all-knowing, and in that vein, as Joanna B. says in a later testimony, he is a “brilliant, life-giving force” who has “given me my life back” (“Patient Testimonials”). As part of the empowerment paradox, patients are forced to rely on testimonials such as these to make decisions about seeking out specialized healthcare, when, really, healthcare providers should be helping patients make such important choices.

More testimonials on Jemsek’s website can be found under the “Knowledge Base” tab, which suggests that Jemsek sees patients’ personal experiences as an important kind of knowledge. The eleven testimonials are prefaced by a short paragraph, which describes them as a “small sampling” of the “thousands of ‘thank you’ letters” patients send to Dr. Jemsek each year

(“Patient Testimonials”). Many of the testimonials use religious language to describe Dr. Jemsek and his practice, while others appeal to his ethos as a heroic doctor who eschews medical guidelines to help suffering patients. Like the testimony from Wallis B., which is repeated in this section, Kimberly R. refers to Dr. Jemsek as “a godsend” and Debbie “want[s] the world to know how blessed we are to have [him]” (“Patient Testimonials”). Perhaps the use of religious language here responds to the unpredictability of managing a chronic and contested illness, the logic of which can only be attributed to a higher power.

Other Lyme Disease healthcare providers also include testimonials on their websites. Like Jemsek, Dr. Jane Marke, a psychiatrist, has a testimonial on her homepage as well as a separate tab with multiple testimonials. The testimonial on the front page is from J.E. and appears to be a comprehensive letter, which is different from the snippets on Dr. Jemsek’s website. The letter from J.E. tells a compelling narrative: Dr. Marke—a “rare person with an amazing gift to see people for who they truly are and guide them towards reaching their full potential”—“[equipped]” J.E. with the tools to become “the person I knew I could become” (2014a). Although J.E. is “flawed still, of course,” the letter implies that J.E.’s recognition of his or her flaws makes him or her fundamentally less flawed and able to “[embrace] life’s joys and [tolerate] its woes with grace and humility.” J.E.’s ability to “change my life, process my painful past, and move forward in life-affirming directions” is a perfect example of what Arthur W. Frank calls a “restitution narrative”: an illness story plotline that begins when the author is ill and ends in cure or wellness (77-78). Such a narrative would be particularly compelling for Lyme Disease patients who see their suffering as unending and, thus, restitution impossible—yet another component of the empowerment paradox.

Dr. Marke's other eight testimonials are located in a separate tab called "Testimonials" and are designed to capture a reader's attention: they are written in large, purple handwriting-like script fonts. A play/pause button appears below the testimonials, which allows readers to review them at a slower pace, suggesting that they are meant to be either skimmed quickly or read deeply. Each testimonial is written in a different font reminiscent of handwriting, which makes them appear more personal and closer to the well-known genre of the thank-you note. However, some of the testimonials are only partially displayed and appear to show the "body" sections of the letter instead of the whole letter or salutation and introductory paragraphs. In turn, Marke is primarily using the testimonials as a persuasive tool to show that she cares about patients' needs without proving how she effectively treats them.

Dr. Steven G. Meress also includes a link to testimonials on his homepage ("Home"). The testimonials are previewed at the bottom of the homepage. Of the eight testimonials, three are featured in a purple sidebar, which would generally indicate emphasis, but it is unclear how these testimonials differ from the others. These testimonials appear to be full letters, which are compelling because they appear to tell a patient's' entire health story—which are generally windy and full of frustration, meandering, disappointment, and near-death illness. Meress's patients' testimonies emphasize his ability to listen and provide effective treatment when all other doctors and options have failed. They appear more authentic than the testimonials on other websites because they mention some of the problems with seeing Dr. Meress: Andrea waited six months to get an appointment with him, Amber had to wait two months to see him and drive two and a half hours each way, and Leah notes that he "DOES run late sometimes," but provides an admirable reason for it—" understand it is because he wants to help everybody in his care to the best of his ability. It's seriously a good thing" ("Home"). However, the testimonials are

structured to rhetorically balance out these complaints. Andrea emphasizes that Meress is in high demand, but it is worth waiting a few additional months for the chance to become his patient. Leah thanks Meress for “making an appointment as long as it needs to be so everything gets addressed,” which makes the fact that he runs late to appointments appear to be less annoying; his lateness is in service of focused, individualized patient care instead of overbooking or disorganization.

Similarly, Amber notes that Dr. Meress was “listening” to her “rather than telling [her] to take more medications” (“Home”). “Sure,” she notes, “there were a few medications I still had to take but they were short term,” whereas she was told by other providers that she would have to be on medications for “the rest of [her] life.” Here, Amber sets up a comparison between “good” doctors who listen and “bad” doctors who prescribe medication instead of listening. Amber’s use of “sure” softens her initial claim without nullifying it. She appears, instead, to have adjusted her expectations about medication *because* Meress paid close attention to her story and critically selected medications instead of using them as a means of dismissing or invalidating her suffering. Following Amber, another woman named Amber notes, “Sometimes I do have issues but nothing as serious as it used to be.” This phrasing, which prioritizes her continued health problems, might at first suggest that Meress’s treatment was not entirely effective. However, in the next sentence, she happily declares that she can “finally finish college” and “live my life the way life was intended,” going on to say that she currently has “no pain,” which “feels great,” and consequently can now “not be confined to a wheelchair.”

### *Construct Alternate Narratives of Lyme Disease*

Moreover, in their quest to recruit prospective patients and value and validate their stories, Lyme Disease healthcare providers’ clinical websites describe the Lyme Disease

controversy in plain, accessible language. In doing so, healthcare providers are able to explain the complexity of the condition, and share interpretations of complex scientific literature that justify the range of perspectives about diagnosing and treating Lyme Disease. The CDC provides a clinical definition for Lyme Disease and offers plain language educational materials, but these materials articulate a narrative of Lyme Disease that prospective patients have already dismissed: that it is a simple, easily treatable, generally acute condition. As such, Lyme Disease healthcare providers' clinical websites bridge knowledge gaps by explaining the "Lyme Wars" (the controversy around Lyme Disease diagnosis, treatment, and prognosis) and sharing the social and historical context behind them.

For example, on his physician biography page, Dr. Joseph Jemsek claims that he "prefers the term Lyme Borreliosis Complex (LBC)" when talking about Lyme Disease. Merely at the semantic level, "Lyme Borreliosis Complex" has multiple meanings, and Jemsek's claim to his preferred term creates the conditions of possibility for shifting the traditional narrative about Lyme Disease. In this particular paragraph, however, Jemsek does not provide a specific definition for LBC, but merely notes that it "better reflects an immune-compromising syndrome affecting multiple organ systems and caused by multiple coexisting infections" ("Dr. Jemsek"). This explanation is effective because it does not frame itself as an official definition. Instead of boring or confusing potential patients with a jargon-laden scientific definition of LBC, Jemsek merely suggests that the term describes the expansiveness of Lyme Disease: it impacts *multiple* organ systems and might come with *multiple* coexisting infections. This is significant because one of the rhetorical problems with Lyme Disease is that it is often framed as simple and easily curable, which invalidates the experiences of sufferers with persistent symptoms. By resisting impenetrable language and acknowledging the expansiveness of the condition, Jemsek

effectively frames Lyme Disease as a complex condition that requires specialized care; specifically, *his* care. Ultimately, Jemsek assumes that potential patients do not need an explicit definition of LBC to believe that it is legitimate.

If potential patients investigate other pages on Jemsek's website, they will likely come upon a page specifically dedicated to answering the question, "Why does the clinic refer to Lyme Disease as the Lyme Borreliosis Complex (LBC)?" This page is nested under a tab called "Lyme Letter" and a section called "Lyme Questions and Answers." This question is the second of two on the page, positioned after "What happens if you don't stabilize before starting antibiotics?" The placement of this question and answer is notable. Jemsek arguably believes that potential patients are considering seeking his care will examine every page of his website, and that those who are interested will take the time and effort to search for information about LBC. On this FAQ page, Jemsek breaks down the term "Lyme Borreliosis Complex," claiming that he "coined" the term "years ago" and that it is now "widely used." His explanation is exceptionally thorough and readers do not need a high level of health literacy to understand it. Jemsek first states that Lyme is "the common name for *Borrelia*, which is the type of bacteria that causes the infection," then that Borreliosis "refers to the actual infection itself," then that Complex points out the "other infections or microbes that contribute to symptoms." As he notes, "In the grand scheme of things, the terms 'Lyme disease,' 'Borreliosis,' or even tickborne disease' do not encompass the vast variety of infectious microbes and genetic and immunologic factors that result in symptoms—hence, the need for the coined term."

Dr. Jane Marke, MD, a psychiatrist, similarly coins the term "Lyme Psychiatry" to describe the kind of work she is doing with Lyme Disease patients. In the introductory paragraph on her "Lyme Psychiatry" page, Marke uses her concept of "Lyme Psychiatry" to push back

against the CDC's narrative of Lyme. She writes, "Many doctors are convinced that after a short course of antibiotics patients should be well. The huge number of people still ill years after a course of antibiotics belie this assertion." In two short sentences, she validates what many patients spend years trying to convince their doctors: after receiving treatment according to the IDSA guidelines, they are still sick and need additional care. Marke also affirms that experiences of misdiagnosis and suffering due to chronic illness might *cause* psychiatric suffering, claiming, "Patients dealing with Lyme suffer neuro-psychiatric complications that are related directly to the illness, as well as to the emotional challenges and lack of support which often accompanies this difficult illness." Research indicates that many Lyme Disease patients have had their symptoms mistaken for—or worse yet, dismissed as—psychiatric illness, so this explanation affirms patients' experiences and frames their psychiatric symptoms *as* Lyme Disease symptoms.

Marke lists "Lyme Psychiatry" as one of her many specialties, which include "Integrative Psychiatry," "Physiopharmacology," and "Addiction Psychiatry." As I have noted, prospective patients are seeking specialized healthcare, since they are still unwell after undergoing traditional treatments, and providers who articulate a clear specialization in Lyme Disease treatment would be looked upon favorably. Like "Lyme-literacy," there is not an official psychiatric specialization in treating Lyme Disease. As such, Marke claims that Lyme Disease symptoms can "mimic every known psychiatric syndrome," so "[t]reatment aimed directly at symptoms can relieve suffering rather quickly." Additionally, long-suffering patients are seeking expedient relief, which makes Marke's appeal even more persuasive. To elaborate, Marke goes on to list these possible symptoms, which include "brain fog," insomnia, depersonalization, and rages. All of these symptoms are difficult to measure and are thus referred to as "subjective symptoms," rendering persistent Lyme Disease a rhetorical disorder (Rebman et al. 534). Marke notes that

“Lyme is so common” and a “large percentage” of her clientele have it, so she must “keep [it] in mind” when treating psychiatric problems (“Lyme Psychiatry”). She even adds, “Almost everybody knows someone with this illness.” While other healthcare providers discussed thus far frame Lyme Disease as complex and unique, Marke frames Lyme Disease as ordinary. This technique is similarly effective because it suggests that prospective patients will not have to spend most of their appointment time trying to convince her that they might have it. Marke then notes that “antibiotics are needed to undermine the root cause of the illness: the bacteria that causes Lyme: *Borrelia burgdorferi*.” By saying this, Marke basically repeats the idea that prospective patients are not *merely* irrational and that they deserve thoughtful care as they navigate their symptoms. In turn, Marke ends her discussion of “Lyme Psychiatry” with an imperative claim: “You deserve a Lyme-literate physician,” prompting patients to connect her belief in Lyme Disease and its psychiatric symptoms to her position as an expert who can effectively treat it.



**Our Mission**

The Lyme Center of New England was created to diagnose and treat patients with Lyme disease and other tick-borne illnesses. We manage and treat chronic lyme disease, newly diagnosed lyme patients, patients with a known diagnosis who continue to have symptoms, and patients who have been diagnosed with conditions such as lupus, ALS, MS, or fibromyalgia displaying atypical symptoms.

We offer a caring, supportive environment with professionals who have significant experience providing care to patients with Lyme and other related diseases. The practice is open to all ages from pediatric to geriatric.

**Lyme Disease Facts**

- Lyme disease is a clinical diagnosis based on a patient's symptoms, history, and examination
- Lyme disease is caused by a spirochete bacteria *Borrelia burgdorferi*.
- The bacteria can persist long after treatment.
- The bacteria are able to hide in the central nervous system, eyes, and other difficult to infiltrate sites.
- It is possible to contract more than one tick borne illness from the same tick.
- The longer a tick is attached, the greater likelihood of transmission of disease.
- Lyme symptoms can develop days, weeks, or months after a tick bite.
- An erythema migrans(EM) rash in an endemic area is diagnostic of Lyme disease.
- CDC criteria are for surveillance purposes, not to diagnose Lyme disease.
- Lyme patients often get worse before getting better while on treatment.(Jarisch-Hexheimer reaction)
- Lyme disease can cause death occasionally and the bacteria can cross the placenta into the fetus.




Fig. 5: Susan Neuber's list of "Lyme Disease" facts on her homepage. N.d., <http://www.lymecenterne.com/index.html>. Screenshot by author.

Even less subtly, Ms. Susan Neuber includes a bulleted list of so-called "Lyme Disease Facts" on her website homepage (fig. 5). Compared to the CDC website, which summarizes Lyme Disease "facts" in a dense paragraph full of scientific terminology, Neuber's "facts" are visually easier to process and written in plain language. For instance, she uses the first two facts to define Lyme Disease, first describing it as a "clinical diagnosis based on a patient's symptoms, history, and examination," and then as a "disease...caused by a spirochete bacteria *Borrelia burgdorferi*." Structurally, Neuber suggests that Lyme Disease is so complex that merely defining it requires two separate bullet points, and yet she orders the bullet points strategically to define it in the simplest terms first. Then, Neuber's narrative begins to diverge

from the CDC's: her third and fourth bullet points discuss that Lyme Disease "can persist long after treatment" and "hide in the central nervous system, eyes, and other difficult to infiltrate sites." Neuber, then, crafts a narrative that will resonate with her prospective patients: if they only had an acute Lyme Disease infection, as it is framed in the CDC's narrative, they would not be seeking her care. Although some of Neuber's other "facts"—such as that ticks can spread more than one disease at a time and that the bull's-eye rash is a sign of Lyme Disease—align with the CDC, some of her other "facts" are more radical. For instance, Neuber claims that Lyme Disease patients "often get worse before getting better while on treatment." On the surface, this statement does not seem unconventional, since any kind of medical treatment could potentially cause unwanted side-effects. However, it defies the CDC's claim that Lyme Disease patients will immediately improve upon starting treatment.

### **Conclusion**

In their oft-cited book, *Laboratory Life: The Construction of Scientific Facts*, Bruno Latour and Steve Woolgar argue that "[s]cientific activity is not 'about nature,'" but instead, "it is a fierce fight to construct reality" (243). For Lyme Disease patients, the fight to construct reality is a key part of the empowerment paradox: patients must constantly work to prove that they are ill, only to seek out expensive specialized treatment but have little chance at recovery. In this chapter, I have examined four clinical websites created by Lyme Disease healthcare providers to show how they generate multiple social actions, all of which are highly rhetorical. As this case study suggests, especially when knowledge is ambiguous or contested, it is integral to understand not only what information exists about a subject, but who uses it, who finds it persuasive, and why. These healthcare providers' clinical websites use multiple rhetorical appeals and appear to center Lyme Disease patients. But while their websites appear to empower patients, they are also arguably empowering them to purchase healthcare services for an

extraordinary fee, which can be effective but risky. Dr. Jemsek’s practice, for instance, has been closed down, reopened, and investigated by the North Carolina Medical Board several times for inappropriately treating patients.

In all, patients are forced to empower themselves to make sense of the CDC and healthcare providers’ clinical websites. And—most significantly—they must decide how to make sense of these competing perspectives. Do they seek treatment from a traditional healthcare provider who, following the CDC definition and guidelines, does not believe in Chronic Lyme? Do they pay Dr. Jemsek or another healthcare provider thousands of dollars out-of-pocket for potentially dangerous, unverified treatments? For patients who have lived with chronic pain and fatigue for months or years, it feels like a choice between life and death.

To be clear, I am not suggesting that we support bogus science nor untested treatments for healthcare conditions, even chronic and contested ones. Instead, this chapter and my overall project suggests that scholars must consider the crucial role that healthcare providers’ clinical websites and other parascientific genres play in the public’s understanding of science, health, and medicine. Although in theory it is easy to dismiss alternative sources in scholarly work, in moments of crisis we (the scholarly collective) use the symptom checker on *WebMD* to decide if we should go to the hospital, scan blogs for home remedies that might ease pain, and search for alternative healthcare providers when our complaints are dismissed or remain unsolved. Especially when individuals are faced with chronic and contested health conditions, many of which are under-researched and/or inadequately addressed by typically “good” sources such as the CDC, we turn to alternative sources—critically examining them for their framing, content, and overall rhetorical effectiveness in our search for answers.

Accordingly, scholars must ask: How do we ethically engage a source that is not academically validated but seems to include incisive reasoning and high-quality evidence? And on the other hand, how do we ethically engage a source that that the public finds persuasive but does not include incisive reasoning nor high-quality evidence? As scientific information is found far beyond the pages of scholarly journals, how do patients navigate the digital deluge? I hope that Chapter 4 will begin to answer these questions.

## CHAPTER 3: HEALTH INFORMATION SHARING WEBSITES

When I first came across *MyLymeData*, I felt energized for the first time in months. It was as if the website creators knew me and my Lyme Disease story and were speaking directly to me. I was immediately drawn to the text in the center of the homepage, which reads, “IMAGINE A WORLD where people with LD are diagnosed and treated correctly and go back to living their lives” (see fig. 6; emphasis original). I have imagined this world for ten years, since I was diagnosed with Lyme Disease in November 2009 and never fully recovered. I am one of 300,000 or more people who are diagnosed with Lyme Disease each year, and I am one of the 10-20% of patients who are affected by long-term “subjective symptoms,” such as fatigue, joint pain, headaches, and sleep disturbances (Rebman et al.).



Fig. 6: MLD homepage, 19 February 2019, <https://mylymedata.org/>. Screenshot by author.

Reading on, MLD tells me, “YOU CAN BE PART OF MAKING THIS HAPPEN” (emphasis original) and implores me to “Add your Lyme data to MyLymeData to help find a cure for Lyme disease.” As a Lyme Disease patient and researcher who studies the rhetoric of Lyme Disease, I am doubly intrigued. I would do almost anything to prevent others from suffering: from negotiating with well-intentioned but disbelieving doctors, from trying drugs that cause intolerable side effects, from spending thousands of dollars on medical tests, from sleeping away their 20s. I had long wondered about my diagnosis and treatments, which sometimes caused more harm than good: antibiotics, anti-inflammatories, and immuno-suppressing biologics, in addition to complementary and alternative medical practices. I have long wondered when I’ll be able to return to, as the MLD calls it, “living” my life. I have felt so powerless over my own body—which my doctors tell me is my responsibility to control—and it is exhilarating to think that I can use my experience to help others. And, perhaps more importantly, to help myself. The next paragraphs explain the goals of the website, but I have already clicked the bright orange “Count Me In!” button to sign up. This is the moment I have been waiting for: I can be “counted on” to share my experience of suffering, which, more importantly, will finally “count” for something, towards something better.

