

ABSTRACT

Are Lyme Disease Controversies Harming Patients?: A Social History of the Roles of Research, Education, and Treatment in the Patient Experience

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Lyme disease is a tick-borne infectious illness causing symptoms that can range in severity from mild to debilitating. It is important for a diagnosis to be made quickly after infection in order to prevent the development of more severe symptoms. However, challenges related to healthcare issues can delay diagnosis. In this thesis, three such challenges are identified: (1) testing and the need for improved diagnostic procedures, (2) a culture of uncertainty and the need for more education, and (3) chronic symptoms and the need for more treatment. These issues are further explored from what are termed the personal, relational, and population perspectives in order to demonstrate their effects on the patient experience. To contextualize these effects, direct quotations from interviews with Lyme disease patients and a caregiver are incorporated. Changes are proposed with respect to research, education, and treatment in order to encourage action that will improve patient experience.

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ARE LYME DISEASE CONTROVERSIES HARMING PATIENTS?:
A SOCIAL HISTORY OF THE ROLES THAT RESEARCH, EDUCATION,
AND TREATMENT PLAY IN THE PATIENT EXPERIENCE

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CHAPTER ONE

Introduction

Chapter Overview

Controversies that have arisen in the medical approach to Lyme disease prevent patients from experiencing effective healing and treatment. By devising strategies that better integrate the scientific background of the disease with complexities of the patient experience, the medical community can equip itself to more effectively identify Lyme and to treat patients holistically, taking heed of their physical, emotional, and mental well-being.

It is imperative to begin rethinking how we address Lyme because the disease is becoming endemic in more areas, making the challenge of effective treatment more relevant, both in clinical and public health contexts. Additionally, questions over the role of the government and insurance companies in Lyme disease are being asked more frequently in scientific, political, and economic spheres. Such questions can only be answered through a liberal examination of the disease from multiple perspectives. This study seeks to initiate this conversation through providing a social history of Lyme disease, including a summary of clinical and epidemiologic features as well as discussion of current controversies in research, education, and treatment.

Case Definitions

This study considers the effects of Lyme disease on patients from several perspectives. Clinically, Lyme borreliosis, known as Lyme disease, is a tick-borne disease caused by bacteria of the order *Spirochaetales*. In North America, *Borrelia burgdorferi* is the causative bacterium. However, in Europe, *B. burgdorferi sensu stricto*, *B. garinii*, and *B. afzelii* are genomic groups known to cause Lyme.¹ These bacteria are transmitted to humans by the *Ixodes scapularis* ticks and the *I. pacificus* ticks in the United States. Additionally, *I. ricinus* ticks and *I. persulcatus* ticks transmit the disease in Europe and Asia, respectively.²

The ticks become vectors when they feed off of reservoir hosts, which include small mammals such as the *Peromyscus* and *Neotoma* species of wild rodents.³ Only ticks in their first two stages of life, the nymph and larval stages, can feed off of these animals. Thus the Lyme bacteria can only be transmitted to the young ticks. Ticks in their adult stage feed off of deer, hence why they are colloquially called deer tick. Deer are reproductive hosts because they are needed for adult ticks to survive and reproduce, but they do not transmit the bacteria to ticks.

Lyme disease is most commonly identified by a lesion on the skin, but it can present with many symptoms. The lesion, erythema migrans, is seen at the spot of infection in 70 to 80 percent of Lyme cases.⁴ Additional symptoms include extreme joint pain and flu-like symptoms, such as fever, headache, and fatigue. These symptoms can be more

severe if there is a coinfection. If the tick transmits another disease, such as *Babesia microti* or *Anaplasma phagocytophilum*, then the patient will experience more severe symptoms, even though these infections are usually asymptomatic when occurring on their own.⁵

Lyme disease occurs in three stages.⁶ The first stage is the early localized stage, in which the erythema migrans is visible and general flu-like symptoms are present. This stage lasts from three to thirty days after the tick bite. With early detection, the disease can be treated with simple antibiotics. If untreated, the patient will enter stage two, which can last from days to weeks after the initial bite. During this stage, the disease disseminates and can begin presenting more severely with facial or Bell's palsy and extreme joint pain, headaches, and swelling. If still untreated, the patient enters stage three, the late disseminated stage. In this stage, sixty percent of patients develop arthritis and five percent develop chronic neurological complications.⁷

What is referred to in this study as chronic Lyme disease occurs specifically when patients experience chronic symptoms after receiving treatment. This occurs in ten to twenty percent of Lyme cases.⁸ It is separate from the chronic symptoms experienced by untreated stage three patients. To make this difference clear, chronic Lyme disease is sometimes also called post-treatment Lyme syndrome.

Chronic Lyme disease is an area of controversy because the mechanism of chronic symptoms is unclear. As part of this disease or

syndrome, some physicians recognize treatment-resistant Lyme arthritis, which occurs in ten percent of patients with arthritic symptoms.⁹ While early stage Lyme disease can be combatted with antibiotics and natural immune responses, treatments are not clear for these chronic syndromes. The usual protocol includes drugs that target the symptoms, including anti-inflammatory and antirheumatic drugs, and other treatments used for chronic fatigue.¹⁰

Because this study is interested in how Lyme disease affects patients in all areas of their life, including health status, personal identity, and emotional well-being, it is important to look at manifestations of chronic Lyme disease, though there is not a singular consensus in the medical community about such manifestations. Chapter Two will include a review of the literature surrounding chronic Lyme disease. These chronic symptoms can be life-altering and severely debilitating to patients. However, the mechanism of these symptoms is unclear and often attributed to other conditions, like fibromyalgia or chronic fatigue syndrome.

Further research can clarify the cause of these symptoms and how to address them. Presently, there are many conflicting reports and studies regarding Lyme disease tests, treatments, and symptoms. These controversies perpetuate misinformation and make accurate management of Lyme cases more challenging.

Media and Infectious Diseases

Infectious diseases have an ongoing presence in society that is difficult to ignore. In a longitudinal study from 1996 to 2002 about health news coverage, an average of 42 percent of participants indicated that they follow health stories closely.¹¹ However, stories about infectious diseases and bioterrorism have garnered even more national attention. In December, 2001, 83 percent of people surveyed indicated paying close attention to reports of anthrax cases.¹² In October, 2002, 78 percent of people surveyed indicated paying close attention to reports of the spread of West Nile virus to America. In a similar survey conducted in October, 2014, 69 percent of respondents reported paying close attention to news stories about the diagnosis of the first Ebola case in the United States.¹³ These data indicate both a public desire to be informed about health related issues, particularly public health issues and infectious diseases, and a heightened concern for safety.