MLD is one of many “big data” sharing platforms that patients may encounter. Although there are many definitions of what constitutes “big data,” Graham et al. argue that it is the “production, storage, and analysis of vast quantities of data—data that may exceed the ability of available technologies and methodologies to process” (70). Big data can help rhetoricians gather, organize, and analyze large quantities of information, and in Tarez Samra Graban’s terms,

“account for all dimensions of recovery—unfinished and undetermined, discursive and imagined, demonstrative and generative, methodological and epistemological” (188). For rhetoricians of health and medicine, big data projects offer a wealth of possibilities for learning about how persuasion is working among health providers and patients. For researchers and healthcare providers, big data projects offer novel insights into disease management and prevention. New organizations, such as the Patient-Centered Outcomes Research Institute (PCORI), which was chartered in 2010, were created to get patients to share their personal health information to find cures and treatments for a range of health problems (“Our Story). The difference, however, is that PCORI is a nonprofit that was “authorized by the U.S. government,” whereas MLD, like *23andMe* and *Ancestry*, is private.

Patients may have compelling personal reasons for sharing their health data with government or private organizations. Patients’ participation in data sharing does not adversely affect their ability to obtain healthcare—both traditional biomedical care as well as complementary and alternative healthcare treatments. It does not render patients noncompliant, and it does not directly interfere with their current treatment plans. Many chronically ill patients worry about being perceived as drug-seekers, since they have been on and off of powerful medications to control their symptoms, and consulting with too many medical providers—even innocently—may be seen as suspect. Data sharing, instead, is seemingly private and separate from patients’ medical spheres and because their data is de-identified, their participation should not impact their current care or treatment situations.

MLD claims that its immediate goal is quickly producing research that improves Lyme Disease diagnosis and treatment processes, and perhaps eventually developing a vaccine or discovering a cure. To achieve this goal, MLD collects, synthesizes, analyzes, and shares users’

health data with selected partners. Throughout this process, users are both an “integral, participatory force” (Johnson 30) but also “inevitably ancillary” (27). MLD cannot conduct research without users’ health data, but users are not invited to “negotiate” parts of the process such as suggesting research questions, directions, or publication venues. Ultimately, users’ health data appears to be shared with for-profit companies, which aim to fund profitable vaccines, medications, and diagnostic tools, and there is no guarantee that MLD users will personally benefit from these research endeavors. In turn, the creators of MLD must leverage visual and textual rhetorics of patient empowerment to persuade users to share their health data without realizing that “the system is the source and ultimately the determiner of all” (27). By looking at how MLD leverages rhetorics of user-centeredness, rhetoricians can better understand how patients are persuaded to share their health data despite the problematic nature of the platform.

In this chapter, I conduct a rhetorical analysis of *MyLymeData* (MLD), a “big data,” so-called “patient-powered research project” that collects, aggregates, and publishes data from people with Lyme Disease (LD) in hopes of finding a cure. I examine how big data is leveraged not only as a research method, but also rhetorically—in Johnson’s terms, as a “popular argument of the twenty-first-century world” (“Modeling” 97). In what follows, I will consider Robert Johnson’s definition of user-centered technology and offer an analysis of *Women and Their Bodies*, the first version of the foundational women’s health text, *Our Bodies, Ourselves* (OBOS), which I will argue is an example of a truly user-centered technology. Within this context, I will then analyze MLD and three topoi that are used to persuade users to share their data. I contend that MLD appears to be a user-centered technology, but that it is instead primarily serving the for-profit company it ultimately supports. I conclude by considering larger challenges



with using “big data” in rhetorical studies and suggesting a framework for a truly user-centered version of MLD.

### **User-Centered Technology vs. User-Centered Rhetoric**

In Robert Johnson’s (1998) foundational book, *User-Centered Technology: A Rhetorical Theory for Computers and Other Mundane Artifacts*, he theorizes the role of the user and considers how users “unwittingly surrender knowledge and power due to our lack of reflection on our mundane interactions with technology” (10). Johnson defines users quite simply as “the audiences of technology” (xv). User-centered technologies, he argues, offer users an opportunity to be “active participants” in the “*negotiated process of technology design, development, and use*” (32, italics original). Alternatively, Johnson defines a “user-friendly” technology as one that has an “interface that is easy to use but may not necessarily be in the best interest of the user” (Johnson 28). Although “user-friendly” technologies can be, in Johnson’s terms, “quite helpful,” they can also be “problematic” and “dangerous” because users are “far removed from the central concerns” of the product’s design and are mere recipients of a technology that is “created in a system or system designer’s image” (28).

From its instantiation as *Women and Their Bodies*, the feminist health education tome, *Our Bodies, Ourselves*, has been a prime example of a user-centered technology. In the introduction to *Women and Their Bodies*, the authors discuss how the users were “an integral, participatory force in the process of writing” (Johnson 31). There is a long section about the iterative writing, drafting, and revision process, which involved groups of women from across the Boston area. The authors note that the text is “not final” (3) and “not static” (3), recognizing that it “should grow and include other topics” based on users’ needs (4). To further emphasize the user-centeredness of the technology, the authors urge readers to use the papers “as a tool” for

prompting “discussion and action, which allows for new ideas and change” in an effort to ensure that users’ needs are met (4). The content of the document similarly centers users’ ambitious needs and goals: to “act together on our collective knowledge to change the health care system for women and for all people” (4).<sup>1</sup>

*Women and Their Bodies*, then, functions as both a manifesto and a manual, offering critiques of the capitalist, “pay-as-you-die” (7) healthcare system alongside instructions for how users might explore their own bodies and personally benefit from reading the text. The 193 pages, divided into twelve sections, include diagrams of human reproductive systems, arguments about sexism and racism in the healthcare industry, definitions of medical terminology, and anecdotes about sexual violence. Throughout the work, the authors offer many opportunities for readers to self-investigate as a means of learning about their bodies. Even their directions are user-centered. To take one of many examples, in the Women, Medicine, and Capitalism section, the authors discuss female sex organs and suggest methods and reasons for self-investigating them. Specifically, they offer a short, friendly description of how a reader can palpate her cervix:

You can touch your own cervix; it feels like a large nipple with a small dimple in its center, extending from the top part of the vagina way towards the back. The uterus changes position during the menstrual cycle, so where you feel the cervix one day may be slightly different from where it will be next! The entrance into the uterus through the cervix is very small, about the diameter of a very thin straw. This is the little dimple that you feel in the middle of the ‘nipple.’ (12)

---

<sup>1</sup> OBOS, and especially *Women and Their Bodies*, primarily reflects the perspectives of the white, upper-middle class women who composed it.

The description is conversational rather than technical, clearly oriented towards the user population: women who were self-aware but unfamiliar with their reproductive anatomy. Readers are addressed in second person. They “can” touch their vaginas—they are able to and empowered to if they wish, but they are not forced to do so. The description of the cervix as a “large nipple with a small dimple in the center” and the entrance to the uterus as “a very thin straw” are colloquial and would have been easily understood by users at the time. The use of an exclamation point signals the surprising joy that can be found in learning about one’s body, which is another affordance of self-investigation that benefits the user personally. Later in that section, the authors note, “We emphasize that you take a mirror and examine yourself. Touch yourself, smell yourself, even taste your own secretions. After all, you are your body and you are not obscene” (14). Here, the language is more directive, but the authors know that most users have internalized shame about their bodies, particularly their vaginas, and they must prompt users to work through this shame to become more educated and, thus, be able to be more empowered as they make decisions about their healthcare.

Since the publication of *Women and Their Bodies*, many other print and digital texts about women’s health have been released. Moreover, with the advances in genomic and precision medicine, patients of all genders are encouraged to self-investigate and, perhaps more importantly, keep track of their data. They record every meal in *MyFitnessPal*, note their menstrual cycles in *Flo Period and Ovulation Tracker*, and bookmark their most commonly used medications in *Calm* and *Insight Timer*. Smart watches track users’ activities and transfer the data to mobile apps, where they can look at their daily, weekly, monthly, and yearly trends. Users can download their data for personal use or to share with their healthcare providers. Previously, users who wanted to learn basic information about their genetics had to seek out

experts and their council. Today, users who are interested in disease prevention can send vials of saliva to *23andMe*, *Ancestry*, and other health data companies for analysis.

Unlike *Women and Their Bodies* and OBOS, which aimed to convince users to self-investigate as a way to counter the “corporate capitalist entities” (7) that make up our healthcare system, these new technologies are created and sustained by the self-care industry. In *Women and Their Bodies*, the authors suggest that users seek additional resources to further their health education, but they warn them to be wary of Ortho and Tampax, “capitalist organizationsp” [sic] that “[push] their own products for profit” (5), and Planned Parenthood, which “pushes population control and birth control pills” (5). Instead, current companies deploy a rhetoric of user-centeredness that is eerily similar to OBOS, but has a different end: to earn money. Chronic disease patients in particular are targeted because chronic diseases are expensive and it is difficult to coordinate care for these conditions among multiple providers (Vest and Gamm 292).

The next section will discuss MLD, a data collection platform for individuals diagnosed with Lyme Disease. The problem is that it is almost impossible for weary, vulnerable patients to distinguish between true user-centeredness and a rhetoric of user-centeredness, and thus they end up self-investigating and sharing their data in ways that do not serve them. I will show how MLD draws on three of the same tensions that emerge in *Women and Their Bodies*—power, community, and simplicity—in a way that appears to empower users but ultimately serves MLD.

### **About MyLymeData**

Although researchers in fields such as entomology, public health, rheumatology, and infectious disease are studying Lyme Disease, there have been only a few clinical trials. Some argue that the clinical trials that have occurred have been too limited in scope and that the inclusion criteria are so strict that most Lyme Disease patients cannot participate (Johnson, Shapiro, and

Mankoff n.p.). Others argue that the Lyme Disease clinical diagnosis guidelines are too strict, which prevents many ill people from receiving a Lyme Disease diagnosis (Johnson and Stricker). In turn, MLD, along with other advocacy organizations such as the International Lyme and Associated Diseases Society (ILADS), has stepped in to meet patients' unfulfilled needs: to feel heard, affirmed, and reassured that their pain can be lessened and that there is reason to hope for a cure. Patients and their allies face a difficult crossroads. Since there are no simple cures, they are left with one option: they can take comfort in sharing their pain, their stories, and their data to prevent others from experiencing the same suffering. This makes Lyme Disease patients prime candidates for sharing their health data with platforms like MLD.

MLD appears to center users in many ways: through its use of second person (“you” and “your family” and “your friends); through visuals that are simple yet bold; through accessible colors (blue and orange); through easy-to-read sans serif, bolded text; through specific, yet simple and memorable, subtitles that accurately summarize the key points (e.g. “What It Is” and “Help Us Advance Science”), its easy-to-find FAQ page; and use of easy-to-view, short yet informative videos, which explain the website’s mission and rely on the authority of a variety of experts. In this section, I focus on three prominent tensions—patient vs. power and individual vs. community, and simplicity vs. complexity—which are meant to persuade users to share their health data with MLD. Big data projects have what Elizabeth Losh calls “persuasive goals,” some of which are visible, and many of which are purposely rendered invisible; as rhetoricians, it is our job to analyze MLD and other big data project in ways that “[make] our present moment visible” (239). As Scott, Segal, and Keranen note, “research need not be ‘applied’ in order to be ‘useful’” (2). However, this is one opportunity for rhetoricians to use their skills to benefit the broader public.

## *Patient vs. Power*

MLD's use of the term "patient-powered" is its most significant rhetoric of user-centeredness. However, rhetorical analysis reveals how the empowerment paradox is working in this case. There are two irreconcilable tensions between "patient" and "power": 1) the idea that patients *power* the website by sharing their data, but that patients have little power in what happens to their data once they share it, and 2) the idea that sharing health data is *powerful* enough to harm patients, but MLD mostly ignores this possibility.

Traditional clinical trials are "patient-powered" in the sense that researchers gather and process patients' data, from which they draw results and make broader conclusions and recommendations. Alternatively, MLD creators conceive of "patient-power" as both a research method and a practice. On a page titled "Patient Powered," they explain, "MyLymeData expects to gather more data about Lyme disease than any research study has done before and build a patient-centered research community. That's what patient-powered research is about!" But looking at these two sentences alone creates some holes in their "patient-powered" argument. Here, the creators mask the definition "patient-power" as a kind of labor and instead focus on a rhetoric of "patient-centered research community," the benefits of which they, arguably, suggest should outweigh the labor of "patient power." Further down the page, they note that "New technology allows patients to take the lead" and "MyLymeData lets patients lead the way to help find a cure." Again, this language is presumptive. Although technology may "allow" patients, a population not usually in a position of biomedical authority, to "take the lead," it does not value data sharing as a kind of labor. This phrasing also looks at technology as unreflexively beneficial: there is no mention of how data sharing technologies might actually harm patients—by, say, allowing the culling, sharing, and interpreting of data by novices who do not have clear

ethical commitments. Ultimately, this is a classic example of neoliberalism at work, in which patients are conscripted into sharing their data and are not compensated for their work.

On this page, however, users are distracted by the appearance of legitimacy that the creators grant them, particularly phrases such as “Lyme patients are experts in their illness.” Expertise is an interesting term to use here, and a powerful one at that. Lyme Disease patients must often become informal experts on the disease because it is difficult to receive a diagnosis and effective treatment. However, some healthcare providers balk at patients’ experiential expertise because “expert” patients ask for controversial treatments, contest providers’ recommendations, and perhaps most significantly, to choose explicitly not to comply with a provider’s treatment plan and seek care elsewhere. In turn, attending to expertise suggests that the MLD creators are attuned to this particular brand of user-centeredness, the kind needed to find better treatments for Lyme Disease. Still, MLD primarily relies on scientific, medical, and legal experts to interpret their data, and it is not clear how patients are part of the data analysis or publication process. On the “About” page, it says that “LymeDisease.org will analyze data and provide information to the community through publication of white papers and peer reviewed articles. We will also partner with researchers and clinicians who are interested in research that puts patient interests at the center and seek to cure or improve quality of life.” Although white papers could be considered public genres that are accessible to broad audiences, MLD users are not invited to contribute directly to the writing or revision processes. Although MLD’s partnerships with researchers and clinicians might, ultimately, help patients, there is no evidence that MLD are partners in the research process.

At the same time, MLD's focus on "patient-power" offers something important and meaningful to patients: the opportunity to engage in Lyme Disease research, which is otherwise elusive. As MLD explains,

How it works: Patients with Lyme disease tell us about their experience, symptoms, treatments, and results. Periodically, they update their information to let us know what has changed. This allows us to better understand the progression of the disease and what works—and doesn't work—to help people get better. It lets patients learn from each other and provides data that can drive research to improve patients' lives. ("Home")

This means that, unlike in regular scientific studies, there is no exclusionary criteria, no travelling to and from study facilities, no commitment to participating for a certain length of time, and, thereby implicitly, no risks. Since Lyme Disease clinical trials are so restrictive, few Lyme Disease patients have a chance to share their data. The potential benefit of gathering a much larger, "patient-powered" data set is attractive. Theoretically, a larger data set will reveal undiscovered trends and better information about effective treatments. Since MLD is "patient-powered," anyone can contribute their data to the platform, including adults on behalf of their children or relatives who have died from Lyme Disease. In fact, people are encouraged to participate on behalf of others—including people who are too disabled to participate themselves and people who have died—which rarely occurs in clinical studies. Although MLD frames their inclusivity in an exclusively positive way, it comes at great risk. Users are tasked with interpreting their own medical charts, doctor's notes, and test results. Even if users have high levels of medical literacy, they may draw false conclusions from their own or a family member's data, and MLD does not have a method for validating users' data. As a result, users may circulate and rely on false data, unknowingly choosing treatments that could harm them.



Moreover, even if MLD's "patient-powered" data can "improve lives," it is not clear how this happens nor whose lives are improved. It is especially unclear how users are involved in this process. The MLD creators' names and contact information is not easily available on the MLD website. Users are left to infer that, since it is a "project" of LymeDisease.org, the creators and board of directors are the same, which is not necessarily true. The MLD website "Contact" page (which is accessible only via a small link at the bottom of the home page that says CONTACT) has two buttons: one for "MyLymeData Support" and one for "Researchers." If users click on the "MyLymeData Support" option, they must select one of five ambiguous subcategories, none of which directly address potential issues with data breaches or other negative consequences of data sharing.

To find this information, users must read through the entire FAQ page. There are no links at the top of the page to help users more easily find questions about data use, privacy, benefits, etc., and the questions are ordered in a way that appeals to the needs of the MLD administrators, not users. Questions that users might actually have, including "How will my data be used?" and "What about privacy?" are buried in the middle of the FAQ list, which doesn't have numbers or bullet points, so users have to make more of an effort to locate this information. The second-to-last two questions—"Is there IRB approval for the study?" and "Who can I contact if I have questions about the study?"—may be the most important of all, but again, they are buried in the FAQ list and are not organized in a user-centered way.

Relatedly, some of the FAQ questions are also framed in a way that appears to prioritize the needs of MLD over the needs of users, but draws on user-centered rhetoric. For example, Question 5 reads, "What is expected of me?" and Question 7 reads, "How can I participate?" These questions prioritize the user by using first-person language, but the content of the

questions is not particularly helpful, since most of that information is available on every single other page of the website.

To take another example, Questions 10 and 11 are about the benefits and risks of participation, and the discussion of benefits comes before the discussion of risks. Answers are organized rhetorically as well: the response to the benefits question is two paragraphs long, while the response to the risks question is one paragraph, which also visually suggests that there are more benefits than risks. Moreover, the answer to the risk question reports that risks are “minimal” and refers users to the “privacy question above” for additional information about the “substantial safeguards in place to avoid a security breach.” This requires the user to scroll back to the top of the page and search for the privacy question, since the Q&A questions are not numbered or organized in a particular way.

Overall, MLD claims that users’ data “will not be sold or leased to others,” but it will be “used for Lyme disease research that is patient-centered,” which they claim “is intended to improve quality of life for patients with Lyme disease or to increase our understanding of the disease.” This is rather nonspecific. The MLD “study team” is responsible for data analysis, both “on its own and in partnership with researchers and clinicians who are interested in patient-centered research” (“FAQ”). MLD notes that “independent researchers” with a focus on patient-centered research may also have the opportunity to study the de-identified data. This strategically worded section is ambiguous enough to allow anyone to gain access to the MLD data, including paying corporations. Patient users, however, are not considered to be potential research partners, which is yet another example of how MLD forwards a rhetoric of user-centeredness and is not, in fact, a user-centered platform.