While much attention is paid to these health stories in the news, there are still large gaps in knowledge about the issues covered. In the October, 2014, survey conducted about Ebola news coverage, only 36 percent of people surveyed correctly knew that Ebola can only be transmitted once the infected person is showing symptoms.¹⁴ Thus, only 52 percent of the respondents who indicated paying close attention to the reports were able to correctly answer this question about the disease. This is indicative of either the dissemination of misinformation or a lack

of retention of correctly-conveyed facts. In a study of how media influence people's perceptions of disease, it was demonstrated that "individuals consider infectious diseases that receive repetitive media exposure to be more severe and have higher disease-like status than diseases of comparable objective severity that receive less media attention."¹⁵ Because of this correlation between media coverage and public knowledge, it is important for public health and political officials to distribute correct data and reports about health issues and to make sure that correct facts are presented. The mass media "function as a critical interface between the scientific community, government, and the public."¹⁶ There must be a three-pronged approach, spearheaded by the scientific community, funded and supported by the government, and disseminated by the media, in order to ensure that the public is prepared, informed, and protected.

Dangers of Infectious Diseases

Though Lyme disease poses less of a threat of becoming an epidemic than other infectious diseases because it is not proven to spread from person to person, infectious diseases can be extremely dangerous globally. A national report noted that "infectious diseases have long raged through human communities, but forces of globalization—including rapid growth in international trade and travel and increasing urbanization—have amplified their spread and impact."¹⁷ In a world

changing with the constant introduction of newer and faster technology and travel methods, it is important that infectious diseases are considered from a global perspective. Both traditional and nontraditional methods of disease containment and eradication should be enacted in order to mitigate the effects of rampant infectious disease spread. Traditional public health measures include but are not limited to emergency preparedness, disease surveillance and monitoring, and immunization programs.¹⁸ Additionally, nontraditional methods that bridge economics, politics, ethics, and medicine must be considered.

Vaccination

One of the most obvious and traditional ways to prevent the spread of infectious diseases is the widespread use of a vaccine. For example, the Global Polio Eradication Initiative in the 1980s, a worldwide vaccination movement, caused a 99 percent decrease in the number of polio cases.¹⁹ A vaccine for Lyme was used in the 1990s. However, it was not widely accepted and administered because of the low prevalence of Lyme in most of the United States and the high cost of booster shots.²⁰ Therefore, it is not in use today.

A public health issue that is a common feature in the evaluation of many diseases is the comparison between the cost of prevention and the cost of treatment. In the case of the Lyme vaccine, it costs more to develop, produce, and administer the vaccine than it would to administer antibiotics. This is because the vaccine requires new research and

development, which form an expensive sector of the pharmaceutical industry. However, the antibiotics that are used to treat Lyme disease are common treatments for many other diseases, making them both less expensive to produce and the preferred method for containing Lyme disease.

It is in the hands of public health officials to decide how to handle this issue of cost. Because Lyme disease is inexpensively treated when diagnosed early, officials have chosen to endorse antibiotics as opposed to the vaccine. Though this is currently effective, the number of cases of Lyme disease is rising. Because it can be challenging to detect Lyme disease at the early stages when these inexpensive treatments are effective, more attention needs to be given to prevention methods, such as vaccination. Eliminating uncertainties about Lyme disease can help improve reporting behaviors for Lyme disease, thus providing public health officials and pharmaceutical companies with more accurate information about the incidence and prevalence of Lyme. With this information, the plausibility of introducing a vaccine widely could be better considered.

Disease Reporting

An additional concern with Lyme disease is the lack of thorough reporting, thus calling into question current estimates of its incidence. Due to physician misinformation and issues with the accuracy of tests, many regions of the United States report far fewer cases of Lyme than

may actually exist. Additionally, areas where Lyme is endemic might over-report cases. Without accurate reporting, it is harder for public health officials to implement important prevention and education measures. Therefore, physicians need to be more diligent about diagnosing and reporting Lyme disease. Also, public health officials need to simplify the reporting process to encourage this behavior.

In Texas, the disease-reporting process happens through county health departments. Physicians can utilize online reporting sites or reporting hotlines to notify the department of potential cases of diseases. These are diseases specified by the Centers of Disease Control and Prevention (CDC) as being particularly contagious or indicative of unsafe food, hygiene, or medical practices. The disease-investigation process is executed by local epidemiologists, who follow up with patients of the reported diseases and gather laboratory or test results to learn more about the potential cause of disease. These cases are then reported to state health departments, who handle further proceedings with national reporting, if necessary. Without the collaborative efforts of physicians to accurately diagnose and report Lyme, efforts of patients and communities to recognize symptoms and take preventative measures, and efforts of public health officials to monitor, educate, and prevent the disease, there is a dangerous risk of increased incidence of the disease.

While improving disease reporting is ideal in theory, it is a difficult and multi-faceted issue to tackle. The World Health Organization (WHO)

is the coordinating body for health issues among countries of the United Nations (UN). Additionally, countries have their own organizations to monitor and control health concerns. For example, the United States has the CDC, and the European Union has the European Centre for Disease Prevention and Control. Other countries have Ministries of Health to provide and promote health services. In order to provide a framework under which these separate entities can operate, the WHO passed the International Health Regulations (IHR) in 2005 to set common surveillance and response standards in UN Member States. However, critics have identified “domestic political interests of influential Member States or economical forces” as potential factors complicating the impartiality of the WHO.²¹ Additionally, political and economic issues within a majority of UN Member States prevented them from being able to successfully implement the IHR, causing the WHO to offer two-year extensions, placing the implementation deadline at June 15, 2014.²²

Clearly, disease containment is no longer an issue that can be addressed from the medical front alone. The cooperation of governing bodies at both the national and international levels is necessary for globally-minded programs like the IHR to see success. Because “the core argument over global surveillance has moved from public health concerns toward foreign and security policies, and economic interests,” the issue of disease containment must be a priority for leaders in all fields, from enterprise to government and medicine to education.²³

CHAPTER TWO

Research Review

Chapter Overview

In this chapter, three tasks are accomplished. First, I provide an introduction of the epidemiology of Lyme disease. This includes information about how Lyme disease is spread and about areas where the disease is particularly endemic.