### *Individual vs. Community*

In addition to the focus on “patient power,” the MLD creators deploy user-centered rhetoric that acknowledges users as both individuals and members of the Lyme Disease community. This is a compelling binary through which the creators can mobilize users as individuals with the capacity to make substantive change and mobilize these same people as part of a community that, together, can generate even more significant change. MLD’s focus on individuals and individuality is primarily constructed through two key phrases, which appear on multiple pages of the website: “Count me in!” and “Can one make a difference?” (fig 7). These phrases appear to be user-centered, but ultimately work to persuade patients to contribute their data to MLD, which may not necessary help patients directly.

The phrase “count me in!” has multiple meanings, particularly for Lyme Disease patients. The Centers for Disease Control and Prevention estimates that 300,000 Americans are diagnosed with Lyme Disease each year, but this number is generated based on very strict definition of Lyme Disease. As I noted earlier, many patients do not “count” as having Lyme Disease because they do not meet certain criteria, and as such, they have been disbelieved, dismissed, and misdiagnosed. In turn, the language of “counting” honors individuals’ identities, stories, and experiences, especially Lyme patients who do not “count” in other settings. This user-centered rhetoric invites users to contribute their data and authorizes them to share diverse experiences.

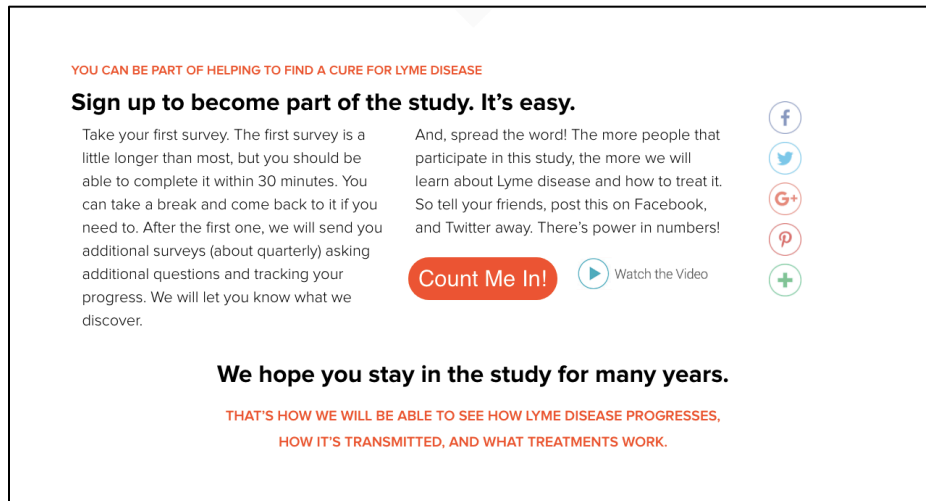


Fig. 7: “Count Me In!” button on the “About MyLymeData” page, 19 February 2019, <https://www.lymedisease.org/mylymedata/national-study-chronic-lyme-disease/>. Screenshot by author.

The second phrase—“one can make a difference”—suggests that that “one” can be you personally. This phrase is primarily presented in the 1:28 minute video, “Can 1 Have Power?” which is featured at the top of the MLD “Home” page as well as on the “Videos” page (Fig. 8). This video, which begins by asking “Can one person have power?” tells viewers that “If you have Lyme Disease, you’re not alone. More than 300,000 people in the United States develop this tick-borne disease every year” (“MyLymeData Videos,” emphasis original). By using second person, viewers—who may be as diverse as healthcare professionals, patients, and family members—are immediately drawn in and made to think about themselves in relation to others. By 00:25, the video begins discussing “big data” and frames it through the user individually: “Today, there’s a new kind of research that allows you to fight Lyme Disease with your own health information. It’s called big data, and big data research is a big deal.” This definition is too

simplistic to be meaningful; more significantly, viewers are prompted to think that “you” can help cure Lyme Disease by using your own data (*italics added*). Users, then, do not need to be able to understand anything about science or “big data” to feel agented (or perhaps more significantly, obligated) to contribute to Lyme Disease research.

The video closes with the question, “Can 1 person have power? Can 10? 1,000, and then tens of thousands have power?” This question is rhetorical; the content of the video articulates a clear “yes.” The video implies that, yes, one person can have power, and that individual power is exponentially stronger when compounded with everyone’s power. The video concludes, “It’s within your power to change the future, starting right now. Add your Lyme data to my Lyme data, and help find a cure for Lyme Disease.” This statement integrates both the individual and community aspects of MLD to compel people to contribute their data. In fact, it almost seems unethical for users *not* to contribute their data and increase the seemingly exponential power of MLD’s “big data” project.

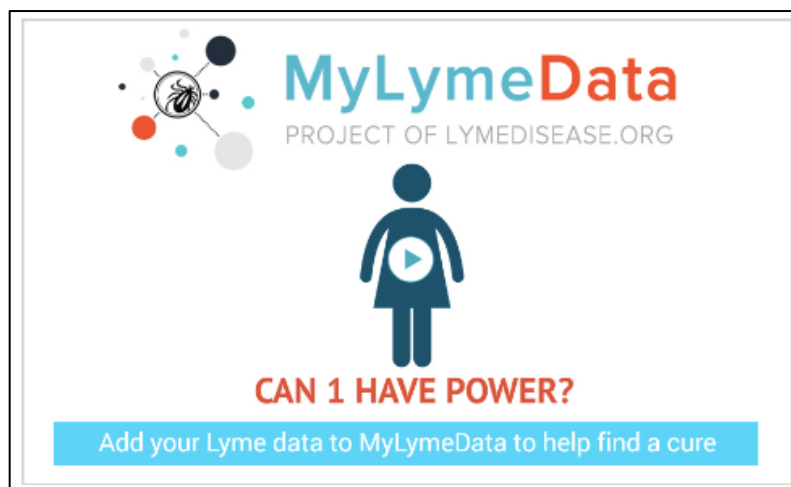


Figure 8: “Can 1 Have Power” video slide, 19 February 2019, <https://www.lymedisease.org/mylymedata/videos/>. Screenshot by author.

The phrases “Count me in!” and “Can one make a difference?” are effective for a variety of reasons. First, they emphasize that individual voices are not merely important, but in fact integral, to finding a cure for Lyme Disease. Second, they create two communities: one of Lyme Disease patients, survivors, and advocates, and “everyone else.” There is a kind of exclusivity created by isolating the Lyme Disease community. As it plays out on MLD, users must become members and share their data in order to gain access to the data. In turn, MLD facilitates an exclusive sharing economy, which economist Chris J. Martin defines as the exchange of knowledge, tools, skills, or other information that is primarily “driven by digital technologies” (152). Although sharing economies may lead to “a more sustainable form of consumption,” they may also be rhetorically “reframed by regime actors as purely an economic opportunity” (149). In other words, sharing economies may reinforce system-centered practices and technologies; in this case, in addition to helping suffering patients alleviate their Lyme Disease symptoms, MLD and its industry partners may profit financially from products they develop with users’ data. By focusing on the language of individuality, MLD aims to bring people together by agenting them as individuals who can make an impact on behalf of a larger, amorphous, nondescript, ambiguous community.

Accordingly, MLD establishes one particular community: “us” versus “you.” At different times, the website speaks on behalf of LD patients—and thus the Lyme Disease community—and at others it speaks on behalf of itself as a research authority. The website creators strategically make their role as both arbitrators of the community and members of the community ambiguous. For example, on the “About” page, the website creators note, “Our previous surveys have been published in peer-reviewed articles and used to inform healthcare policy issues affecting the community. Our last published survey has been downloaded over 4,000 times.”

Using “our” takes a kind of ownership and authority over the materials, hinging both on MLD’s role as a repository for patient voices and a representative of those voices. Of course, “our” does not include all regular users of MLD, i.e., members of the general public who share their data. Although these users can download and repurpose the disaggregated data, only high-level creators make decisions about developing, analyzing, and circulating it for broader audiences.

The “Home” page emboldens users via imperative phrases to “Help us advance science,” “Join the study,” and “Become part of something big by providing your vital piece” (“Home,” emphasis added). There are also explanatory notes, such as “When people are sick, they may feel they can’t even help themselves, let alone help anyone else. This is something any patient can do” (“Home”), but these imperative phrases are more directive and better at compelling users to contribute. This strategy is present throughout the website. On another page, users are prompted to “Take your first survey” and are told that “You can take a break and come back to it if you need to.” This kind of flexibility removes barriers that would typically prevent individuals needing accommodations from participating (“What”).

On that same page, the website creators note, “After the first one, we will send you additional surveys (about quarterly) asking additional questions and tracking your progress. We will let you know what we discover” (“What”). The We-You-We pattern here illuminates a persuasive yet peculiar hierarchy: MLD is the organizing and authoritative power that propels you into action, but they cannot have power without you. It is important to consider how the “us” versus “you” perspective that the website presents plays into universal insecurities about fitting into identity groups and discovering a greater purpose in life. This is another component of the empowerment paradox. Patients who are empowered enough to research their symptoms may

find that they do not fit neatly into one diagnosis, but websites like MLD allow them to participate only if they have at least one specific condition.

In all, people want to be part of a community because they want to feel seen, understood, and recognized. The MLD creators are using this same formula to compel people to contribute their data, but they are shaping their community in very strategic ways. This approach, which combines the best of exclusivity, community, helplessness, helpfulness, and guilt, has broad appeal and can therefore attract a broad spectrum of users.

### *Simplicity vs. Complexity*

The final (and perhaps most revealing) rhetorical move that the MLD.org creators make is to frame their requests around a rhetoric of simplicity, ease, and speed, which contradicts the rhetoric of complexity that undergirds scientific work. MLD suggests that “big data” is what makes their study so simple and easy. They cite three easily comprehensible benefits of big data research: it “provide[s] lots of information,” “uses very broad entry criteria,” and “examines treatments used in the real world” (“About”; see fig. 9).



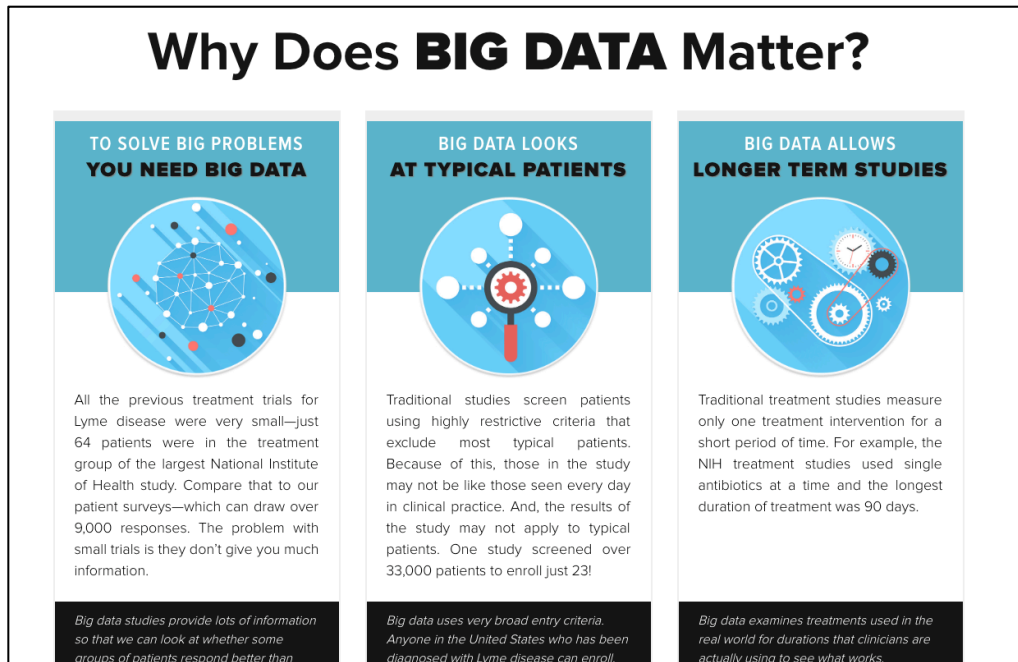


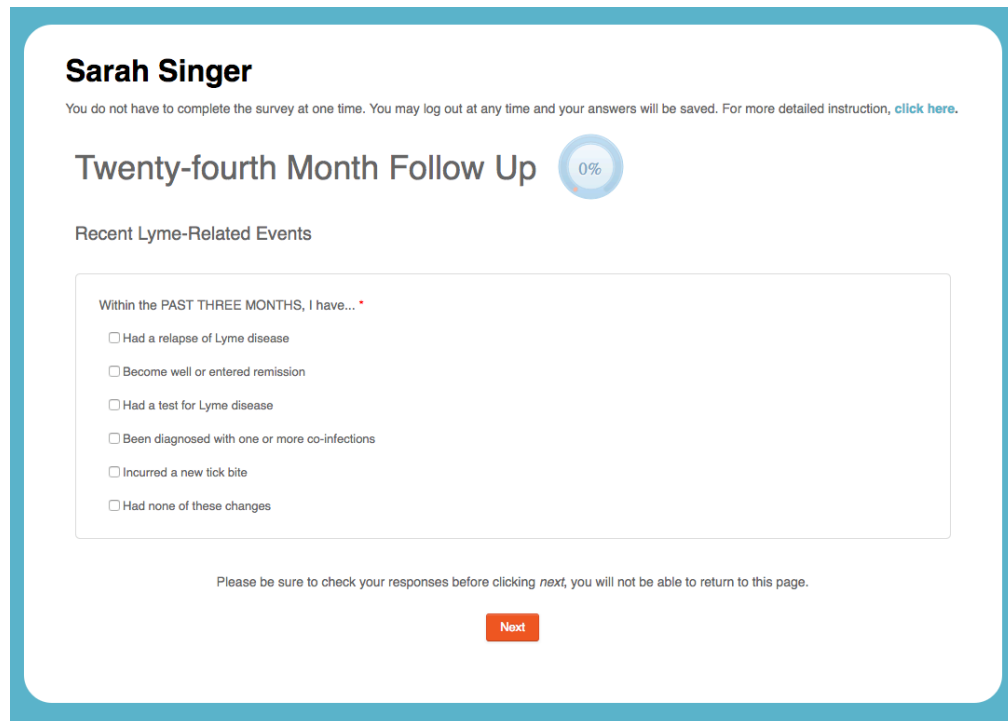
Fig. 9: Explanation of Big Data on the “About MLD” page, 19 February 2019,

<https://www.lymedisease.org/mylymedata/national-study-chronic-lyme-disease/>. Screenshot by author.

However, in reality, “big data” research methods make it easier for researchers to gather and analyze large quantities of data, but they do not help patients access nor use the data. For instance, as an MLD member and contributor, I am able to access all five of their current surveys. Thus far, I have filled out three of them. If I wanted to go back and view my results from the “Unwell Survey – Phase 2,” which has 149 questions distributed over 11 pages, I would need to manually click through the entire survey. Even though the MLD creators appear to offer PDF versions of completed surveys, the PDFs only include two pages of the survey at a time, making it laborious for users to access their own data. This is another example of how the MLD appears to center users but has designed the website to serve their own interests.

Relatedly, for the “Twenty-Four Month Follow-Up” survey, which I have not filled out, I am unable to discern how long it is or what information will be required until I complete it (fig.

10). Although the directions tell me that I can “log out at any time” and my “answers will be saved,” it is impossible for me to preview the survey and, in turn, evaluate how it might serve me, what kinds of information I would prefer to share or not, etc. Again, this structure works in service of MLD. Users may choose to stop at any point or skip some questions, but they must take the chance and begin filling out the survey to figure out what it entails.



The screenshot shows a survey interface for Sarah Singer. At the top, it says "Sarah Singer" and "You do not have to complete the survey at one time. You may log out at any time and your answers will be saved. For more detailed instruction, [click here](#)." Below this is the title "Twenty-fourth Month Follow Up" with a circular progress indicator showing "0%". The section is titled "Recent Lyme-Related Events" and contains a list of options with checkboxes: "Within the PAST THREE MONTHS, I have...":

- Had a relapse of Lyme disease
- Become well or entered remission
- Had a test for Lyme disease
- Been diagnosed with one or more co-infections
- Incurred a new tick bite
- Had none of these changes

At the bottom, there is a warning: "Please be sure to check your responses before clicking next, you will not be able to return to this page." and a red "Next" button.

Fig. 10: The first page of the Twenty-Four Month Follow Up survey in my user profile, 19 February 2019, <https://www.mylymedata.org/view-data/detail/737/61/757.html>. Screenshot by author.

Additionally, MLD frequently uses terms like “simple” and “simplicity.” For example, the home page reports, “Our patient surveys draw over 9,000 responses! We’ll use the information provided by patients to help figure out how to prevent and treat all stages of Lyme disease. It’s that **simple**” (“Home,” emphasis added). The “About the Study” page urges users to “Sign up to become part of the study. It’s **easy**” (“About,” emphasis added). It is strange to think

about the MLD surveys as “simple,” since there are multiple surveys that ask hundreds of questions about users’ experiences with Lyme Disease. Answering all of the questions might require looking back at one’s records (or ideally this would happen so that users could include accurate information), speaking with one’s family or doctor to clarify names of medications or the types of tests, etc. Furthermore, “simply” taking the survey requires a relatively high level of medical literacy that may go beyond most users’ traditional knowledge scopes. In turn, the language of simplicity belies the reality of using the MLD website.

The language of simplicity also, surprisingly, is emphasized on the FAQ page. The purported purpose of an FAQ page is for the content managers to anticipate and respond to the intended audience’s questions and concerns. FAQs are thus powerful documents that are instrumental for technical communicators who aim to make their materials user-centered. The presence of an FAQ page implies that the content creators know that users will have questions and that they want to attend to them. However, an FAQ page can also be used as a tool used for silencing by suggesting that any possible questions that users might have are already answered and that the answers are obvious.

The MLD FAQ page relies on the language of simplicity and ease to convince potential users to sign up and share their data rather than answer important questions about privacy and data use. Users are immediately confronted with this concept, starting with the first question: “How do I sign up for the study?” (see fig. 11). Rhetorically, the content managers have chosen to put this information first because they want users to pay the most attention to it. The answer to this question, accordingly, is “Signing up is easy. Just fill in the required information. Then, **simply** take your first survey” (“FAQ,” emphasis added). Although this question might appear to cater to users, it is unlikely that users are confused about the sign-up process because there are

bright orange “Count Me In!” and other sign-up links on every page, sometimes multiple times. In turn, it is clear that the MLD FAQ page is just another place where the creators aim to recruit participants regardless of potential harm to users. Two FAQ questions in particular focus on the language of simplicity. In the answer to Question 7, the content creators report that “If you are of legal age (18 years old in most states), **simply sign up.**” Similarly, in question 9, which is about privacy, the answer notes that if users get uncomfortable, “[w]ith few exceptions, [they] can **simply** skip questions [they] prefer not to answer” and that if users decide to withdraw from the registry, they can “[s]imply contact the registry and all of [their] data will be removed from the database” (“FAQ”). The repetition of the word “simply” here is notable because it is unclear, exactly, how easy it is for participants to skip questions and revoke their data.