Second, I discuss the influence of Lyme disease on patients. In addition to describing the physical effects of the disease, I elaborate on how pain and suffering are common in Lyme disease patients and discuss how patients' identities and mental well-being are affected.

Third, I identify three controversies surrounding the current approach to Lyme disease. I then suggest ways to address these challenges, including calls for more focused research, education, and treatment moving forward.

Epidemiology of Lyme Disease

Areas of the United States where Lyme disease is endemic are primarily areas where ticks and their feeding hosts are found. Ninety five percent of cases in the United States in 2013 were found in Connecticut, Delaware, Maine, Maryland, Massachusetts, Minnesota, New Hampshire,

New Jersey, New York, Pennsylvania, Rhode Island, Vermont, Virginia, and Wisconsin.²⁴ However, as more research is conducted about Lyme, health care providers are becoming more aware of its occurrence in non-endemic areas. Thus, the disease has been reported in 47 states.²⁵ The incidence (number of new cases) nationally in 2013 was 8.6 confirmed cases of Lyme disease per 100,000 people.²⁶ However, the incidences in each state vary greatly. For example, the highest incidence is found in Vermont, where there were 107.6 confirmed cases per 100,000 people in 2013. For comparison, Texas had only 0.2 cases per 100,000 people in 2013. When reporting the disease in the nonendemic and hyperendemic areas, physicians are asked to identify tick species that are causing infection so that more effective and specific prevention methods can be taken.

Prevention methods for Lyme disease are easy to follow because the disease has only been proven to transmit to humans through tick bites, specifically bites where the tick remains attached to the human for more than 24 hours. Therefore, avoiding tick-infested areas greatly reduces the risk of infection. Additional prevention methods include education regarding zoonotic disease, checking clothing and the entire body (including clothed areas, scalp, and feet) for ticks, use of tick repellent, effective removal of ticks from the body, and reduction of the tick population.²⁷ These efforts need to be taken by both individuals and health departments in order to combat the transmission of Lyme disease.

While Lyme disease is not transmissible in person-to-person contact, it is not uncommon for family units to be infected simultaneously. This is because families that travel together to or live in endemic regions and participate in outdoor activity are exposing themselves to the Lyme disease concurrently. Thus, when a person is infected, the American Public Health Association asks that the following steps be taken to ensure control of the disease²⁸:

1. Report disease.
2. Remove ticks from patient.
3. Determine source of infection if:
 - a. the patient is in a non-endemic area;
 - b. the patient is in a hyper-endemic area.
4. Treat the patient.

It is extremely important that physicians and patients recognize, diagnose, and treat Lyme disease in its early stage, so as to prevent dissemination of the disease and the chance of chronic symptoms. The symptoms of Lyme disease can be extremely life-altering if the disease is left untreated. In order to reduce this, we call for more research, education, and treatment regarding Lyme disease.

Influence of Lyme Disease on Patients

Physical Influence

As with any disease, the physical symptoms that Lyme disease causes can influence a patient's activities of daily living in many ways. While early diagnosis of the disease can allow for quick treatment and minimization of lasting symptoms, delays in testing and treatment can cause long-term effects.

In a study performed at Columbia University, the ways that such long-term effects influence quality of life were examined.²⁹ Fatigue experienced by Lyme patients was associated with a lower quality of both physical and mental health. Further association between depression and sensation of physical pain was found, as were ties between depression and cognitive abilities. Patients experienced challenges in daily living, including lack of energy and strength to perform physical tasks, due to fatigue. They also experienced challenges in mental health, such as a lowered desire to participate in social activities, due to depression. Fatigue and depression were also associated with lesser cognitive abilities, such as short-term memory capacity.³⁰

In these ways, the physical symptoms experienced by Lyme disease patients are interrelated. However, treatment for one symptom, such as physical pain, might not be successful in also treating other factors, such as depression. It is suggested that studies focus on treatment strategies

to address combinations of these factors in order to address physical and cognitive impairments experienced by patients.³¹

Suffering and Identity

While people often associate Lyme disease, especially its chronic manifestations, with pain, it is important to also evaluate the suffering endured by patients. Cassell describes humans as living in a constant relationship between many forces—the world, other people, emotions, thoughts, and the body.³² Suffering arises when there is imbalance between these forces, causing the person to feel segmented and to not feel whole. By taking this relational approach to illness and suffering, physicians, family members, and patients can better understand the influence that Lyme disease has on a person. However, there can be a lack of attention to this element of the human condition by multiple parties involved in the Lyme disease discussion. As a result, physicians might only focus on how to treat biological symptoms. Families might focus on how their ill family member is changing. This can leave patients to focus on the changes in their emotions and thoughts with no outlet for counsel. In this way, Lyme disease can be a very isolating experience for a patient.

Because of the medical controversies regarding diagnosing Lyme and treating its chronic symptoms, it can be challenging for patients to explain their pain, be diagnosed, receive treatment, and cope with the disease's effects on their lives. For many chronic patients, the disease

marks their identities, for their pain becomes suffering. Overcoming this suffering can be especially difficult when the root of the suffering, the biological pain caused by Lyme disease, is not seen by others. A misconception about Lyme disease patients is that they are paranoid or faking their illness. Additionally, some physicians view it as a “yuppie disease [that is] hard to catch, easy to cure.”³³ This inhibits the healing process because the pain is ignored while the chaos between forces in the patient’s life grows, increasing the sensation of suffering.

Accepting Illness

A part of the healing process, as identified by Cassell, is the patient’s recognition of his or her sickness. This must happen before any healing (physical, cognitive, or emotional) can occur. Social and psychological factors influence this recognition.³⁴ Social misperceptions of the disease, such as the thought that it can only be contracted in certain areas or that patients feign symptoms in order to receive prescriptions and attention, can cause patients to delay seeking treatment out of fear of the physicians’ or their families’ responses. Psychological factors can cause a patient to struggle with why he or she is experiencing pain. Sometimes this manifests as a patient blaming himself or herself for the pain rather than attributing it to a disease.

In some cases, patients seek alternative treatments in order to address these psychological struggles.³⁵ While traditional Lyme treatment courses focus on antibiotics, alternative treatment courses

utilize acupuncture, hypnosis, relaxation techniques, and herbal medicines. Additionally, patients might choose to receive counseling in order to have an outlet for discussion about their experiences with illness and how it affects daily life and their relationships. A patient can come to have a better understanding of his or her body, perceptions of pain, and outlook on daily living through such treatments. By addressing these social misperceptions and seeking out ways to address psychological struggles, patients can initiate the healing process and begin to relieve the suffering that they are experiencing.