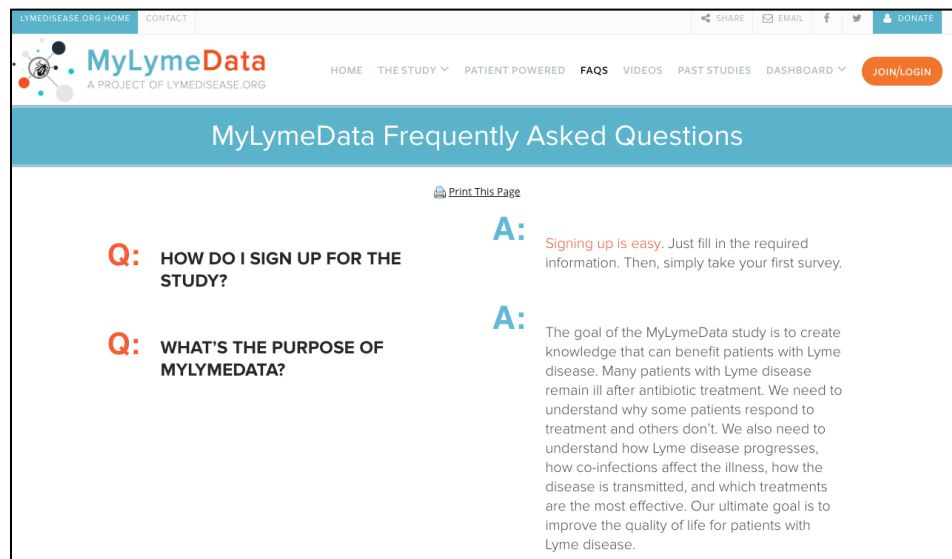


Fig. 11: MLD FAQ page, 19 February 2019,

<https://www.lymedisease.org/mylymedata/faqs/>. Screenshot by author.

And perhaps most significantly, navigating the user profile portion of the website is anything but simple. By sharing their Lyme Disease data, users are given access to MLD’s pool of deidentified, aggregated data. However, the platform’s interface does not help users interpret

the data. To take one example, I have included a screenshot of the “Disability” question from the baseline survey (see fig. 11). The data is organized thematically on the left side of the page, purportedly in the same order as the initial survey questions. Users are able to click on each topic (derived from the survey questions), and when they do, two graphs—one bar and one circle—appear. Strangely, an orange and white subtitle that reads “Your response” appears above the graphs, but it is unclear how or where your response is included.

In this particular case, it appears that only five people responded to this question, and as such, the graphs are somewhat meaningless because it is easy to parse such a small data set. This example illuminates multiple problems with MLD’s framing and distribution of “patient-powered” data. First, it makes clear that even though thousands of people might have filled out the MLD surveys, many skipped particular questions. The “big data” research method here, then, might not be as all-encompassing nor as useful as the MLD creators suggest. Second, in this format, it is unclear how this data will help patients personally. In this example, the five people who answered the question reported that they were “disabled” from a range of one year to more than ten years. This question and the accompanying answer lack necessary context. What, exactly, does it mean to be “disabled” in this case? Since there is no clear trend among the answers, how should a user make sense of this data?

Ultimately, this example makes it clear that giving users access to a “big data” set not only does not necessarily benefit users, but it might actually harm them. Although MLD users are likely highly health literate patients who have long been researching Lyme Disease, they may not know how to interpret data, and they may be alarmed by the responses to this question and others. Although a sample size of five people is probably too limited to be useful, there is no

background section that provides information of this nature. Moreover, there is no mechanism for helping users deal with the distress caused by looking at this data.

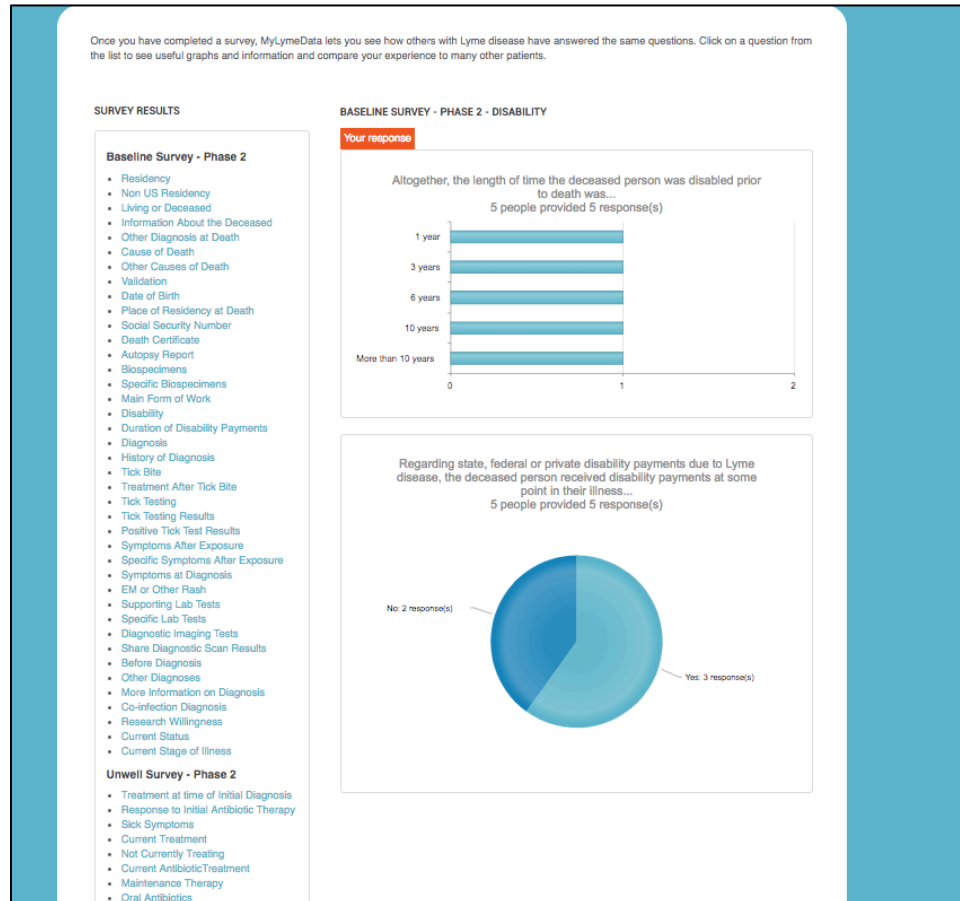


Fig. 12: The user view for “Disability” question in the first MLD survey, 19 February 2019, <https://www.mylymedata.org/view-data/detail/737/61/757.html>. Screenshot by author.

## Conclusion

This case study of MLD provides an opportunity to reconsider several of key assumptions central to rhetoricians of health and medicine as well as health humanities scholars. As this chapter demonstrates, proponents argue that big data is integral to research because it represents a very large—and purportedly diverse—data set. Big data studies have the capacity to expand small, localized research studies whose results must be retested in other places in order

for them to become generalizable. However, the language and use of “big data” must always be understood as a tactical, technical rhetorical tool used to gain power. Rhetoricians in particular are equipped to discern when and how rhetorics of big data are used to serve systems instead of users. These rhetorics may be part of what Katz calls the “ethic of expediency” (266)—the problem of making something so efficient that “[p]rogress becomes a virtue at any cost” (265). In this case, the creators of MLD make a clear, nearly irrefutable case for why users should add their data even though doing so may have invisible or unanticipated consequences.

MLD claims to be “a project of LymeDisease.org,” a 501(c)(3) nonprofit organization. However, MLD is not itself a nonprofit. More importantly, MLD’s ambiguous language about privacy and data sharing means that it can connect with whomever it desires in order to advance research. In turn, MLD is listed as one of many possible “Patient Insight Networks” on Invitae’s website. Invitae is a genetics company, and its primary function is to make genetic data collection as fast and patient-oriented as possible. At the same time, Invitae is ultimately owned by Thomas, McNearny, & Partners, a hedge fund (or, in their terms, a “health care venture firm that invests in life science and medical technology companies at all stages of development”). To be sure, MLD has crafted flexible policies to allow for these kinds of collaborations. And yet the idea of producing data and capital for a for-profit organization does not exactly match the vision that MLD portrays: that of a patient-powered, user-centered platform meant to advance research. In this case, it is difficult for users to disentangle where patient-power ends and corporate power begins.

Ultimately, MLD epitomizes the effects of the empowerment paradox, which has created a culture in which patients are supposed to feel empowered by collecting and sharing their data. For rhetoricians of health and medicine, big data projects offer a wealth of possibilities for

learning about how persuasion is working among healthcare providers, patients, corporations, nonprofits, and the federal government. Big data research methods allow rhetoricians who study “rhetors with limited agency,” such as patients. These research methods may also permit access to rhetors who are otherwise un- or underrepresented, as well as a variety of audiences “who may or may not share the intentions, values, beliefs, or practices of the rhetor” (Reed 17). Big data also creates opportunities to study both individual and collective health experiences; as Sarah Hallenbeck argues, the “collected” aspect is important because it draws on ordinary, unexceptional people who are otherwise missed, yet collectively their efforts create significant rhetorical velocity (xv). One affordance of big data is that it aggregates many experiences and offers a range of quantitative data for analysis. At the same time, this aggregation erases the texture of individuals’ stories and “big data” projects present yet another example of how patient empowerment has been appropriated in ways that may not always empower patients.

There will only be more big data sets and platforms to analyze as we move forward. Many questions remain: How do we deal with this “archival abundance” (Enoch and Bessette 638) and how do we know when we’ve reached data saturation? How can rhetoricians ethically engage with ambiguous big data sets? And what would it look like for MLD to be truly user-centered? As Brian McNely notes,

We have reached the paradox of big data: we now generate and collect so much data that the challenge is no longer only quantitative. Instead, the paradox of big data suggests the inverse: we need more situated, contextualized, qualitative studies of communication practices in an age of big data, not less. (28)

Accordingly, Pflugfelder (2013) argues that technical communicators should engage big data projects to “produce coherent and meaningful narratives” and “understand how meaning can be



made through and across various data sets” (19). The deidentified data from MLD is full of promising possibilities; however, these possibilities are only available to certain researchers. I attempted to gain researcher-level access to this data and was quickly denied. Initially, I emailed MLD to ask if they would be willing to provide me a complete copy of the first patient survey, since I was interested in looking at the rhetorical moves made in the questions. Lorraine Johnson, the CEO of LymeDisease.org, replied in an email that she agreed that the rhetoric of Lyme Disease was an “interesting and rich topic matter,” but that it was “unlikely” that she would give me a copy of the full survey because it is “confidential and proprietary.” And so the question remains: Is there an ethical way for me to use my insider access as a member of MLD to study the survey questions and/or data? Ultimately, Johnson’s response implies that MLD is most concerned about organizational matters, not helping patients nor advancing research.

It is easy to imagine how MLD would be different if it were created by and for patients with Lyme Disease. In Kirstin Arola’s book chapter, “Indigenous Interfaces,” she considers how Facebook would be different if it had been created “by and for” American Indian users (209). Drawing on interviews with twelve American Indian people, mostly from the Keweenaw Bay Indian Community Lake Superior Band of Chippewa Indians, Arola argues that a Facebook for American Indians would look different, perhaps using Native colors and “iconic image[s] like a feather or medicine wheel” (212). She also suggests that it would be used differently, in a way that “allows and encourages certain actions important to a group of people” (215).

Building on Arola’s findings, I believe that a truly user-centered version of MLD would include questions about diagnosis, treatment, and prognosis, but this information would be situated in a more accessible way. There would be large fonts with high-contrast colors to accommodate users with low vision. Users would be able to provide input about how the

platform should work, what kinds of research questions users should be asked, and more. The research questions would be expanded to account for the diverse skillsets that Lyme Disease patients must develop. For example, how did users figure out which doctors were “Lyme literate”? How did users learn which scholarly journals publish about Lyme Disease and which are open-access? How do users make sense of discussion board posts and make the most of their time on social media sites?

Since MLD does not address many of these questions, I sought answers from Lyme Disease patients, which I will explain in the following chapter.

## CHAPTER 4: CLINICAL LYME LITERACY

Scholars in rhetoric, composition, literacy studies, and the health sciences have long connected literacy to empowerment. Rhetoric, composition, and writing scholars have looked at how reading and writing practices develop, shift, and circulate across contexts. As scholars such as Deborah Brandt and Elspeth Stuckey have demonstrated, literacy is highly charged. It requires “sponsors” to “enable, support, teach, [and] model” it, and these sponsors may choose to empower some people with literacy knowledge while restricting access from others (Brandt 169). At its worst, literacy may be “a system of oppression that works against entire societies as well as against certain groups within given populations and against individual people” (Stuckey 64). Over time, scholars have forwarded many terms and theories of literacy: critical literacy, cultural literacy, gaming literacy, and more. Perhaps the most contested type is functional literacy, which is, as Stuart Selber argues in his foundational book, *Multiliteracies in a Digital Age*, the basis of all types of literacy (33). He argues that functional literacy is often “reduced to a simple nuts-and-bolts matter, to a fairly basic skill based on mastery and technique” (32). Selber agrees that functional literacy may cause harm and increase inequality when it is not “socially or rhetorically embedded” and focused on “expressions of grammar, style, and form, all of which could be learned in prescriptive and decontextualized ways” (32).

The most popular definitions of health literacy used in the health sciences are very similar to Selber’s definition of “functional literacy” (Selber 2004). A high level of health literacy is thought to empower patients. Thus, health literacy has long been a focus for adult educators and

English language learning experts, but it is now becoming a national focus because of its emphasis in the Affordable Care Act (ACA) and because studies suggest that it is integral to obtaining good healthcare and maintaining good health (Aldoory; Singleton; Taggart et al.). Accordingly, scholars from the health and medical sciences have identified populations that lack health literacy, provided health literacy instruction, developed print and e-health literacy assessments to measure health literacy, and researched connections between health literacy and overall health outcomes (Sørensen et al.). Although there is an assortment of commonly used, well-calibrated health literacy tests, such as eHEALS, Research Readiness Self-Assessment instrument (RRSA), and Digital Health Literacy Instrument (DHLI), few examine the critical nature of health literacy nor explore the complex contexts in which individuals develop or use their health literacy skills (Petric et al.; Stellefson et al.; van der Vaart and Drossaert).

My work builds on other critiques of health literacy, which argue that these definitions put the burden of responsibility on patients and deflect attention from structural vulnerabilities. To better understand the complex demands placed on patients, who must navigate print and digital health resources, I conducted interviews to bridge health sciences research on literacy with rhetorical research on literacy. In what follows, I provide context for my decision to interview Lyme Disease patients by outlining the biomedical definitions of health literacy alongside rhetorical definitions of literacy. Interviews can offer a window into the complex sociocultural process of developing health literacy, particularly for individuals with chronic health conditions. I will then draw on data from my interviews to define the concept of “Lyme Literacy,” a derivative of health literacy that emerged from the contested, chronic rhetorical situation in which Lyme Disease exists. My research suggests that there are two types of Lyme Literacy: what I call *Clinical Lyme Literacy*, which is an attunement of empirical, experiential,

and embodied knowledge that healthcare providers cultivate, and what I call *Patient Lyme Literacy*, which is a set of practices that Lyme Disease patients and their advocates develop in order to navigate contradictory claims about etiology, best practices, diagnosis, and treatment coming from doctors, researchers, other patients, and advocacy groups. In this chapter, I will focus on Clinical Lyme Literacy. I will address Patient Lyme Literacy in the Coda.

Since health literacy is most often a skill or capacity expected of patients, I will consider how complex, chronic conditions like Lyme Disease require healthcare providers to gain new types of literacy as well. Existing explanations of Clinical Lyme Literacy fixate on a healthcare provider's stance on Lyme Disease's etiology and treatment: whether or not Lyme Disease is a chronic condition and whether or not it requires long-term antibiotic treatment. Instead, I argue that Clinical Lyme Literacy is a social, material, and context-specific practice and that Clinically Lyme Literate providers leverage a combination of empirical scientific and medical knowledge, experiential knowledge from treating other Lyme Disease patients, and, at times, embodied knowledge, drawn from their personal experiences of suffering from Lyme Disease. I contend that the arduous process of becoming Lyme Literate—especially for healthcare providers—suggests that health literacy is not merely a kind of singular, simplistic, easily assessable, top-down type of functional literacy. To conclude, I will suggest possibilities for how this research contributes to the larger goals of rhetoric of health and medicine. Recent research suggests that “narrative” and “techne” are bridging terms for rhetoric, the medical and health humanities, and medicine itself (Edwell, Singer, and Jack). Extending this work, I will show how literacy also functions as a connector between rhetoric, writing studies, and biomedicine. Ultimately, this provides a helpful corrective to assumption that the only legitimate type of biomedical

knowledge is empirical; my interviews suggest that patients value multiple types of knowledge derived from multiple ways of knowing.

### **Connecting Functional Literacy with Health Literacy**

Multiple definitions of health literacy are circulating across biomedical communities. A 2012 review found that the three most cited definitions come from the American Medical Association (AMA), the Institute of Medicine (IM), and the World Health Organization (WHO) (Sørensen et al. 3). These definitions are necessarily broad but notable in that they frame health literacy as, first and foremost, a measurable skill set. The American Medical Association defines health literacy as a “constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health care environment.” Like Selber’s explanation of functional literacy, two key constructs in this definition are “basic reading and numerical tasks” and “function.” But what does a “basic” task entail, and what does it mean to “function”? Notably, the AMA imagines that health literacy is required “in the health care environment,” but what counts as the healthcare environment? Could it be a provider’s office—during a patient-provider clinical encounter—or also someone’s home in which Lyme Disease patients, for instance, must suffer through a Jarisch-Herxheimer reaction?<sup>2</sup> The AMA also notes that “[p]atients with adequate health literacy can read, understand, and act on health care information.” Two of these verbs— “read” and “understand”—are similarly vague and it is unclear what they might look like in practice.

---

<sup>2</sup> A Jarisch-Herxheimer reaction (often called “herxing”) is a flu-like response to antibiotics that are used to treat Lyme Disease. The symptoms are highly unpleasant but not fatal. Lyme Disease specialist believe that people with Lyme Disease experience this response because antibiotics cause the bacteria to die, causing a temporary form of sepsis. For this reason, many Lyme specialists prescribed antibiotics on a “pulsed” schedule in which individuals are treated for one week, not treated for another week, and so on to avoid the reaction and to prevent the body from toxicity.

The Institute of Medicine’s definition of health literacy is focused not only on skills, but also “[t]he degree to which” individuals have those skills. Beginning the definition with “[t]he degree to which” suggests that health literacy skills are measurable. Specifically, “the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.” Are individuals expected to “obtain” health information via pamphlets from their doctors’ offices or are they expected to conduct online research about their health conditions? What does it mean to “process” health information? What is involved in “understand[ing]” health information? Like functional literacy, the IM definition emphasizes “basic” literacy skills.

WHO, on the other hand, specifies that health literacy involves “cognitive and social skills,” which together “determine the motivation and ability of individuals to gain access to understand and use information in ways which promote and maintain good health.” In this definition, “motivation” is at the forefront and not merely implied, reinforcing that individuals are responsible for and should be held accountable for their own levels of health literacy. “Ability,” like “capacity” and “degree to which” in the IM definition, appears to be easily measurable and quantifiable. Like the AMA definition, WHO expects people to “understand” and “use” health information. But in this case, WHO intends for users to leverage it to “promote and maintain good health,” which are not easy tasks. Moreover, it does not take contingencies into account: food allergies, work schedules, limited income, and limited mobility, just to name a few.

At first glance, these definitions suggest that health literacy is a skills-based, easily measurable, and concretely taught practice, much like functional literacy. However, this is where the empowerment paradox emerges. What does it really look like, for example, when people “act

on healthcare information”? Should people know how biologic medications work to suppress the immune system, or should they just understand how to properly inject them? How can people go about “gain[ing] access” to health information and then apply it to “promote and maintain good health”? Who is responsible for teaching people what sources are “good” for finding health information or how to search for data about new clinical trials? According to these sources, health literacy means making significant physical, emotional, and intellectual shifts, which is no small feat for the average person, especially the average American who has one or more chronic illnesses (Maeve and Duggan, *The Diagnosis Difference* 3).

As a recent literature review from *Community Literacy Journal* reports, rhetoric and composition scholars are rarely involved as primary researchers in health literacy studies (Shaw et al. 52). Although rhetoricians of science, health, medicine, and disability have long investigated how rhetoric works in these fields, only Bivens et al. have focused specifically on health literacy despite these renewed exigences. In their work, Bivens et al. (2018) take a modality-based, “multisensory” approach to understanding health literacies and see them as “fundamentally shaped by the use of specific healthcare technologies” (n.p.). Most notably, they understand health literacy to be a “dynamic, engaged, participatory set of practices that enables and/or facilitates particular kinds of actions” (n.p.).

### **Framing “Clinical Lyme Literacy”**

“Lyme Literacy” is a key concept for Lyme Disease patients and healthcare providers. Over time, it has been examined in medical journal articles, on personal websites and social media platforms, and in advocacy group materials. Although health literacy is most often focused on assessing patients’ skills and knowledge, in the Lyme Disease community, many stakeholders are more concerned with healthcare providers’ health literacy—the training, experience, and knowledge that they leverage to care for Lyme Disease patients. Although most



definitions of health literacy focus on patients, most definitions of Lyme Literacy focus on providers. In Pamela Weintraub's *Cure Unknown: Inside the Lyme Epidemic*, arguably the most well-known illness memoir about Lyme Disease, she defines "Lyme Literacy" as "a term used by patients to describe the physicians who viewed their illness as a chronic persistent infection, thus treating them with antibiotics for longer periods of time" (56).

"Lyme Literacy," "Lyme Literate" and "Lyme Literate Medical Doctor" have appeared in medical literature since the early 2000s, but these terms tend to be viewed with suspicion. What appears to be the earliest, most concrete definition of "Lyme Literate" comes from an *Annals of Internal Medicine* article, aptly titled, "Misconceptions about Lyme Disease: Confusions Hiding Behind Ill-Chosen Terminology" (2002). I offer the author's full definition of "Lyme Literate" to elaborate on the rhetorical work it is doing, which will allow me to better explain the rhetorical work of "Lyme Literate" in other contexts. Here, Leonard H. Sigal, a rheumatologist and Lyme Disease expert, defines "Lyme Literate" as

A neologism, coined by lay support groups, that seems to identify clinicians subscribing to the empiricists' approach. "Listening to the patient" is not an attribute unique to clinicians in this group, just as all "Lyme literate" practitioners do not eschew the development of an appropriate and thorough differential diagnosis in order to make Lyme disease a "diagnosis of exclusion" (Sigal 417).

Much can be learned from this two-sentence definition, which invokes the three kinds of knowledge that I believe constitute Clinical Lyme Literacy: empirical knowledge, experiential knowledge, and embodied knowledge. However, it is clear from Sigal's definition that he singularly supports empirical knowledge when it comes to diagnosing and treating Lyme Disease, whereas my interview participants value providers who can triangulate all three types of

knowledge. To define “Lyme Literate” as, first and foremost, a neologism, situates it at best as an unscientific “attribute” (“neologism”). By invoking this language, Sigal is implying that the kind of experiential or embodied knowledge understood by “Lyme Literate” people is unempirical, and thus unworthy of investigation. Sigal then notes that the term “Lyme Literate” is “coined by lay support groups,” which by itself is not disapproving but reminds readers of the primacy of empirical knowledge, which comes out of clinical trials and peer-reviewed journals, instead of public discourses. His use of “seems,” a quasi-adverb, however, expresses doubt in this group’s work to “identify clinicians subscribing to the empiricists’ approach” (“seem, adj.”). His inclusion of “empiricism” reminds readers again of his—and the biomedical community’s—commitment to empirical knowledge.

Sigal also mentions the phenomenon of the “listening doctor,” or an individual who prioritizes a patient’s embodied knowledge. As Sigal notes, all healthcare providers can listen to patients, but here he is subtly arguing that “Lyme Literate” clinicians are rejecting empirical knowledge, which is the “gold standard” in the scientific community, in favor of merely “listening” to stories of illness, which are subjective and thus not considered authoritative scientific knowledge. Further, Sigal’s sentence patterning—“*not* an attribute...*not* eschew” (emphasis added)—suggests that although it is possible that “Lyme Literate” healthcare providers might invoke empirical knowledge to diagnose Lyme Disease, they are more likely to consider it a “diagnosis of exclusion,” or a diagnosis via embodied knowledge over empirical knowledge. Consequently, Sigal indicates that a diagnosis based on empirical knowledge would lead providers to “the development of an appropriate and thorough differential diagnosis,” meaning a diagnosis other than Lyme Disease. As this definition suggests, the discourse itself requires translation to resonate beyond empiricists.

### *Overview: Interview Participants*

The Lyme Disease patients who I interviewed did not conceive of Lyme Literacy in such a negative light. Instead, they specifically sought out Lyme Literate providers, who they often referred to as Lyme-Literate Medical Doctors (LLMDs) even if they never attended medical school, for the exact qualities that Sigal rhetorically shames: their choice to diagnose not simply using empirical data and their ability to listen. In this section, I provide a brief introduction to the interview participants who are featured in this chapter.

Abishai is a twenty-something musician who grew up in the U.S. northeast. He has had at least three acute Lyme Disease infections, which have been treated with antibiotics, dietary restrictions, ozone therapy, antimicrobials, cryotherapy, heat therapy, neural therapy, and fecal transplant. He now identifies as a Myalgia Encephalitis/Chronic Fatigue Syndrome patient based on his current symptoms.

Benjamin is a thirty-something university staff member who grew up in the U.S. northeast. After living in North Carolina for five years, he became ill with ambiguous symptoms and was eventually diagnosed with Lyme Disease after consulting with multiple specialists. Benjamin has been treated with a range of antibiotics, herbs, and alternative healthcare practices such as acupuncture.

Denise is a married mother of two and former physical education teacher who was diagnosed with Lyme Disease by an LLMD. She attributes her near-recovery to lifestyle changes, such as limiting gluten, dairy, and sugar; seeking balance; avoiding unpasteurized products; and maintaining daily routines.

Elvis is a middle-aged father and business man who believes that he was infected with Lyme Disease five years ago while on vacation in Massachusetts. He has been treated with oral

and intravenous antibiotics, antimicrobials, tranquilizers, and immune-suppressants, but he attributes his near-recovery to three years of bee venom therapy.

Emma is a self-identified Christian college student who has lived her entire life in central North Carolina. She was first diagnosed with Fibromyalgia and eventually with Lyme Disease. Her faith has been integral to her disease management, and she has sought out healthcare providers who share similar religious beliefs.

Ethan is a middle-aged man who has worked in the natural and computer sciences. Currently, he helps his wife care for their farm and is waiting to hear if he has been approved for disability benefits. He may have been infected with Lyme Disease multiple times, but most recently in 2006. His condition has been chronic for the last four years. He primarily suffers from fatigue, cognition, and issues with balance.

Hannah is a retail manager who was diagnosed with Lyme Disease eight years ago, during her senior year in college. She believes that she was infected when she worked at a camp in Pennsylvania. Hannah has been treated with multiple courses of oral antibiotics, and she maintains a strict exercise and sleep routine to remain well.

Heidi is a nurse who was diagnosed with Lyme Disease after she moved to North Carolina ten years ago from the U.S. northeast. She has been treated with short courses of antibiotics. Heidi remains actively ill with Chronic Lyme symptoms, suffering from severe neurological issues and fatigue.

Joe is a twenty-something retail manager, who grew up in the Great Lakes region. After a series of what was thought to be allergic reactions, Joe was diagnosed with idiopathic optic neuritis, and later, Lyme Disease. He is unable to see out of his left eye and continues to experience fatigue and cognitive issues.

Kelly is a distance educator for a large public university. She had been experiencing episodes of joint pain and fatigue since high school and was eventually diagnosed with Lyme Disease. She sees multiple doctors, but she primarily relies on a biotoxin specialist, who treats her symptoms with herbal and other holistic treatments.

Liam is a middle-aged, stay-at-home father who has been experiencing episodes of fatigue, musculoskeletal pain, and neurological issues since he was in college. He has experimented with a range of antibiotic and holistic treatments.

Megan is a middle-aged office manager who recently finished her bachelor's degree. After suffering from unexplained, escalating fatigue and arthritis for years, she was diagnosed with Lyme Disease six years ago. Megan has been treated with two brief courses of oral antibiotics.

Nicole is a former elementary school teacher who moved from the west coast to North Carolina to live with her parents after her illness became severe. She has a Chronic Lyme diagnosis and sees a range of traditional and holistic healthcare providers to treat her symptoms.

Olivia is a university staff member who grew up in the U.S. northeast and recently moved to North Carolina. She has had at least three acute Lyme Disease infections and first became ill when she was twelve years old. Through the years, she has been treated with oral and intravenous antibiotics. She currently manages her symptoms through dietary restrictions.

Sophia is a young college student who had to take a leave of absence from her university in western North Carolina to pursue treatment. She primarily suffers from depression and anxiety, which emerged as a result of a Lyme Disease infection. Sophia has pursued a range of treatments but relies primarily on antidepressants and anti-anxiety medications to manage her symptoms.

Participants provided additional nuance about the identification of LLMDs as well. As they explained, there are at least two types of LLMDs: 1) providers who are “out” and market themselves as Lyme specialists, and 2) providers who attract patients on a referral basis.<sup>3</sup> Providers who are “out” may claim that they are Lyme Literate or that they are an LLMD, using this language on their clinical websites and in interviews with news outlets. Other providers, however, choose not to advertise that they treat Lyme Disease to avoid legal trouble. In addition to intense public and professional scrutiny, popular “out” Lyme Literate healthcare providers such as Dr. Joseph Jemsek have been charged and punished by various medical boards for inappropriately diagnosing and treating patients. In this case, patients often identify “closeted” LLMDs using their personal networks and circulate their names in Lyme Disease communities.

Study participants had strong opinions about seeking out “Lyme Literate” healthcare providers and most had consulted with at least one during the course of their illness. Broadly, there were five reasons participants frequently cited for enlisting an LLMD: 1) they would not have to spend the entire appointment defining and explaining Lyme Disease; 2) the provider was open to the idea of chronic Lyme; 3) the provider might be more open to a combination of holistic and western treatments; 4) the provider might have practicum experience with treating Lyme Disease patients, thus increasing their chance of success at treating these people, and 5) the provider might have additional education about Lyme Disease, ranging from continuing education courses and treating other diseases that are thought to be like Lyme Disease, such as HIV/AIDS. Abishai, a musician in his mid-twenties, explained that patients “don’t have to explain the history of things” nor educate LLMDs about Lyme Disease, which is one of the main

---

<sup>3</sup> It is also important to note that nothing systematizes LLMDs nor their care. They range in specialization, treat Lyme Disease using different approaches and philosophies, and undertake varying types and amounts of continuing education courses.

reasons why participants sought them out. In Ethan’s words, Lyme disease, among other chronic illnesses, “requires you to actually be a doctor and actually look at somebody symptomatically,” suggesting that traditional kinds of literacy that are cultivated in medical school, such as how to read test results and scans must be coupled with the ability to read patients and understand their perspectives.

*Empirical: “realizing our bodies are whole things”*

The quotation in the subtitle— “realizing our bodies are whole things”—comes from Nicole, an interview participant, and signals how LLMDs’ engage their traditional academic training in their work with treating Lyme Disease patients. On one hand, healthcare providers must, first and foremost, “do no harm,” which requires them to consider how the body’s multiple systems work together and affect one another. However, providers also must reconcile this with the limited formal education they have about Lyme Disease. If providers were to use these educational materials alone, or perhaps even coupled with the CDC guidelines—which as many participants argued, were created to rule Lyme disease *in* and not *out*—they would miss the 10-50% of Lyme Disease cases in which participants do not present with a traditional bull’s-eye rash and have a wide range of seemingly random symptoms (Rebman et al.). Even for infectious disease specialists and rheumatologists, providers who specialize in fields in which they are more likely to encounter Lyme Disease, diagnosis and treatment are tricky. For Lyme patients, this unfolds in multiple ways. For one, many patients spend a lot of time being treated for their symptoms because many providers don’t consider that their symptoms—which are often very diverse and arise intermittently—have the same etiology. As Eileen remarked, she needed a doctor who treated her as a “whole person” in order to recover; for her, this meant seeking out an integrative medicine provider.

Study participants who were born and raised in North Carolina were particularly concerned that their doctors were not trained to identify, diagnose, or treat Lyme Disease and other tick-borne illnesses due to geographic constraints. At the beginning of their journeys, most participants did not realize how difficult it would be to locate and maintain a relationship with a Lyme literate provider. Many participants noted that their Lyme Disease specialists are in function in a state of perpetual precarity. They are committed to treating Lyme Disease patients by whatever means necessary, but they are concerned about punishment from the North Carolina Medical Board. For instance, Ethan mentioned that his doctor, a primary care provider who became a Lyme specialist, asked him “Will you testify at my hearing?” The provider is convinced that the North Carolina medical board will scrutinize her practice, which focuses exclusively on Lyme Disease patients, and disapprove of her treatment protocols. If complaints are filed against her, the board could easily revoke her medical license. To limit oversight, this provider stopped taking insurance. Previously, Ethan had heard about problems with finding and maintaining providers “anecdotally,” but he thought it “seemed kind of hysterical” and “along the lines of conspiracy theory.” Through his own Lyme Disease diagnosis and continued conversations with his doctor, he concluded that the situation was more critical than he realized.

Similarly, Sophia, a college student who was enrolled at a large university in western North Carolina, remarked that Lyme Disease is scary because “no doctors know anything about it, or like in North Carolina, at least.” To her, “your doctor’s supposed to be your, like, the person you go to for like anything that’s wrong with you and they’re supposed to like magically have an answer and it’s like, people just didn’t have answers for me.” Sophia argued that “most doctors in North Carolina are not” Lyme Literate, and that’s part of the reason why she had to leave her rural college town because “no one in [town] knows anything about Lyme Disease.”



Although her college town in the western North Carolina mountains has an increasing tick population, the town “doesn’t have the same resources” as larger towns; it was hard for her to get regular specialists appointments, such as psychiatry and dermatology, so it was “easier” to move back to her hometown, where three renowned universities are located. Even when she sought care from doctors in her hometown, however, Sophia was frustrated that most doctors treated her symptoms instead of seeking out the greater cause. She mimics this in the way she manages her condition by, for instance, taking Xanax to treat her anxiety, noting “I don’t really treat my symptoms as if they’re all from one thing because no doctor treats it like that.” Having Lyme Disease and not making any headway with western medicine doctors, she turned toward holistic practices.

Beyond geographic influence, my participants were also concerned that clinical specializations sometimes inhibited them from getting care. In turn, many rely on primary care providers and integrative healthcare providers to diagnose and treat Lyme Disease. As Ethan noted, “the problem you run into is that a GP is more likely to be an active listener and such but not have the understanding. An infectious disease specialist may get it, but they also tend to be far less likely to listen to anyone else’s opinion.” Accordingly, Emma, a college student, credits her current doctor—the same integrative specialist that Nicole sees—for “really listen[ing] and think[ing] about me,” investigating why a 20-year old woman was so sick with so many disparate symptoms. She believes that because he looked at her holistically, examining her stomach pain, leg issues, and joint pain in addition to asking about her diet and lifestyle, he was able to make an accurate diagnosis. Like Nicole, Emma noted that, when she saw a GI specialist, that specialist didn’t care about her muscle pain. Based on her experiences, Emma argued that

specialists were too focused on their specialties, and to effectively treat Lyme Disease, clinicians need to put all of their specialties together.

Hannah, a college-aged woman who left school due to illness, made an even more radical argument: that the specialists she saw were so focused on their specializations that they misdiagnosed her. In her opinion, to effectively treat Lyme Disease, which impacts so many different areas of the body, doctors must work as detectives, knowing that “there’s so much we don’t know.” Hannah believes that doctors are constrained by their reward mechanisms and want to pursue certainty as much as possible. Moreover, her experiences suggest that “doctors are punished for not being certain” about diagnoses. Since doctors learn very little about Lyme Disease in medical school, and since most are taught to abide by the CDC treatment guidelines, their academic education can get in the way of them prescribing effective treatments. Paradoxically, Hannah asserts that her health only improved after a Lyme doctor treated her as if she had a CDC-approved infection even though she did not.

Many people who are eventually diagnosed with Lyme Disease have been ill for years, and they blame that—at least in part—on doctors, particularly those in certain geographic areas, who don’t know about tick-borne diseases. Nicole attributes her long periods of illness to the fact that “no one ever, ever mentioned Lyme Disease ever.” Part of the reason for that might have been her location: California is not—at least according to the CDC—a hotbed for tick-borne illness, so it may not have occurred to her doctors that that was ultimately the root cause of her illness.

Beginning in young adulthood, Nicole experienced cycles of chronic illnesses such as anorexia and seemingly related mood disorders, and it was only many years later that she realized that some of her psychiatric symptoms could be attributed to Lyme Disease. After years

of suffering, Nicole's mom referred her to an integrative medicine practice in the Piedmont region of North Carolina, which she says "changed the course of [her] history." Nicole extolled his virtues, assuring me that she was not trying to "make him a god" while discussing how she has been transformed under his care. First and foremost, Nicole emphasizes that her Lyme doctor is "a full-out MD" and can "do anything he needs to as a doctor but he realizes our body is a whole thing." This approach works especially well for Nicole, who for years, sought care from renowned specialists in multiple states. Instead of assessing all of her issues collectively, Nicole asserted, they were "just prescribing medications upon medications" and "doing what they know to do"; retrospectively, she realized that these clinicians were "out of the loop" regarding tick-borne diseases in general, so the diagnosis may never have occurred to them.