Three Current Controversies

Testing and the Need for More Diagnostic Research

One of the main problems that Lyme disease patients could face is receiving a timely diagnosis. This problem can be caused by inaccurate testing, delayed testing, or an incorrect evaluation of symptoms. These barriers to entry keep patients from receiving the best treatment and prevent their abilities to recover well. Delays in diagnosis could also be responsible for long term chronic Lyme disease.

The test used for Lyme is a two-tiered test. First, an enzyme immunoassay (EIA) is administered.³⁶ This type of test measures whether a patient has an antibody response to the *B. Burgdorferi* bacteria. If the EIA test is positive or indeterminate, then a Western blot test is

administered. This test measures how many antibody responses a person has to different antigens of the bacteria.³⁷

There is a potential for inaccuracy here because it can take a patient up to three weeks to develop antibodies to Lyme bacteria. If a patient is tested too soon, the ISA will return a false negative.³⁸ In this case, false negatives indicate that patients with an active immune response to Lyme bacteria or patients who have already been infected but have not yet developed an immune response received a negative result. In a 1999 study of eleven EIA tests for immunoglobulin M (IgM) antibodies, the sensitivity (the measure of actual positives that are correctly identified) of tests for patients with stage one Lyme disease ranged from 35 to 81 percent and ranged from 46 to 92 percent for patients with stage two or later Lyme.³⁹ This indicates a potential for false negatives ranging from 19 to 65 percent for stage one patients and from 8 to 54 percent for later stage patients. The IgM EIA tests in the study had an 89 to 100 percent specificity rate (the measure of actual negatives that are correctly identified).

There is also potential for inaccuracy with the Western Blot test. A Western Blot test for IgM or immunoglobulin G (IgG) is administered if the patient has been experiencing signs and symptoms for less than thirty days. Only the test for IgG is useful if the patient has been experiencing symptoms for longer than thirty days.⁴⁰ This is because patients develop an IgM response more quickly, thus it can be detected

with the Western Blot sooner. However, this can cause a higher false positive rate because patients who suppress the disease with a natural response or who inadvertently treat the disease by taking antibiotics for another condition could have a false positive IgM Western Blot result.⁴¹ The 1999 study does not report specificity for the IgM Western Blot, so the frequency of these false positives cannot be compared to the other data.⁴² The sensitivity of the four Western Blot tests studied in that report indicate a maximum sensitivity of 50 percent for the IgM tests and 46 percent for the IgG tests. These data indicate that approximately one in two patients receive an false negative test result. Lyme disease is rarely diagnosed without the presence of a positive result for both the ISA and Western Blot tests, so these inaccuracies can bar patients from receiving the correct diagnosis.

Another issue with testing comes with the subjectivity of the interpretation of Western Blot testes. The technician administering the test must count the number of bands that are produced on the immunoblot. Each band represents an antibody response to one of the antigens of the bacteria. For an IgM test to be positive, two of three specific bands must be present. For an IgG test to be positive, five of ten specific bands must be present.⁴³

The subjectivity comes into play when the Western Blot produces multiple bands but not these specific bands. When a patient clearly has an immune response but does not perfectly fit the testing interpretation

recommendations, the technician and physician must decide how to proceed. In some cases, physicians will move on with treatment despite a confirmed laboratory test. These patients are considered probable cases. Other physicians will conclude that the patient does not have Lyme disease. This creates potential for both false positives and false negatives, depending on the particular technician or physician's opinions and beliefs. This potential room for error can keep patients from receiving the care that they need.

In order to better treat the disease, physicians need more accurate tests. Many trials are being conducted to improve the sensitivity and specificity of tests for Lyme disease. For example, an immunoblot test has been developed in place of the Western Blot that does not require human interpretation.⁴⁴ However, this new immunoblot is not considered the golden standard for testing. Thus the potential subjectivity persists.

In addition to potential problems with the tests themselves, there can be difficulty in recognizing the symptoms of Lyme disease. The symptoms, especially in the early stages, are very flu-like in nature. Because of the high prevalence and non-specificity of flu-like symptoms, the diagnosis of Lyme disease can be delayed or missed.⁴⁵ Additionally, these symptoms can decrease in severity or be intermittent with periods of wellness.⁴⁶ In order to guide the decision-making that physicians must perform, the *Journal of Clinical Investigation* published algorithms to aid in diagnosis.⁴⁷

According to the algorithms, patients must first recognize a tick bite, rash, flu-like symptoms, or problems with joints, the heart, or the nervous system and then report these problems to a physician. Additionally, physicians must take such concerns seriously and consider their possible indication of Lyme disease. Even with these algorithms and additional guidelines for diagnosis from other organizations, confusion can arise due to the limitations of testing described above. For example, if antibiotics are given for an erythema migrans rash prior to the administration of a serological test for Lyme, a later test can appear negative. This raises the question of whether physicians should treat Lyme empirically, such as upon recognition of erythema migrans, or if they should delay treatment until positive test results are received. This controversy will persist until further research improves diagnostic and testing methods, for choosing to treat on empirical evidence can have harmful influence on later tests but relying on tests alone can leave a patient's symptoms untreated.

Culture of Uncertainty and the Need for More Education

An overarching lack of education about Lyme disease and lack of dissemination of new discoveries from researchers to clinicians has created a culture of uncertainty toward Lyme disease. In endemic areas, physicians may be quick to recognize symptoms of Lyme, even when a visible rash is not present. However, in areas where vectors of *Borrelia* are not believed to live, physicians are much less versed in the handling

of the disease. This can generate a bias among some physicians, who refuse to test for or diagnose Lyme due to their beliefs that it cannot be transmitted in their area. Such biases were experienced by patients interviewed in this study. Even if a physician is not biased against Lyme disease, he or she might fail to reach a proper diagnosis or treatment because the patient might not have a rash, the patient might not remember being bitten by a tick, the patient's symptoms are flu-like and hard to distinguish from symptoms of other diseases, and thorough guidelines for treating chronic pain do not exist.⁴⁸ This creates a variance in treatment quality between endemic and non-endemic areas.

To overcome this, patients will often seek out treatment from infectious disease and Lyme disease specialists. However, these specialists are in short supply and are usually located in the endemic areas. Therefore, patients will drive or fly out of state to be seen by these specialists. This places a burden on the patient's time, energy, and finances.