Nicole continues to consult with other specialists in addition to her Lyme doctor, since he primarily prescribes plant-based and/or vitamin treatments and she still benefits from certain pharmaceuticals like Xanax. As such, Nicole argued that many specialists in particular were not only unfamiliar with Lyme Disease but also so focused on their area of expertise that they failed to understand the complexity of her condition. Moreover, these specialists were unable to conceptualize how her seemingly disparate symptoms were connected. However, Nicole was eager to share a surprising anecdote about seeing a "big wig," "reputable" psychiatrist in the Piedmont region of North Carolina. When Nicole first started seeing the psychiatrist and told him about her Lyme Disease diagnosis and antibiotic treatment regimen, she said that he kept repeating something to the effect of, "Well, Lyme Disease is a very controversial thing." Nicole noted that she could understand his initial concern, since "testing is a little wonky." But despite his initial hesitation to discuss Lyme Disease, the psychiatrist reached out to Nicole's integrative medicine specialist, who was managing her Lyme Disease, to learn more about it. For Nicole,

this was an exciting turn of events in her treatment process. Nicole's experiences with Lyme Disease have affirmed her belief in the mind-body connection; in her work as an educator, Nicole teaches students that "our bodies are whole things" that are intimately connected to our emotions. Nicole credits her Lyme doctor's training as an integrative specialist with preparing him to recognize how Lyme Disease affects multiple systems and should be treated holistically, and she credits her psychiatrist for wanting to learn more about it. Nicole hopes that more doctors will reach out to one another and learn more about Lyme Disease, since that would improve care for patients like her.

Similarly, Megan, a project manager and mother in her early 40s, shared a representative anecdote about the difference between LLMDs and non-LLMDs. Although Megan's primary care provider willingly tested her for Lyme Disease and treated her twice per the CDC guidelines, Megan recalled a conversation in which she asked her PCP, "If this doesn't work, what are we gonna do?" and the doctor responded, "Well, this is all we're gonna do." In this case, the doctor's commitment to empirical and purely evidence-based medicine constrained her from addressing Megan's continued suffering. This prompted Megan to seek care from an LLMD who "sees this all the time" because, in her words, "If I go back to [my PCP], what is it gonna do?" Megan noted that LLMDs "don't always follow what's in the book" and "look outside" the traditional guidelines, potentially eschewing "whatever they're told from a medical standpoint." Importantly, these providers "use their experience as well" to make diagnoses and create treatment plans. As Megan's example demonstrates, merely knowing enough about Lyme Disease to test for it is not enough. Accordingly, LLMDs do not merely know about Lyme Disease. Instead, as I will discuss in the following sections, they draw on their embodied and

experiential knowledge to treat it via alternative means, which sometimes go against medical board regulations.

*Experiential: “[H]e sat and he listened to everything I said”*

With a condition as complex and controversial as Lyme Disease, experiential knowledge is integral to successfully diagnosing and treating it. As Megan lamented, the slow nature of scholarly publishing and lack of research funding and attention to Lyme Disease means that doctors are forced to rely on their experiences with diagnosing and treating patients in addition to data from clinical trials. In effect, as Liam, a forty-two-year-old stay-at-home father, noted, it’s like the doctor is “basically conducting a scientific, you know, experiment, sort of on you.” Experiments do not come with guarantees. As Megan noted, she was “taking a risk” when she allowed her Lyme doctor to treat her, but she realizes that scientists are now publishing papers in peer-reviewed journals about her controversial treatment regimen. She feels satisfied knowing that her doctor’s controversial methods were justified and is now confident that her doctor did “the right thing.”

Most of my participants gauged a provider’s experiential knowledge by evaluating their “listening” skills, as Nicole does in the quotation that begins this section. For some, the “listening” piece was literal. Abishai noted that Lyme Literate doctors—though they may have some faults—do “listen” to patients tell their winding, lengthy illness stories. Since many people with Chronic Lyme report having cognitive problems, the process of sitting and telling the illness narrative can be challenging. For example, Nicole emphasized twice that her Lyme doctor “sat—just like you’re [meaning me, the researcher] doing—he sat and listened to everything I said.” Rhetorically, Nicole is drawing a parallel between our two-hour phone interview and a typical doctor’s appointment. Generally, doctor’s appointments are short, so providers must quickly

identify problems and focus on specific outcomes. However, Nicole's Lyme doctor spent time analyzing her health history and illness story instead of rushing to reach a diagnosis. Although Nicole used an eight-page long summary of medical notes as a guide, she found herself "repeating" symptoms that recurred, such as "deathly exhaustion," among other issues—partially due to the windiness of her journey, and partially due to the difficulty of telling a linear narrative during a clinical encounter. Nicole suggested that most providers would not have the time, patience, or desire to piece together her extensive health history; the choice and ability to do so was unique to her Lyme doctor.

Nicole's difficulties with telling a clear and concise illness narrative were not uncommon. Some study participants had difficulty recounting their illness narratives during our interview. A number of them brought their medical records with them for reference since, in Heidi's terms, "you never know if you're really gonna get your mind back" after Lyme episodes. And significantly, many participants made self-reflexive comments about "wandering," or in Heidi's terms, "rambling." For the average healthcare provider, who is trained to call a zebra a zebra and make a diagnosis based on causation, the combination of recurring, ambiguous symptoms and the inability to tell a linear narrative would be a very frustrating process, quickly eating through the short appointment slot.

Participants also recounted how healthcare providers may try to make it appear that they are listening, but patients may still feel like they are not being heard. Ethan discussed how—due to the way Lyme disease "mimics but also masks" health problems—he is used to not being heard and that he often depends on his wife, his "medical advocate" to be "aggressive" with clinicians. According to Ethan, his wife approaches providers with a "prove me wrong attitude," which was perhaps inspired by her search for treatment for a rare chronic condition that was

diagnosed when she was in her 20s. Similarly, “listening” is a temporal experience and some healthcare providers may start and stop listening to patients at different times. Megan recounted that, initially, her doctor listened to her and tested her for Lyme Disease, but after she continued complaining of symptoms and didn’t seem to be getting better, Megan decided that she “might as well” go to a Lyme specialist, since her PCP had stopped hearing her and thus stopped reacting to her reports.

For others, the “listening” piece is a more metaphorical or rhetorical practice, although it still produces particular social actions. Abishai told a story about one of the most successful experiences he’d had with a doctor, in which she was knowledgeable but respected his knowledge, seemed “open,” and wanted to work with him to collaborate on an effective treatment plan. In this case, the listening was part of a deliberate, noncompetitive exchange in which the doctor enlisted Abishai’s help to figure out what might help him get well. Similarly, Elvis, a middle-aged business executive, noted that each of his LLMDs “listened” to him in contrast to other doctors (both PCPs and specialists), who had already made up their minds. By “listening,” Elvis meant genuinely engaging him about his complaints, spending time connecting his symptoms, and willfully dedicating a large chunk of his appointment time to examining his complex medical history. Because Elvis valued this kind of interaction so much, he waited six months to see a particular LLMD many states away. For Liam, listening meant that “they’re not gonna...throw out...the possibility that you have an infectious disease of, you know, let’s say tick-borne origin.” More specifically, “the doctor is willing to consider alternative hypotheses” if you “don’t fit into one of the [hypothetical] boxes they created.” Liam expects a Lyme Literate doctor to be “literate as far as what types of drugs and how long and intervals” for Lyme Disease

treatment, but more broadly that they “[do] the research themselves,” that they “aren’t afraid to be challenged,” and that they’re willing to consider patients’ ideas and perspectives.

“Listening” can also be a rhetorical means of talking back to healthcare providers. Olivia, a university staff member in her mid-twenties, described a conversation she had with her doctor about making dietary changes to kill off Lyme bacteria. After the doctor proposed a strict no-carbohydrate diet, Olivia remembered asserting herself to make her needs clear: “Listen here. You take my cookies and my ice-cream, you’re gonna leave my bread! And you’re gonna leave my fruit!” In this case, Olivia used the word “listen” in an imperative form to draw attention to her needs and the rhetorical process of negotiating treatment plans. In the context of the clinical encounter, there are two primary listening transactions: the patient sharing their complaint and the doctor listening, and based on the complaint, the patient listening to the doctor’s response and recommendations. Instead, Olivia reframed the concept of listening to redirect the guidance from her doctor and persuade him to provide an alternative solution, which as I will explore in the coda, is a difficult process due to the extreme power differentials between healthcare providers and their patients.

*Embodied: “Why don’t you step in my body and then you’ll have a different thought?”*

As Nicole notes above, participants generally trusted providers who had been diagnosed with Lyme Disease or had a close friend or family member suffer from the condition. I delineate these “embodied experiences” because participants sacrificed time and quality care to see providers with this particular type of knowledge. Talking about her LLMD who also suffers from Lyme Disease, Megan argued, “by her experiencing it herself, she knew what other people were goin’ through. So...I felt like...when I talked to her, she was relating to everything I was sayin’ because she had either had heard it or she had experienced it herself.” For Megan, this was more



important than “the [empirical knowledge] training to know how to treat it based on the symptoms I was having.” As Megan explained, doctors often do not have formal training about diagnosing Lyme Disease beyond the CDC guidelines, so other doctors might have dismissed her negative Lyme Disease test and ambiguous symptoms. Megan suggests that her doctor’s ingenuity was directly connected to the doctor’s own experience with suffering from chronic, cryptic symptoms and misdiagnosis. (But paradoxically, perhaps Megan’s doctor’s empirical training is what prompted her to acknowledge but ignore the CDC guidelines).

Likewise, Liam suggested that experiencing illness—in themselves or in a close family member—might even inspire practitioners to become Lyme Literate. He said it was “quite amazing to see” a doctor who herself was “being challenged” by Lyme Disease. He was impressed by the provider’s efforts, noting that they were “trying to help as many people as [possible].” He believes that patients may be willing to accommodate doctors who themselves have Lyme disease because

one, they’re going to be personally knowledgeable of um, especially if it’s specifically tick-borne illness but any sort of chronic condition, of that type of life, as well as empathy...cause that’s something that some doctors lack in their bedside manner. And that’s not something that maybe can be taught. I mean, that’s just something somebody has or doesn’t have. But certainly, suffering from the same illness can give you new insight, so maybe it can’t be taught but it can be gained through experience.

Here, Liam suggests that experiences of illness beget empathy. The connections between patient-doctor relationships, empathy, and health outcomes are widely debated. A recent literature review suggests that that reading literature, analyzing art, role playing, and writing reflectively may increase healthcare providers’ empathy (Kelm et al.). More research is necessary to discern

if Liam's suggestion is generalizable. In any case, since Lyme patients are often met with disdain and disbelief, and as Liam notes, they may be willing to tolerate ineffective care if the provider appears empathetic.

Relatedly, participants argued that providers who had Lyme Disease—and were forced to rethink their empirical and experiential training in the process of diagnosis and treatment—seemed more likely to trust patients' embodied knowledge. Far beyond alphabetic literacy or general knowledge about Lyme Disease, this is a special kind of knowing. As Ethan noted, “there's this tendency to assume that the patient doesn't know their own body, and I mean, it is lessening over time, but you know it's still at the point where I think an advocate is necessary, especially in the cases of chronic illnesses.” Similarly, Emma noted that “you don't get it until you get it”—a sort-of aphorism to explain the lack of knowledge around Lyme Disease. She noted that it was difficult—particularly as a young person—for her friends to understand what she was going through since most of them couldn't relate to it. For patients like Emma, perhaps this is why they place a high value on providers who themselves have been sick: they can only appreciate the burden once it has weighed them down. Lucy lamented that Lyme Disease “lives in her but pays no rent;” healthcare providers who have personal experience with the disease can especially appreciate its power.

On the other hand, having Lyme Disease does not prevent LLMDs from having other flaws. Joe asserted that his ill LLMD was not punctual and did not appear to remember him or his case. This is an interesting contradiction because fatigue and brain fog, along with memory and other neurological issues, are hallmark symptoms of Chronic Lyme, and most of my participants asserted that this was the worst part of being ill. And yet because they are so ill, they need providers who do have the cognitive and physical capacity to treat them and consider their

cases appropriately. Joe stopped seeing this LLMD for this reason. Kelly had a similar experience with the same LLMD. Although her LLMD was “very knowledgeable” and “very kind,” Kelly noted that she’s “not the most reliable” nor “reachable,” which makes it impossible for patients with urgent needs to receive prompt attention and care. However, her ill LLMD was particularly helpful as she was getting diagnosed, so she continues to see her because of that allegiance. On a different note, Heidi suggested that an ill LLMD’s experiences may constrain how they think Lyme should best be treated. Heidi is a nurse who saw an ill LLMD for a time, and she continued seeing her even though she cancelled appointments. However, Heidi was frustrated when the ill LLMD insisted that she begin IV antibiotics and get a PICC line. As a nurse, Heidi is active all day, coordinating with patients and physicians, and because taking antibiotics causes her to have a Jarisch–Herxheimer reaction, she cannot work while receiving that treatment. Because Heidi has already missed so much work due to illness and is afraid of losing her job because of it, she cannot risk undergoing the recommended treatment. Heidi felt frustrated that her ill LLMD was unable to recommend anything besides IV treatment, because even if it had the potential to help, it would not work with her circumstances.

### **Conclusion**

In a place like North Carolina, where Lyme Disease is not thought to be a public health crisis, my participant Megan told me, “Since it can be difficult to find doctors who treat Lyme in the first place, You have to keep pushin’ when you know yourself and there’s somethin’ wrong.” She argued Lyme patients must “trust [their] instincts” since “just because you go to four doctors and they tell you, well, no, I think it’s arthritis or something else, it doesn’t mean that you *don’t* have Lyme.” Many of participants told similar stories. Accordingly, participants argued that Lyme patients cannot depend on doctors or the biomedical community to be “up to speed” and

cannot blindly follow doctors, telling themselves, in Megan's words, "Okay, well the doctor said so, well that's the way it must be."

The lack of providers, the consternation around specialization, and the challenges of accessing adequate training have created a culture in which LLMDs can leverage their positions as board-certified medical doctors to seduce patients into undergoing radical treatments, for which they charge patients extraordinary non-reimbursable fees. As Abishai noted, this dynamic is part of the empowerment paradox. He argued that LLMDs are prescribing treatments that are "reckless and dangerous" without much regulation, and there are few means for holding these providers accountable. As he put it, patients are doomed even if they find ways to report iniquitous providers because doing so does not help them get better. To Abishai, LLMDs who expect patients to take enormous quantities of antibiotics, effectively "destroying different parts of the body," are using their licensure irresponsibly. But since there are so few LLMDs available, and since many providers do not acknowledge nor address Chronic Lyme, patients have no choice but to turn to imprudent LLMDs for care. In Abishai's words, since so many other doctors "brush off Lyme" and say that patients are "making things up" since they look "perfectly healthy," patients are forced to turn to LLMDs even if they are offering risky treatments. Abishai notes that "some Lyme Literate doctors are more aware of what's going on" and "understand the disease...but that doesn't mean that they know how to treat it."

Similarly, for some time, Denise was treated by a well-known LLMD, but she pursued other providers because he "doesn't see the price tag" and may be "money hungry" and "hot head[ed]," so quick to defend himself that he loses sight of her best interests. These characteristics stem from the rhetorical situation in which the doctor practices: since his services

are rare and thus in high demand, he is able to charge patients out-of-pocket for radical and potentially harmful treatments.

This chapter demonstrates that health literacy does not merely involve patients' acquisition of empirical scientific knowledge. Instead, health literacy is an important skillset for healthcare providers. Although the biomedical community prioritizes empirical knowledge, my study suggests that patients also value embodied and experiential knowledge and seek out doctors who have significant experience treating patients with Lyme Disease. At times, patients will continue seeking care from a clinician—even if s/he is not providing high quality care—because the physician themselves has experienced Lyme Disease and brings that perspective to the clinical encounter. Although my work focuses on Lyme Disease, future research might consider how other chronic disease healthcare providers have acquired multiple types of literacy to effectively treat patients.

## **CODA**

If Christa Teston is examining what she calls the biomedical backstage, I am studying its opposite: the patient decision-making backstage, how patients are “dwelling with disease” (175). Like anthropologist Annemarie Mol, I am trying to “disentangle the practicalities” and examine the “intricacies of daily practices” of living with Lyme Disease (60). What stories do people tell about Lyme Disease? How do people’s experiences shape their motivations, interests, and ability to be persuaded by information? What resources do people think are authoritative and why? How do Lyme Disease patients negotiate empirical, experiential, and embodied knowledge? As patients straddle the so-called kingdom of the sick (Sontag; Edwards), how do they develop health literacy? My project takes on the patient perspective to examine how various backstage sites—specifically digital ones—are informing patients’ senses of authority and contributing to their decision-making. Although there are many potential sites to examine, I have selected two that, I believe, have risen out of the specific context of Lyme Disease rather than the more general context of being ill and suffering from an ambiguous chronic illness: healthcare providers’ clinical websites and health information sharing websites. Making this distinction is helpful to illuminate the specific rhetorical work that is being done around Lyme Disease.

## **Future Research**

When I began this project, I was invested in understanding how Lyme Disease patients mined and vetted the extraordinary amount of conflicting information about Lyme Disease on the Internet. I imagined that people had to come up with a process for deciding what to believe

and what not to believe, since there are many perspectives about the effectiveness of Lyme Disease testing, which treatments are most effective, if the condition is chronic or curable, and if Lyme Disease is acute but makes the body vulnerable to other autoimmune conditions, thus evolving into something else entirely. Within provider and patient communities, there is also contention about which kinds of dietary restrictions, holistic therapies, antibiotics, and antibiotic use patterns (sometimes called “pulsing”) are most effective. By reporting on individuals with Lyme Disease about what health literacy means to them, what skills they have acquired to become health literate, and what resources they seek when they have health questions, my study yields valuable information about how people develop health literacy.

Preliminary data analysis from the interviews suggests that Lyme Disease patients have developed a range of reading and communication strategies in pursuit of better health. Future research would further investigate what I call Patient Lyme Literacy, which seems to involve three components: 1) cultivating social networks; 2) inventing information-sorting practices; and 3) developing alternative testing protocols.

### *Cultivating Social Networks*

Lyme Disease patients’ ideas about diagnosing and treating Lyme Disease shifted radically based on their social networks. For the Lyme patients in my study, social networks primarily involved immediate family members, friends, local community members, support group members, and online connections. Because of the sheer variety and disparate nature of online health information, patients drew on other people’s experiences of having Lyme Disease as evidence for pursuing particular treatment paths. As Liam noted, “people go through phases” in their research—searching for a diagnosis, confirming diverse symptoms, learning about new treatments, hearing about the progress and prognosis of different treatments, maintenance, and

more. In the initial phases of illness, most participants looked to friends and family members. For some participants, this meant sharing their stories with their local communities. Joe, for example, started the interview by noting that “HIPPA doesn’t matter” because everyone knows about his diagnosis of Lyme Disease. Although I asked him to sign a consent form and agree to anonymity, he claimed it was unnecessary. Similarly, Sophia argued that secrecy around Lyme Disease broadens its impact, and she “doesn’t understand why it needs to be a secret because it’s just like any other illness that anyone else has.” Even though Sophia was debilitated by mental health issues related to Lyme Disease, which can be stigmatizing, she noted, “Everyone has issues, so why is it such a secret?”