In order to alleviate this burden, there needs to be an increased supply of providers who are knowledgeable about Lyme disease in both endemic and non-endemic areas, allowing patients to have access to the medical care that they need near their own homes. Public health education programs need to be created to ensure that high-quality treatment is available across the country. Additionally, reporting of the disease to the CDC needs to improve.

An example of more systematic reporting is found in British Columbia, where laboratory results of Lyme disease tests are automatically forwarded to Canadian authorities. These tests are only performed by one laboratory in the province. This decreases error in testing and reporting because the same interpretations of results are used and are consistently reported.⁴⁹ While such a system is impractical in the United States as a whole because it would limit access to testing, it would help to have a more-regulated system of reporting. Relying on physicians to report Lyme cases results in under-reporting of cases. Under-reporting makes it more challenging to identify endemic regions and target education efforts to such places. Therefore, better reporting systems are needed to make implementation of education efforts meaningful.

Chronic Symptoms and the Need for More Treatment

Chronic Lyme disease refers to the continuation of symptoms after the administration of antibiotics. Scientists debate whether the infection itself is persisting or if additional conditions have developed causing similar symptoms. Hypotheses regarding this debate include that the *Borrelia* infection persists despite treatment, that there is an autoimmune mechanism involved causing persisting symptoms, that the infection causes a genetic immunological response based on susceptibility, that the symptoms are due to post-infective fatigue syndrome that is common after many infectious diseases, and that the

symptoms are caused by fibromyalgia or chronic fatigue syndrome as a result of Lyme disease.

Studies have shown that repeated use of antibiotics does not lessen the severity of the symptoms.⁵⁰ It can be confusing to explain these symptoms because many of them (memory problems, fatigue, joint pain) are ailments experienced routinely by many people, not just Lyme patients. Studies trying to explain these symptoms have suggested that bacterial debris causes an immune response and glial apoptosis (death of glia tissue). Another study suggests post-treatment arthritis as the cause of the symptoms.⁵¹

Though there is much discussion over the potential existence of chronic pain symptoms, not enough attention has been given to treatment and alleviating chronic joint and body pain. Patients often experience pain for years after their initial tick bite or treatment. Thus, more attention needs to be given to funding and conducting studies of how to effectively treat these chronic issues, and not just to funding and conducting studies that try to explain their causes.⁵²

CHAPTER THREE

Analysis and Discussion

Chapter Overview

This chapter delves further into the three controversies identified in Chapter Two. In order to propose an agenda in Chapter Four for action regarding the challenges surrounding testing, uncertainty, and diagnosis of chronic Lyme, these issues are examined here from three distinct angles. These are termed the personal, relational, and population perspectives.

First, because Lyme disease is ultimately experienced by individuals, whether or not it is diagnosed, treated, or accepted by others, the initial perspective to be considered involves an exploration of the personal experiences that patients have with the disease. Examining each controversy from this perspective will reveal the motivation for finding solutions.

Second, while symptoms and suffering are internalized personally by patients, these experiences can be exacerbated or relieved by medical professionals and family members or friends. Exploring how healthcare providers contribute to these controversies will demonstrate how patients' quality of life is influenced by the dynamics of the patient-physician relationship. Additionally, considering the role of caregivers

and community in the process of suffering and healing will provide insight into how patients can confront these controversies and any additional tension in the healthcare field.

Third, Lyme disease is explored from a population perspective. The underlying viewpoint of epidemiologists is population health, which considers “the health outcomes of a group of individuals, including the distribution of such outcomes within the group.”⁵³ This perspective is pertinent here because it forms the basis of public health advocacy and policy. By examining how Lyme disease influences the American population and its constituent communities, researchers and public health officials can better inform policymakers about necessary changes to social determinants that influence health outcome.

Methodology

In order to fully explore the first perspective discussed above, three Lyme disease patients were interviewed to collect a narrative of their experiences. The interviews were evaluated for commonalities and differences between participants’ experiences, particularly pertaining to the three controversies proposed in this study. Participants were recruited from information gathered on the Lyme Disease Network website.

The Lyme Disease Network is a non-profit 501(c)(3) organization founded in New Jersey in 1991. In 1993, the Lyme Disease Network began the LymeNet website, which offers online libraries, legal resources,

newsletters, discussion boards, and information about support groups. Participants for this study were found by searching for support groups. To limit the scope of the search to fit within the amount of time available and the amount of information needed, only support groups in Texas were contacted.

After emailing the support group leaders for the five support groups in Texas, correspondence began with the leaders of the groups of three groups. The leaders contacted support group members, who were given the Principal Investigator's contact information. Fifteen potential participants were then sent the Informed Consent document and a summary of the research study. Once potential participants consented to the terms of the study, they were interviewed by the Principal Investigator.

Interviews were conducted by telephone or by email. When the interview was conducted by telephone, the participant was asked if the interview could be recorded. In all cases, the participant consented. The telephone interviews lasted 15 to 20 minutes. Both the telephone interviews and email interviews consisted of a combination of the following questions:

1. Can you briefly describe your experience with Lyme disease?

2. Were you satisfied with the care, education, and treatment provided by your doctor? What could s/he have done differently to improve your experience?
3. Were you able to access care close to home? Or did you have to travel out of city or out of state to find a doctor who is Lyme-literate?
4. What types of treatment did you undergo? How did these treatments influence your daily life and quality of life?
5. Did you feel like you could talk openly about your diagnosis with family, friends, and coworkers? Did you find resistance or bias from any doctors, family members, friends, or coworkers because of your diagnosis?
6. Did you rely on any family members or friends as caregivers? How did your diagnosis affect those who are important in your life?
7. Have you been part of any Lyme disease support groups? If so, what motivated you to get involved and how did they impact your experience?
8. Did you do any research about Lyme disease on your own? If so, how did you go about doing this? Did you find that reliable information was easy or hard to obtain? Did you use this

information when discussing your diagnosis and treatment options with doctors? How did they respond to your knowledge?

9. Overall, can you explain the biggest ways that Lyme disease has influenced your life? (physical abilities, cognitive functioning, finances, professional abilities, relationships, etc.)

The responses were informal (i.e., conversational, qualitative, subjective) in nature in order to allow for an organic narrative to be communicated. There were no possible risks to participants. In order to protect the participants' privacy, participants are referred to by randomly-assigned numeric identifiers throughout this study. Any identifying information is being kept anonymous.

In addition to interviewing patients with Lyme disease, a caregiver was interviewed so that her perspective could also be considered.

Controversy One: Testing and Diagnosis

Level One: Personal Level

Patients either learn about Lyme disease through self-education, public education, or clinical education. In modern society, self-education is becoming increasingly popular due to the availability of information online. Self-education allows a patient to gain autonomy and proactively seek information to inform future direction and treatment. "That medicine needs demystifying is an oft-repeated theme in [breast cancer

patient] narratives, which repeatedly describe how the world of medicine can seem alien to laypersons.”⁵⁴ This theme is also widespread across different diagnoses. Interviews with Lyme patients similarly depict a need for patient self-education in order to simplify otherwise advanced ideas.

This need is inherently rooted in the controversy over Lyme testing and diagnosis. When healthcare providers, researchers, and public health practitioners have varying levels of education and varying opinions about Lyme disease, patients are forced either to agree blindly about what individual practitioners tell them or to self-educate and form their own opinions about Lyme disease. Patients who self-educate often turn to other patients and the internet to voice confusion and seek answers.

The patients interviewed were found through the LymeNet website. This website includes information about both physical and electronic support groups. The physical support groups are more common in states where Lyme is considered endemic. The CDC reports that 95 percent of confirmed cases of Lyme in 2013 were reported in Connecticut, Delaware, Maine, Maryland, Massachusetts, Minnesota, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, Vermont, Virginia, and Wisconsin.⁵⁵ These states are home to 114 of the 214 support groups listed on LymeNet for the 50 United States and the District of Columbia.⁵⁶

Because 53 percent of the physical support groups are located in only 14 states, the electronic support group, found on LymeNet’s discussion board feature, allows people who might not have access to a physical support group or who need more immediate assistance to seek support. In this way, the development of electronic support groups (ESGs) has allowed people from all over the world to connect about Lyme disease.⁵⁷ The following table shows the amount of content on LymeNet’s discussion board.⁵⁸

Table 1: LymeNet Content

Forum	Number Topics	Number Posts	% of Total Posts
Seeking a Doctor	22,957	80,872	06.52%
Activism	2,717	16,886	01.36%
Medical Questions	99,615	917,026	73.95%
General Support	22,363	225,281	18.17%

That nearly 74 percent of posts on LymeNet’s discussion board pertain to medical questions is reflective of the confusion that patients experience with respect to this controversy. Both posters and the patients interviewed express feeling a sense of trust and camaraderie with other patients who understand their mutual experiences. A sort of legion of Lyme patients has formed through these ESGs because they are

able to share support and information that they do not find in relationships with healthcare providers or family and friends.

On one hand, ESGs are a huge step forward for the application of technology to medicine. In a culture that emphasizes the privacy of the physician-patient relationship, there is little opportunity for connection with other patients or informed discussion with people other than the primary care provider. By moving these discussions to the internet, patients have the freedom to form their own communities, voice their own problems, and discuss their own concerns without the oversight or restrictions of medical professionals. In these ways, ESGs can be a valuable part of a patient's personal experience with her testing and diagnosis. While this element of ESGs allows for independence and freedom for exploration, there are potential negative qualities of such groups.

First, content on the internet can easily be sensationalized. For example, Lyme disease patients posting on an ESG could write only about negative encounters, outcomes, and effects while overlooking any positive experiences. This draw toward the emotional experiences, the ones that grab the attention of fellow readers, could be attributed to the internet's widespread potential for anonymity. Without any real fact-checking or corroboration of experiences, one can easily establish any identity on the internet.⁵⁹

It is possible that people, especially when given this opportunity for anonymity, will choose the most extreme, interesting, devastating, or exciting stories to share, simply for the reason that nobody joins an ESG or social media site to read about other people's mundane lives. Because Lyme disease cases vary in severity and response to treatment, patients could be misled by reading sensationalized stories or by not understanding the differences between their own cases and those of the posters.

Overall, this information about the distribution of LymeNet's support groups and the content on their discussion boards points to a need for medical knowledge and support for patients. Where confusion about testing accuracy and diagnoses abound, there is an opportunity for self-education to fill a void. As patients embrace a Lyme disease diagnosis as part of their personal identities, they should be encouraged by providers to seek this knowledge and support. However, patients interviewed often felt that their own research and ideas were belittled, ignored, or rejected by physicians in impolite, insensitive, or abrupt ways.

Level Two: Relational Level

Power in the Patient-Provider Relationship. Historically in the medical field, there is an imbalance in knowledge and power between patients and providers, with the weight of power falling toward the providers. This gap is not inherently negative. In fact, if the gap did not

exist, physicians would not exist; there would be little need for physicians if patients were equally knowledgeable and equipped to self-treat illness. While this imbalance is inevitable in a patient-provider relationship, attention must be given to relationship dynamics to ensure that the patient is informed and that all care is seeking the patient's best interest.

However, tension is put on this relationship by the testing and diagnostic procedures for Lyme disease. Because current tests for Lyme disease have the potential for inaccurate results, it is possible for patients to live with misdiagnosed Lyme disease. Additionally, biases and miseducation that keep physicians from testing for the disease can leave patients searching for a diagnosis far after their initial infection with Lyme disease.

Patient's Role in the Balance. A patient's choice to self-educate, as discussed with respect to his or her own relationship with the disease, can drastically influence the relationship with the healthcare provider. While, ideally, self-education would result in a more informed conversation between patients and providers, it can create distrust and dissatisfaction for patients and frustration for providers.

This conflict is viewed by some as "undermining key aspects of physician authority"⁶⁰ and could stem from patients' newfound "up-to-date information on any medical condition, informed expectations about what constitutes appropriate practice, and considerable information on

the personal biography of their provider.”⁶¹ When patients self-educate about Lyme testing and diagnoses, they create an atmosphere where they, presumably less trained and educated about technical medical terms and processes than their providers, believe that they are equipped to make complicated decisions without the input of a trained healthcare provider. This can pervert an important level of patient autonomy and cause a reduced level of physician authority.

Provider’s Role in the Balance. Ultimately, the provider has more control over the dynamics of the relationship, even if she does not necessarily exert more power. Providers will inherently or actively follow a specific model of balance. Here, three models of the balance of power are considered: the paternalistic model, the independent choice model, and the enhanced autonomy model.