Friends and family members changed the course of participants’ treatment. Joe noted that he was hesitant to get a PICC line,<sup>4</sup> but once he learned that an old friend’s father worked at the PICC line company, he got one without hesitation. Previously, Joe had been wary of PICC lines due to the potentially severe side-effects of intravenous antibiotics. However, his personal connection immediately changed his outlook. Relatedly, Olivia’s uncle was a pediatric oncologist at a local hospital, and he connected her with the neurologist who helped her get diagnosed with Lyme Disease. At the same time, Olivia knew a number of students in her high school who had Lyme Disease, and her neighbor ultimately referred her to one doctor who took over her care. Likewise, when Kelly first became ill, she contacted one of her brother’s former colleagues who had been diagnosed with Lyme Disease. They exchanged potential doctor’s names, and the colleague recommended that Kelly consult with a biotoxin specialist. A researcher by training, Kelly notes it was “one of the less thought-through, less researched things

---

<sup>4</sup> A PICC line is a tube inserted under the skin to more efficiently distribute medication. Lyme Disease patients who are critically ill may receive PICC lines with antibiotics and other treatments. For more information, see the Columbia University Irving Medical Center page on Lyme Disease treatment options: <https://www.columbia-lyme.org/treatment-options>.



I've ever done." But Kelly's risk paid off: the biotoxin specialist ran a unique set of bloodwork tests that "looked at some other things that nobody had ever thought to look at before," which eventually helped Kelly achieve a degree of homeostasis.

Local and community connections were also important to my participants. Abishai talked about how he relies on his support group, which meets regularly in-person and has a robust text messaging chain. In Abishai's experience, desperation is more powerful than science. Thus far, he has experimented with an incredible range of treatments, including ozone therapy, anti-microbial therapy, cryotherapy, a fecal transplant, IV therapy, and treatment at a specialized Lyme Disease clinic in Germany. When he begins researching a new treatment or comes upon a medical question, he immediately texts his support group for advice.

However, my participants noted that their in-person social networks were circumscribed by illness. Although she sought out friends and other support networks at certain times, Lucy noted that some of her social isolation was self-imposed. Besides not feeling well overall, she was embarrassed that she forgot people's names and got lost in trains of thought in the middle of sentences. She felt "very self-conscious" about these issues and, in turn, spent a lot of time alone. Heidi, a nurse, worried that her hospital colleagues did not understand Lyme Disease, and she stopped socializing with them so that she would not have to discuss her symptoms. Heidi also discussed the sociality of eating and lamented that the specialized diets she used to control her Lyme Disease symptoms isolated her from friends and family.

In turn, many participants had looked through discussion boards and created extended social networks. Often, they engaged with online Lyme Disease support groups early on, and as their health changed, transitioned to other illness-specific groups, such as ME/CFS, and sometimes to tool-specific groups. For instance, Elvis claimed that the bee venom therapy groups

on Facebook are different from Lyme Disease groups because they don't "turn to negative town" and are instead hosting "sophisticated discussions" by "intellectually invested people." Many participants noted that online discussion boards and groups were depressing, which emerged as yet another aspect of the empowerment paradox: ill people do not have the emotional energy necessary for engaging with other people's stories of suffering, but they are forced to mine these stories for treatment ideas and provider recommendations. Additionally, my participants were forced to make sense of the competing insights offered by online discussion boards—yet another way in which they are held responsible for their healing. Heidi described some discussion board participants as "wacked out" due to the lack of recognition of Lyme Disease and their increasing desperation. Joe noted that a lot of people who post about their experiences with Lyme Disease blame every new symptom on it, even though they could simply be experiencing the common cold. For this reason, Benjamin and other participants eschew discussion boards entirely, but they acknowledge that in doing so, they maybe missing out on vital information.

#### *Inventing Information-Sorting Practices*

As part of the empowerment paradox, patients are urged to conduct research and find solutions for Lyme Disease. Although participants hoped to alleviate or cure Lyme Disease by doing their own research, their cognitive issues limited their ability to do so. Ethan, for instance, sometimes reads abstracts of scientific journal articles to learn more about Lyme Disease. However, he primarily relies on his personal connections to learn about new developments in diagnosis and treatment due to his frequent "cognitive dropouts." When Ethan has a Lyme flare, he has difficulty navigating between paragraphs and his comprehension is "unpredictable." Thus, he has deepened his relationships with his expert friends, relying on them to provide advice at critical junctures. Similarly, Heidi attempted to read *Cure Unknown*, but she experienced

cognitive problems from her Lyme Disease and could not finish it. Previously, Heidi read medical literature about Lyme Disease, but her “comprehension level fluctuates” and does not allow her to do so on a regular basis. Overall, as Kelly argued, patients who do not have medical training struggle to read professional scientific and medical genres, but Lyme Disease patients struggle even more because of their condition:

You’re faced with a lot of conflicting information. It is a disease with a lot of controversy surrounding it. And so you’re kind of...um... if you’re not a medical expert...you’re forced, to some degree, to kind of just choose who you’re going to trust and go with it because you’re gonna get all different kinds of opinions. And you’re gonna have to face a lot of people not agreeing with you. You’re gonna have to face a lot of people—quite honestly—thinking you’re crazy. And so, you know, it’s tough. So you’re just gonna have to ultimately decide what you’re gonna go with—what you think is best. You’re gonna have people saying it’s not the right thing, but you do it.

Most participants began researching Lyme Disease by reading discussion boards, which is a physically and emotionally-daunting practice. Some participants established specific protocols for mining discussion boards and other qualitative data on the internet. Joe’s tactic for processing a lot of information, particularly on internet discussion boards, was to systematically go through people’s stories and attempt to deduce patterns about what worked. When he first became ill, he and his parents did a lot of Google searching, particularly looking up medical and/or scientific terms with which they were unfamiliar. They printed and stored all of the materials they found in a box, and as he read them, Joe looked up and wrote down definitions for terms. Joe noted that he relied on his parents to do a lot of research when he first became ill because he was too ill to sort through and make sense of all of the available information.

Relatedly, Elvis navigates the digital deluge by parsing through discussion boards (usually in Facebook groups) to see who is getting well—mostly after three years—and trying to replicate those treatments. Elvis believes that there is a “method to the madness” of Lyme Disease research and that symptoms are “beyond anecdotal”; in his quest to return to good health, he looks across related conditions for validated treatments and sees how they might apply to Lyme Disease.

Despite the steep learning curve for developing medical knowledge and literacy, most participants kept track of their symptoms and carefully gathered and assembled their health histories. A few participants brought copies of their medical records to our interview, mostly for their own reference. Many participants noted that having the data in front of them would help them tell the “right” story, or simply help them remember the timeline of events. One participant, Lucy, gave me a list of all of the medications she had been on; it was helpful because it provided the complex spellings of many medications, a few of which were unfamiliar to me. Throughout her illness, Lucy kept lists of her symptoms on her phone so she could figure out how her condition was changing over time. She noted, “as new symptoms would come along, I would add...and so that then I could go like, ‘Well how is this related to this? How is this related to this?’” Many participants also brought their medical records to doctor’s appointments. Elvis, for instance, discussed how he immediately shared his “dossier” with clinicians at the beginning of an appointment to keep them from misdiagnosing his symptoms as depression or another mental illness.

#### *Developing Alternative Testing Protocols*

Lyme Disease is typically diagnosed using two tests. First, patients are given the Enzyme-linked immunosorbent assay (ELISA) test, an antibody-detecting test; since the ELISA

is often inaccurate, Lyme Disease diagnoses are confirmed using the Western Blot test, a protein-detecting test (Mayo Clinic). However, some research suggests that these tests are flawed and/or that the interpretation guidelines too strict (Johnson and Stricker; Rebman et al.). Many participants felt that their illness was prolonged because of faulty tests. Grace, for instance, noted that when she was first diagnosed, “none of the tests back then were very accurate.” However, after being ill for a long time and seeing many doctors, she has come to the conclusion that “[t]he test can basically rule it in, not rule it out because Lyme hides and stuff.” Throughout her first few years of illness, Kelly also kept “stumbling across” statistics about the Lyme tests missing fifty percent or more of positive cases. She notes that “it wasn’t just the symptoms I was focused on,” though she reminded me that Lyme Disease is called the “great imitator for a reason.” For her it was “the number of symptoms, the diversity...the nature of the illness—the coming and the going of the symptoms, the seemingly neurological involvement, and you know, the trifecta of cognitive issues, fatigue issues, joint issues...that combination can be a hallmark for tick-borne illness.” Kelly’s attention to her various and shifting symptoms helped her overcome what Benjamin calls the “murky territory” of Lyme Disease testing and eventually seek out testing for biotoxin illness, which ultimately gave her more useful answers.

Accordingly, some patients developed their own tests to determine if their Lyme Disease is flaring. Some of these tests aimed to hack the current healthcare system and save money. Lucy, for instance, consults her friend, who works in the lab at a major research hospital, to help decode her bloodwork, which she orders herself through a private company. This enables her to check on markers of illness, such as a high white blood cell count, for a small percentage of what she would pay through an insurance company. Lucy relies on her friend’s expertise as a healthcare professional and asks him to interpret the results. Similarly, Liam uses a Fitbit to track

his steps and sleep, which helps him evaluate his overall health. He notes that the Fitbit allows users to “be your own at-home kind of scientist” and “control, like, you know, only change one variable and see how things change and whatnot.” As Liam experiments with different treatments, he uses Fitbit data to figure out what is working most effectively.

In other cases, participants developed tests to assess their own healthcare in terms that were more meaningful to them than traditional bloodwork. In addition to her laboratory self-testing, Lucy has also developed her own test: seeing if a spot where she has a persistent, Lyme-related blister dries up. She calls it her “barometer.” Lucy notes that, when this spot heals, she will “feel like the Lyme is gone,” and that her blisters indicate whether or not she is dealing with active Lyme bacterium. Contrastingly, instead of observing how her body is trying to heal itself, Hannah engages in regular rigorous exercise, and evaluates the state of her health by judging her recovery time. As she was healing from Lyme Disease, Hannah hiked the Appalachian Trail, which is an extraordinarily rigorous task. She did this without any preparation—purposefully. Hannah was trying to understand the capacities and limitations of her body, and hiking the Appalachian Trail helped her prove to herself that she is hardworking and resilient as well as physically fit. Although this is not a traditional Lyme Disease test, Hannah was trying to understand if she was merely anxious or lazy instead of suffering from a tick-borne disease, a common tension that many participants faced.

### **Implications**

In this project, I drew on interviews that I conducted with self-reported Lyme Disease patients as well as materials that are publicly available on the internet, such as the CDC website and healthcare providers’ clinical practice websites, as well as “private,” deidentified, aggregated data that I had access to as a member of *MyLymeData* (MLD).

## *Digital Research Ethics*

As I have discussed, digital platforms specifically are key for understanding illnesses like Lyme Disease. Although some patients benefit from in-person support groups, others eschew the benefits of these groups or are too ill to venture outside of their homes and doctors' offices. Patients—at least those with whom I spoke—do not merely copy methods and experiment with treatments they find online. Instead, they have developed critical reading and thinking processes to help them digest and manage this ever-changing archive of information.

However, digital tools—especially those unconnected with doctors' offices—allow patients a sort of freedom to discover even the most radical treatments. And yet as Chapter 3 explains, these same digital tools may appear to work in service of patients by allowing them to share information, but they may work in service of other organizations and purposes as well. As such, rhetoric is an integral frame for examining health information sharing sites such as MLD, which have the potential to serve many purposes. As scholars, part of our future work might be better understanding the origin and future directions of tools like MLD. Even if they were first created for and by patients, do they remain that way? How can we alert patients to the various ways in which health technologies are taken up, circulated, reframed, and refigured for different rhetorical purposes?

Many ethical questions remain about conducting rhetorical research about chronic and contested illnesses, which are often disabling. Who is (or should be) allowed to access seemingly “private” digital spaces where ill people gather? How can researchers create a reciprocal relationship with their focus group members or interviewees and find ways to provide them direct benefits for participating in their projects?

## *Pedagogy*

Rhetoric, composition, and literacy scholars continue to be invested in what the *Framework for Success in Postsecondary Writing* terms “evaluat[ing] sources for credibility, bias, quality of evidence, and quality of reasoning” (O’Neill et al. 530). However, the creation, circulation, and uptake of alternative sources are ever-changing dilemmas in the twenty-first century. Through my case study in Chapter 2, I argued that instead of pursuing questions about what counts as “good” or “bad” science, rhetoricians should focus on discerning what different public audiences find persuasive and why. Perhaps more significantly, how do we guide students through the complex process of examining and integrating sources that are not academically validated? As this case study suggests, especially when knowledge is ambiguous or contested, it is imperative to understand not only what information exists about a subject, but who uses it, who finds it persuasive, and why. Such an examination allows college English teachers to contribute to the broader effort needed in public education to equip students for the participatory reality of twenty-first century discourse.

Scholars in rhetoric, composition, and literacy studies who examine “bad” sources have often focused on one in particular: Wikipedia. In a recent *College English* article, Matthew A. Vetter reviews the literature on Wikipedia, which despite its initial “negative reception” in academic communities, has been found to help students understand public audiences, navigate collaborative authorship, and develop digital literacy skills, among other capacities (397). Thus, I propose the term *wildcard sources* to better capture the unpredictable nature of sources like Wikipedia. Wildcard sources cannot be easily validated by their domain name; they may be sponsored by corporations with a vested interest; they may use superlative statements to bolster their authority or claims; they may be—at times—factually erroneous. However, wildcard sources may also be accessible, valuable, and trustworthy. Teaching students to engage



with wildcard sources challenges them to read through a rhetorical lens, not merely for content. While this is true for many contemporary topics, students frequently encounter wildcard sources while conducting research about health and medical topics.

To date, there are many heuristics for helping students and researchers evaluate sources within specific contexts. However, even the most popular ones have trouble accounting for wildcard sources. Jacob W. Craig argues that source evaluation checklists are the most popular tools used for identifying validated sources. Specifically, Craig uses the list of guidelines published by Columbia University's Millstein Undergraduate Library to show how these tools may not focus enough on the "varied nature of networked information," leaving students unprepared to navigate the online "information ecosystem" (12). The Millstein Library's guidelines are divided into six categories—Authorship, Publisher, Accuracy and Objectivity, Timeliness, Footnotes and Bibliographies, and Sponsorship—but these categories do not fully map over wildcard sources nor teach students when it is acceptable to adopt wildcard sources in their work.

For example, most healthcare providers' clinical websites include "[l]egitimate references and links to other sources," and it can be difficult to assess a website publisher's "reputation and trustworthiness" without reading multiple popular and professional sources about a given topic. Although Craig notes that there are new tools, such as Michael A. Caulfield's online textbook, *Web Literacy for Student Fact-Checkers*, they "have been slow to supplant traditional approaches that rely on strategies of immediacy" (30). Heuristics that rely exclusively on "strategies of immediacy," such as most library research guidelines, have a limited capacity for evaluating *wildcard sources* because they misjudge or undervalue the content of non-scholarly material.

Similarly, in her chapter in the 2017 collection, *Information Literacy: Research and Collaboration Across Disciplines*, Kathleen Blake Yancey conducts a “thought experiment” (86) to highlight the challenges of assessing the credibility of *PatientsLikeMe*, an early health information sharing platform (similar to *AncestryDNA* and *23andMe*) funded by pharmaceutical companies. Yancey notes that this website is “impressive” because it is one of the first sites that “compiles patients’ accounting of their own diseases” (88). Although she argues that websites such as *PatientsLikeMe* are part of the “new normal” in the age of the internet (77), her thought experiment suggests that even highly esteemed heuristics—like the American Council of Research Libraries’ Framework for Information Literacy for Higher Education—cannot adequately assess such sites. If such evaluation is difficult for scholars like Yancey, how are students, with only minimal exposure to rhetorical thinking, to appraise the surfeit of information strewn across the internet? As my work demonstrates, such work will be challenging but rewarding.

## APPENDIX

### Interview Questions:

1. Tell me a little bit about yourself.
2. Describe your health before your diagnosis.
3. Before Lyme Disease, what kinds of experiences did you have with doctors and other healthcare professionals?
4. When did you first become ill with Lyme Disease symptoms?
5. How and when were you diagnosed with Lyme Disease?
6. What would you say is your current diagnosis?
7. What is it like to live with Lyme Disease? What does a typical day look like?
8. How often do you have “bad” days? What do you do if you’re having a bad day?
9. Where do you go for support?
10. What kinds of healthcare providers or treatments have you sought? Have any been effective?
11. How confident do you feel about managing your Lyme Disease symptoms?
12. What is the most significant challenge you’ve faced in the process of dealing with Lyme Disease?
13. Do you talk with healthcare providers about your struggles with Lyme Disease? How do they typically respond?
14. Can you tell me about a time when you received “good” care for your Lyme Disease?
15. Do you talk with family members or friends about your struggles with Lyme Disease? How do they typically respond?
16. How do you look for new information about Lyme Disease?
  - a. What kinds of information do you look for?
  - b. How did you find these sources?
  - c. What sources (human, print, and/or digital) have been most helpful?
  - d. What sources do you trust most? Why?
  - e. What cues or signals suggest to you that a resource will be helpful and/or trustworthy?
  - f. How do you distinguish high-quality sources from low-quality sources?

- g. Do you use this kind of health research to make healthcare decisions? If so, in what way(s)?
- 17. Are you familiar with the terms “Lyme Literacy” or “LLMD” (Lyme Literate Medical Doctor)?
  - a. In what context?
  - b. How would you define these terms?
- 18. What is the most important thing you’ve learned in the process of being diagnosed and treated for Lyme Disease?
- 19. If you had to give advice to someone struggling with Lyme Disease, what would you tell them?
- 20. What does “good health” mean to you?
- 21. Is there anything else that you’d like to share?