Some providers argue for a paternalistic model. The following is a definition of paternalism:⁶²

- A is acting paternalistically toward S if and only if A's behaviour (correctly) indicates that A believes that:
- 1) his action is for S's good;
 - 2) he is qualified to act on S's behalf;
 - 3) his action involves violating a moral rule (or will require him to do so) with regard to S;

- 4) S's good justifies him in acting on S's behalf independently of S's past, present, or immediately forthcoming (free, informed) consent, and
- 5) S believes (perhaps falsely) that he (S) generally knows what is for his own good.

According to patient testimony given in interviews, paternalism is demonstrated with respects to statements (1), (2), (3), and (5). For both S1 and S2, physicians hesitated to test for Lyme disease, even when asked, because of their beliefs about how and where it is contracted. This act of paternalism, the physician acting in what he believed to be the patient's best interest even though the patient believed she knew what is best, prevented patients from being diagnosed at an earlier time. This definitely prolonged suffering and potentially could have contributed to the patients' advancements to later stages of Lyme.

Another model of balance that opposes paternalism is called the independent choice model, described below:⁶³

Patient's experience and values dominate

Patient has independence and control

Patient-centered

Physician serves as passive informer

Zero-sum interaction (win/lose)

Control-based

Physician is detached operative

Physician abdicates responsibility to patient

While this model optimizes patient autonomy, it does so at the risk of harming the patient. A patient who self-educates online, in support groups, or through ESGs could fall victim to misinformation and sensationalized stories. These dangers could impair his decision-making. If a physician does not demonstrate some sort of paternalism to correct, educate, or redirect the patient, then improper care could be given.

A model that seems to take into account all of these considerations is the enhanced autonomy model, described here:⁶⁴

Knowledge and expertise are shared between patients and physicians

Patient and physician collaborate

Relationship-centered

Physician serves as active guide

Additive expertise (win/win)

Competence-based

Dialogue-based

Physician is personally invested in outcome

Patient and physician have joint responsibility for patient outcome

The concept of additive expertise in this model is important because it puts weight in the patient's opinions and ideas. Perhaps if physicians had practiced this model in the case of patients interviewed, then they would have been diagnosed and received treatment sooner.

A model like this is thus especially important in circumstances where the diagnosis is initially unclear. Because the symptoms of Lyme disease can easily be falsely associated with many other diseases, a physician's willingness to collaborate and dialogue with the patient towards finding the appropriate diagnosis could help speed up the diagnostic process. This includes a willingness to consider and test for any diagnosis that aligns with the symptoms. For these reasons, the enhanced autonomy model is the most appropriate in application to diagnosis and testing.

Lyme Literate Medical Doctors. There is a push in the Lyme community to find physicians who practice the enhanced autonomy model and who maybe even lean toward the independent choice model. These practitioners are called Lyme Literate Medical Doctors (LLMD). The appeal of LLMDs is their willingness to diagnose Lyme disease, sometimes even when the patient does not test positively, and willingness to consider more holistic or alternative treatments.

Conclusion of Relational Effects of Controversy One. Overall, the patient-provider relationship is most influenced by the patient's self-

education and the provider's adopted model. The most effective combination of these in order to minimize tensions and maximize the patient's experience is if a patient uses self-education with caution and discernment and if the provider chooses to welcome and encourage the patient to share knowledge and input for diagnosis and treatment, as in the enhanced autonomy model. These efforts by patients and providers allow for a quicker diagnosis, thus allowing for reduced economic burden and potential for improved quality of life.

Level Three: Population Level

In the CDC's report of cases of Lyme disease from 2004-2013, they separate cases as being confirmed or probable for the year 2013. According to the CDC's 2011 case definition, a suspected or probable case of Lyme disease involves (i) erythema migrans with no known exposure and no laboratory evidence of infection or (ii) laboratory evidence but no clinical symptoms.⁶⁵ A confirmed case involves (i) erythema migrans with laboratory evidence but no known exposure, (ii) erythema migrans with known exposure, or (iii) laboratory evidence of exposure for at least one late manifestation of symptoms.⁶⁷

While the CDC recommends the Infectious Diseases Society for America (IDSA) guidelines for testing, diagnosis and treatment of Lyme disease,⁶⁸ the International Lyme and Associated Diseases Society (ILADS) recommends its own guidelines.⁶⁹ The ILADS' guidelines assert that testing should support a clinical diagnosis rather than be the

exclusive determinant of whether a patient has Lyme disease. This debate is further evidence of the problems that arise due to differing opinions on Lyme disease.

These different diagnostic guidelines affect Lyme disease at the population level because they skew the reporting of cases toward the IDSA's guidelines. Cases diagnosed by physicians, usually LLMDs, that support the ILADS' guidelines will not usually be considered in the reporting data if they differ in testing styles or diagnostic methods from the recommendations in the IDSA's guidelines. This implies that members of a segment of the population are identifying themselves as Lyme disease positive and are receiving treatment while not being recognized statistically by the CDC. This has extreme implications for policy, budgeting of public health education resources, and insurance coverage.

In the CDC report, there were 9,104 reported probable cases and 27,203 reported confirmed cases in the United States in 2013. Thus 25 percent of the cases of Lyme disease nationally were considered probable rather than confirmed. The implications here are that

- (i) the list of diagnostic criteria is too exclusive, limiting which patients can be confirmed as having Lyme disease;
- (ii) the serological tests are producing too many false negatives or false positives, skewing the data and leading to mistreatment of patients; and

- (iii) physicians are misidentifying the symptoms of Lyme disease and are diagnosing patients with it incorrectly.

The reason that these implications need to be resolved through improved testing and diagnostic criteria is the impact that this diagnosis, or failure of diagnosis, can have on a patient's life.

Controversy Two: Culture of Uncertainty

Level One: Personal Level

One of the drastic effects that the culture of uncertainty surrounding Lyme disease can have is on a patient's perception of himself as a member of society. When a patient experiences pain that is not recognized by others, he is forced to respond by concealing his pain and continuing with daily life or by voicing his pain at the expense of normalcy.

This theme was repeatedly voiced by the interviewed patients. Patients cited other people's perceptions of Lyme disease as influences on their relationships. S1 does not speak with her dad because of his lack of understanding of her symptoms. As S3, now divorced, describes: "I do think [Lyme] put a big strain on my marriage because my husband really didn't believe me. . . . I don't think he really truly believed that I was in so much pain and discomfort and anguish."