## WORKS CITED

- “About Fox Valley Wellness Center.” *Fox Valley Wellness & Midwest Hyperbarics Center*, 2018, <http://www.foxvalleywellness.com/about.php>.
- “About Susan.” *Lyme Center of New England*, n.d., <http://www.lymecenterne.com/about.html>.
- Aldoory, Linda. “The Status of Health Literacy Research in Health Communication and Opportunities for Future Scholarship.” *Health Communication*, vol. 32., no. 2, 2017, pp. 211-218.
- Arola, Kristin L. “Indigenous Interfaces.” *Social Writing/Social Media: Publics, Presentations, and Pedagogies*, edited by Douglas M. Walls and Stephanie Vie, The WAC Clearinghouse and University Press of Colorado, 2017, pp. 211-226.
- Aujoulat, Isabelle, et al. “Reconsidering Patient Empowerment in Chronic Illness: A Critique of Models of Self-Efficacy and Bodily Control.” *Social Science & Medicine*, vol. 66, no. 5, 2008, pp. 1228-1239.
- Bazerman, Charles. “Physicists Reading Physics: Schema-Laden Purposes and Purpose-Laden Schema.” *Written Communication*, vol. 2, no. 1, 1985, pp. 3-23.
- Beemer, Cristy. “From the Margins of Healthcare: De-mythicizing Cancer Online.” *Peitho*, vol. 19, no. 1, 2016, pp. 93-127.
- Berkenkotter, Carol. “Genre Systems at Work: DSM-IV and Rhetorical Recontextualization in Psychotherapy Paperwork.” *Written Communication*, vol. 18, no. 3, 2001, pp. 326-349.
- Bizzell, Patricia. *Academic Discourse and Critical Consciousness*. University of Pittsburgh Press, 1992.
- Boston Women’s Health Collective. *Women and Their Bodies: A Course*. Boston Women’s Health Collective, 1970.
- Brandt, Deborah. “Sponsors of Literacy.” *College Composition and Communication*, vol. 49, no. 2, 1998, pp. 165-185.
- Buchbinder, Mara. *All in Your Head: Making Sense of Pediatric Pain*. U of California Press, 2015.
- Castro, Eva Marie, et al. “Patient Empowerment, Patient Participation and Patient-Centeredness in Hospital Care: A Concept Analysis Based on a Literature Review.” *Patient Education and Counseling*, vol. 99, no. 12, 2016, pp. 1923-1939.
- Caulfied, Michael A. *Web Literacy for Student Fact-Checkers*. PB Press, 2017.

“Mission, Role, and Pledge.” *Centers for Disease Control and Prevention*, 14 April 2014, <https://www.cdc.gov/about/organization/mission.htm>.

Centers for Disease Control and Prevention. “CDC Provides Estimate of Americans Diagnosed with Lyme Disease Each Year” [Press release]. 19 August 2013, <https://www.cdc.gov/media/releases/2013/p0819-lyme-disease.html>.

Charon, Rita. *Narrative Medicine: Honoring the Stories of Illness*. Oxford University Press, 2008.

Cline, Rebecca JW, and Katie M. Haynes. “Consumer Health Information Seeking on the Internet: The State of the Art.” *Health Education Research*, vol. 16, no. 6, 2001, pp. 671-692.

“Consultation.” *Jane Marke, MD, Integrative Psychiatry and Psychotherapy*, 2014, <http://www.janemarkemd.com/services-provided/psychiatrist-consultation/>.

Couser, G. Thomas. *Recovering Bodies: Illness, Disability, and Life Writing*. University of Wisconsin Press, 1997.

Davis, Lennard J. “Introduction: Disability, Normality, and Power.” *The Disability Studies Reader*, 4<sup>th</sup> edition, edited by Lennard J. Davis, Routledge, pp. 1-16.

De Hertogh, Lori Beth. “Reinscribing A New Normal: Pregnancy, Disability, and Health 2.0 in the Online Natural Birthing Community, Birth Without Fear.” *Ada: A Journal of Gender, New Media, and Technology*, vol. 7, 2015.

Dingo, Rebecca. *Networking Arguments: Rhetoric, Transnational Feminism, and Public Policy Writing*. University of Pittsburgh Press, 2012.

“Dr. Joseph Jemsek.” *Jemsek Specialty Clinic*, n.d., <http://jemsekspecialty.com/drjemsek/>.

Dubriwny, Tasha N. *The Vulnerable Empowered Woman: Feminism, Postfeminism, and Women's Health*. Rutgers University Press, 2012.

Edwards, Laurie. *In the Kingdom of the Sick: A Social History of Chronic Illness in America*. Bloomsbury, 2014.

Edwell, Jennifer, Sarah Ann Singer, and Jordynn Jack. “Healing Arts: Rhetorical Techne as Medical (Humanities) Intervention.” *Technical Communication Quarterly*, vol. 27, no. 1, 2018, pp. 50-63.

Emmons, Kimberly. *Black Dogs and Blue Words: Depression and Gender in the Age of Self-care*. Rutgers University Press, 2010.

- Finer, Bryna Siegel. "The Rhetoric of Preiving: Blogging the Breast Cancer Gene." *Rhetoric Review*, vol. 35, no. 2, 2016, pp. 176-188.
- Fox, Susanna and Maeve Duggan. *Health Online 2013*. Pew Research Center, January 15, 2013, <http://www.pewinternet.org/2013/01/15/health-online-2013/>.
- Fox, Susanna and Maeve Duggan. *The Diagnostic Difference: A portrait of the 45% of U.S. adults living with chronic health conditions*. Pew Research Center, November 26, 2013, <http://www.pewresearch.org/science/2013/11/26/the-diagnosis-difference/>.
- Frank, Arthur W. *The Wounded Storyteller: Body, Illness, and Ethics*. University of Chicago Press, 2013.
- "Frequently Asked Questions." *Fox Valley Wellness & Midwest Hyperbarics Center*, 2018, <http://www.foxvalleywellness.com/faq.php>.
- Goldstein, Melissa M., and Daniel G. Bowers. "The Patient as Consumer: Empowerment or Commodification? Currents in Contemporary Bioethics." *The Journal of Law, Medicine & Ethics*, vol. 43, no. 1, 2015, pp. 162-165.
- Graban, Tarez Samra. "From Location (s) to Locatability: Mapping Feminist Recovery and Archival Activity Through Metadata." *College English*, vol. 76, no. 2, 2013, pp. 171-193.
- Graham, S. Scott, et al. "Statistical Genre Analysis: Toward Big Data Methodologies in Technical Communication." *Technical Communication Quarterly*, vol. 24, no. 1, 2015, pp. 70-104.
- Hallenbeck, Sarah. *Claiming the Bicycle: Women, Rhetoric, and Technology in Nineteenth Century America*. SIU Press, 2015.
- "Home." *Fox Valley Wellness & Midwest Hyperbarics Center*, 2018, <http://www.foxvalleywellness.com/doctors.php>.
- "Home." *Jemsek Specialty Clinic*, n.d., <http://jemsekspecialty.com/>.
- "Home." *Lyme Center of New England*, n.d., <http://www.lymecenterne.com/about.html>.
- "Home." *MyLymeData*, 2015, <https://www.lymedisease.org/mylymedata/>.
- Jack, Jordynn. *Autism and Gender: From Refrigerator Mothers to Computer Geeks*. University of Illinois Press, 2014.
- . *Science on the Home Front: American Women Scientists in World War II*. University of Illinois Press, 2009.
- Johnson, Lorraine, and Raphael B. Stricker. "The Infectious Diseases Society of America Lyme

- Guidelines: A Cautionary Tale About the Development of Clinical Practice Guidelines.” *Philosophy, Ethics, and Humanities in Medicine*, vol. 5, no. 1, 2010, pp. 1-17.
- Johnson, Lorraine, Alexandra Aylward, and Raphael B. Stricker. “Healthcare Access and Burden of Care for Patients with Lyme Disease: A Large United States Survey.” *Health Policy*, vol. 102, no. 1, 2011, pp. 64-71.
- Johnson, Robert. *User-Centered Technology: A Rhetorical Theory for Computers and Other Mundane Artifacts*. SUNY Press, 1998.
- Kafer, Alison. *Feminist, Queer, Crip*. Indiana University Press, 2013.
- Katz, Steven B. “The ethic of expediency: Classical rhetoric, technology, and the Holocaust.” *College English*, vol. 54, no. 3, 1992, pp. 255-275.
- Kelly, Ashley R., and Carolyn R. Miller. “Intersections: Scientific and Parascientific Communication on the Internet.” *Science and the Internet: Communicating Knowledge in a Digital Age*, edited by Alan G. Gross and Jonathan Buehl, Routledge, 2017, pp. 221-245.
- Kelm, Zak, et al. “Interventions to Cultivate Physician Empathy: A Systematic Review.” *BMC Medical Education*, vol. 14, no. 1, 2014, <https://bmcmmededuc.biomedcentral.com/articles/10.1186/1472-6920-14-219>.
- Koerber, Amy. *Breast or Bottle?: Contemporary Controversies in Infant-Feeding Policy and Practice*. U of South Carolina Press, 2013.
- . *From Hysteria to Hormones: A Rhetorical History*. Penn State Press, 2018.
- Latour, Bruno, and Steve Woolgar. *Laboratory Life: The Construction of Scientific Facts*. Princeton University Press, 2013. 2<sup>nd</sup> edition.
- Lee, Nancy S. “Framing Choice: The Origins and Impact of Consumer Rhetoric in US Health Care Debates.” *Social Science & Medicine*, vol. 138, 2015, pp. 136-143.
- Linton, Simi. *Claiming Disability: Knowledge and Identity*. NYU Press, 1998.
- Losh, Elizabeth. “Nowcasting/Futurecasting: Big Data, Prognostication, and the Rhetorics of Scale.” *Rhetoric and the Digital Humanities*, edited by Jim Ridolfo and William Hart-Davidson, 2015, pp. 286-295.
- “Lyme Disease.” *Centers for Disease Control and Prevention*, 19 January 2018, <https://www.cdc.gov/lyme/index.html>.
- “Lyme disease.” *Mayo Clinic*. 5 December 2018, <https://www.mayoclinic.org/diseases->



- conditions/lyme-disease/diagnosis-treatment/drc-20374655.
- “Lyme Psychiatry.” *Jane Marke, MD, Integrative Psychiatry and Psychotherapy*, 2014b, <http://www.janemarkemd.com/services-provided/lyme-psychiatry/>.
- Martin, Chris J. “The Sharing Economy: A Pathway to Sustainability or a Nightmarish Form of Neoliberal Capitalism?” *Ecological Economics*, vol. 121, 2016, pp. 149-159.
- Melonçon, Lisa, and Erin A. Frost. “Special Issue Introduction: Charting an Emerging Field: The Rhetorics of Health and Medicine and its Importance in Communication Design.” *Communication Design Quarterly Review* 3.4 (2015): 7-14.
- McNely, Brian. “Big Data, Situated People: Humane Approaches to Communication Design.” *Communication Design Quarterly Review*, vol. 1, no. 1, 2012, pp. 27-30.
- “Meet Our Doctors.” *Fox Valley Wellness & Midwest Hyperbarics Center*, 2018, <http://www.foxvalleywellness.com/index.php>.
- Mol, Annemarie. *The Logic of Care: Health and the Problem of Patient Choice*. Routledge, 2008.
- “MyLymeData Frequently Asked Questions.” *MyLymeData*, 2015, <https://www.lymedisease.org/mylymedata/faqs/>.
- “MyLymeData Videos.” *MyLymeData*, 2015, <https://www.lymedisease.org/mylymedata/videos/>.
- “My Office Policies.” *Jane Marke, MD, Integrative Psychiatry and Psychotherapy*, <http://www.janemarkemd.com/my-office-policies/>.
- OED Online. (January 2018). “*testimony, n.*” Retrieved from <http://www.oed.com.libproxy.lib.unc.edu/view/Entry/199748?rskey=fxG1Ec&result=1#id>.
- “Office Policies.” *Lyme Center of New England*, 20 January 2016, <http://www.lymecenterne.com/forms/Office-Policy.pdf>.
- “Office Policies and Fees.” *Lyme Center of New England*, n.d., <http://www.lymecenterne.com/policies.html>.
- “Our Story.” *Patient-Centered Outcomes Research Institute*, 2019, <https://www.pcori.org/about-us/our-story>.
- Owens, Kim Hensley. *Writing Childbirth: Women’s Rhetorical Agency in Labor and Online*. SIU Press, 2015.

- “Patient Testimonials.” *Jemsek Specialty Clinic*, n.d., <http://jemsekspecialty.com/patient-testimonials/>.
- Petric, Gregor, Sara Atanasova, and Tanja Kamin. “Ill Literates or Illiterates? Investigating the eHealth Literacy of Users of Online Health Communities.” *Journal of Medical Internet Research*, vol. 19, no. 10, 2017, e331.
- Pflugfelder, Ehren Helmut. “Big Data, Big Questions.” *Communication Design Quarterly Review*, vol. 1, no. 4, 2013, pp. 18-21.
- “Post-Treatment Lyme Disease Syndrome.” *Centers for Disease Control and Prevention*, 17 December 2017, <https://www.cdc.gov/lyme/postlds/index.html>.
- Pritt, Bobbi S., et al. “Identification of a Novel Pathogenic *Borrelia* Species Causing Lyme Borreliosis with Unusually High Spirochaetaemia: A Descriptive Study.” *The Lancet Infectious Diseases*, vol.16, no. 5, 2016, pp. 556-564.
- Rebman, Alison W., et al. “Living in Limbo: Contested Narratives of Patients with Chronic Symptoms Following Lyme Disease.” *Qualitative Health Research*, vol. 27, no. 4, 2017, pp. 534-546.
- Rebman, Alison W., Mark J. Soloski, and John N. Aucott. “Sex and Gender Impact Lyme Disease Immunopathology, Diagnosis and Treatment.” *Sex and Gender Differences in Infection and Treatments for Infectious Diseases*, edited by Sabra L. Klein and Craig W. Roberts, Springer, 2015, pp. 337-360.
- Reed, Amy R. “Building on Bibliography: Toward Useful Categorization of Research in Rhetorics of Health and Medicine.” *Journal of Technical Writing and Communication*, vol. 48, no. 2, 2018, pp. 175-198.
- Segal, Judy Z. “Internet Health and the 21st-Century Patient: A Rhetorical View.” *Written Communication*, vol. 26, no. 4, 2009, pp. 351-369.
- Segal, Judy. *Health and the Rhetoric of Medicine*. SIU Press, 2005.
- Selber, Stuart. *Multiliteracies for a Digital Age*. SIU Press, 2004.
- Schryer, Catherine F., et al. “The Trial of the Expert Witness: Negotiating Credibility in Child Abuse Correspondence.” *Written Communication*, vol. 26, no. 3, 2009, pp. 215-246.
- Scott, Blake, Judy Z. Segal, and Lisa Keranen. “The Rhetorics of Health and Medicine: Inventional Possibilities for Scholarship and Engaged Practice.” *Poroi*, vol. 9, no. 1, 2013, pp. 1-6.
- Shaw, Donita, et al. “Who Researches Functional Literacy?.” *Community Literacy Journal*, vol. 11, no. 2, 2017, pp. 43-64.

- Seigel, Marika. *The Rhetoric of Pregnancy*. University of Chicago Press, 2013.
- Singleton, Kate. "Health Literacy and Adult English Language Learners." Center for Adult English Language Acquisition (CAELA), U.S. Department of Education/Office of Vocational and Adult Education, 2002, [http://www.cal.org/caela/esl\\_resources/digests/healthlit.html](http://www.cal.org/caela/esl_resources/digests/healthlit.html).
- Sontag, Susan. *Illness as Metaphor and AIDS and its Metaphors*. Macmillan, 2001.
- Sørensen, Kristine, et al. "Health Literacy and Public Health: A Systematic Review and Integration of Definitions and Models." *BMC Public Health*, vol. 12, no. 1, 2012, <https://bmcpublichealth.biomedcentral.com/articles/10.1186/1471-2458-12-80>.
- Stellefson, Michael, et al. "eHealth Literacy Among College Students: A Systematic Review with Implications for eHealth Education." *Journal of Medical Internet Research*, vol. 13, no. 4, 2011, pp. e102.
- Stuckey, J. Elspeth. *The Violence of Literacy*. Heinemann Educational Books, 1991.
- Taggart, Jane, et al. "A Systematic Review of Interventions in Primary Care to Improve Health Literacy for Chronic Disease Behavioral Risk Factors." *BMC Family Practice*, vol. 13, no. 1, 2012, pp. 1-12.
- Teston, Christa. *Bodies in Flux: Scientific Methods for Negotiating Medical Uncertainty*. University of Chicago Press, 2017.
- "Testimonials." *Fox Valley Wellness & Midwest Hyperbarics Center*, 2018, <http://www.foxvalleywellness.com/testimonials.php>.
- "Testimonials." *Jane Marke, MD, Integrative Psychiatry and Psychotherapy*, 2014, <http://www.janemarkemd.com/testimonials/>.
- Tomes, Nancy. "Did Patient/Consumers Cause the Healthcare Crisis? Historical Talking Points for the 21st Century Patient Advocate." *Patient Advocacy for Health Care Quality: Strategies for Achieving Patient-Centered Care* (2008): 361.
- . "Patient Empowerment and the Dilemmas of Late-Modern Medicalisation." *The Lancet*, vol. 369, no. 9562, 2007, pp. 698-700.
- . "Patients or Health-care Consumers? Why the History of Contested Terms Matter." *History and Health Policy in the United States: Putting the Past Back In*, edited by Charles E. Rosenberg, et al., Rutgers University Press, 2006, pp. 83-110. 83-110).
- . *Remaking the American Patient: How Madison Avenue and Modern Medicine Turned Patients into Consumers*. UNC Press Books, 2016.

“Track 2: Health Literacy and Health Behaviour.” *Health Promotion*, World Health Organization, 2019, [www.who.int/healthpromotion/conferences/7gchp/track2/en/](http://www.who.int/healthpromotion/conferences/7gchp/track2/en/).

U.S. Department of Health and Human Services. *Quick Guide to Health Literacy*, n.d., <https://health.gov/communication/literacy/quickguide/factsbasic.htm#one>.

van der Vaart, Rosalie, and Constance Drossaert. “Development of the Digital Health Literacy Instrument: Measuring a Broad Spectrum of Health 1.0 and Health 2.0 Skills.” *Journal of Medical Internet Research*, vol. 19, no. 1, 2017, pp. e27.

Vonnegut, Mark, et al. *Health Humanities Reader*. Rutgers University Press, 2014.

Wendell, Susan. “Unhealthy Disabled: Treating Chronic Illnesses as Disabilities.” *Hypatia*, vol. 16, no. 4, 2001, pp. 17-33.

“What Makes MyLymeData Different.” *MyLymeData*, 2015, <https://www.lymedisease.org/mylymedata/national-study-chronic-lyme-disease/>.

“Why Does the Clinic Refer to Lyme Disease as the Lyme Borreliosis Complex (LBC)?.” *Jemsek Specialty Clinic*, n.d., <http://jemsekspecialty.com/clinic-refer-lyme-disease-lyme-borreliosis-complex-lbc/>.

Wickman, Chad. “Writing Material in Chemical Physics Research: The Laboratory Notebook as Locus of Technical and Textual Integration.” *Written Communication*, vol. 27, no. 3, 2010, pp. 259-292.

Woolf, Virginia. *On Being Ill*. The Hogarth Press, 1930.

Wormser, Gary P., et al. “The Clinical Assessment, Treatment, and Prevention of Lyme Disease, Human Granulocytic Anaplasmosis, and Babesiosis: Clinical Practice Guidelines by the Infectious Diseases Society of America.” *Clinical Infectious Diseases*, vol. 43, no. 9, 2006, pp. 1089-1134.

Yergeau, Melanie. *Authoring Autism: On Rhetoric and Neurological Queerness*. Duke University Press, 2017.