In these situations where patients do not feel trusted and supported by those closest to them, it becomes apparent how deeply-

influential a general bias and lack of education can be. In order to understand their symptoms, patients must find resources to “organize their experiences, that is, to tell them what they are suffering with, to understand it as meaningful, and to define its role in their lives.”⁷⁰ These resources are found in the patient’s social sphere. As described above in the discussion of Controversy One, self-education can provide these resources. When a patient begins to understand his pain and symptoms in the context of his social sphere and his personal life, then he can begin to normalize his suffering.

Normalization allows a patient to view her health status as a regular part of her life. Any challenges that it presents to work, relationships, energy, and lifestyle are understood as a part of daily life with this disease. However, this process toward normalization demands that those around the patient accept her pain. Without this acceptance, physician and community uncertainty can keep patients from experiencing normalization because she is constantly reminded of her need to suppress or vocalize her symptoms.

To avoid these changes in relationships, patients might try to hide pain. These attempts are often futile because chronic symptoms have far-reaching effects on a patient’s lifestyle.

In America, pain accounts for 40 million visits with billions of dollars spent on health care. Annually, the disability associated with chronic pain is responsible for nearly a half

million lost workdays and hundreds of billions of dollars. The human costs in terms of strained relationships, depression and despair escape quantification.⁷¹

At some point, even those patients who are highly-skilled at concealing their suffering will have to investigate or discuss the cause of their symptoms because of the economic pressure, inability to continue working, and emotional distress that undiagnosed or untreated pain can cause.

S1, when asked about how her symptoms have affected her job and whether she tells people at work about her suffering and Lyme status, gave the following explanation:

I would never tell anybody unless I had absolutely no choice because I just don't think that people understand, especially when you're just doing your job... I'm having trouble because I'm in so much pain. It's hard to concentrate. It screws up your memory so bad. I've kind of learned to compensate. I will write down every single little thing I have to do so that I don't forget everything.

Whether or not people with whom Lyme patients interact have actual biases about the disease, the patients perceive that these biases exist. This perception of bias obviously influences how patients choose to portray their disease status.

While discussing his diagnosis with others seems like a clear way to help a patient and others understand his experiences, doing this can be met with certain judgments. Each patient interviewed described themselves as being pretty open about their disease status. However, as they would elaborate on their answers, it became clear that when talking with acquaintances and coworkers, they withhold information about their health except when absolutely necessary or when they absolutely trust the outside party.

Therefore, these patients could perceive themselves as being in open communication about Lyme disease and their symptoms when they actually are not. A lack of communication about symptoms could cause other people to perceive these chronic patients in certain ways, perhaps as lazy or unmotivated. Patients could then perceive their peers' responses as intentional biases. In order for patients to avoid this situation, they need to be mindful about how they are actually communicating about Lyme disease with others. If patients feel uncomfortable communicating about Lyme, then they need to be more mindful about how their lack of expression could be misleading. They also need to be cognizant that they perceive other peoples' responses fairly.

Level Two: Relational Level

Uncertainties and biases from providers can also prevent normalization. Physicians might resist testing for Lyme disease based on

their lack of education about Lyme. As discussed earlier, they could be misinformed, undereducated, or unethically influenced by other factors. Patients experiencing pain search for a diagnosis because it could lead to treatment, could help them communicate their experiences to others, and could validate that their experiences are understood and even expected.⁷² When physicians resist diagnosis because of lack of education, they have an unintentional but direct negative influence on the patient's ability to cope with disease.

Physicians who will not treat a patient based on a clinical diagnosis of Lyme instead of a serological diagnosis could leave patients with many untreated symptoms.⁷³ These symptoms affect patient's general health, gastrointestinal and genitourinary systems, psychological processes, head/face/neck, musculoskeletal system, mental capability, eyes/vision and ears/hearing, respiratory and circulatory systems, and nervous system. Such symptoms could easily be mistaken for other diagnoses. It is for this reason that all physicians need to be more educated about recognizing Lyme disease and about its testing procedures.

In addition to simply failing to identify Lyme when presented with seemingly unconnected symptoms, physicians could also fail to diagnose Lyme disease because they do not believe the patient's description of symptoms. Though rare, this is a controversial diagnosis called Munchausen's syndrome or factitious disorder. People with this

syndrome manifest symptoms in order to satisfy a need for attention.⁷⁴ This syndrome has also been expanded and called Munchausen's by Proxy. In these cases, a caregiver exploits, falsifies, or prolongs symptoms in a child in order to gratify his or her own desire for attention.⁷⁵

Munchausen's is a severe diagnosis or approach that rapidly deteriorates trust in the provider-patient relationship. If a patient believes that his complaints and needs are not being met by a specific provider, he might seek the opinion of another provider. However, because some providers might view this exploration as continued efforts to find attention, this kind of shopping for providers can be used as further support for a Munchausen's diagnosis.

Because of the controversy surrounding the legitimacy of Munchausen's and Munchausen's by Proxy, it is preferred that physicians use a higher level of discretion when questioning a patient's motives. By working in a healthcare model that encourages patient involvement in education and exploration, providers can improve their information available when making a diagnosis and can prevent the rare, accusatory diagnosis of these syndromes in cases of legitimate symptoms and disease.

S4 expressed that she and her daughter had many negative interactions with physicians. In these circumstances, the physicians approached her daughter with "disbelief, disinterest, dismissing [her] as

not having anything valuable to suggest, or denying the possibility of Lyme disease.” However, when S4 described her daughter’s effective treatment, she says that the physicians in that case “not only accepted the research [she and her family] had done and ideas but also believed [she and her family] were, in part, responsible for bringing these types of information into the treatment plan. These doctors included [her] daughter and [family] as part of the healthcare team. They also encouraged [her] to research and question the treatments they suggested and put into practice.” This is an example of the approach to the patient’s symptoms and experience that more physicians could take in order to eliminate biases and misconceptions.

Level Three: Population Level

The distribution of Lyme disease in America inherently creates pockets of uncertainty about the disease. In the areas where Lyme is endemic, there are more resources directed toward prevention and education than in areas where Lyme is not endemic. Additionally, physicians in endemic areas have more incentive to treat Lyme disease because of its prevalence. Thus, patients in endemic regions have better access to Lyme Literate Medical Doctors.

For patients in non-endemic regions, there are fewer resources, less educational efforts, and fewer skilled physicians. To combat these deficiencies, patients might choose to travel and spend more money to seek care. Additionally, patients could spend countless hours

researching their symptoms in order to figure out what type of physician to visit and what potential diagnosis they will receive. All patients interviewed did extensive research online in order to inform themselves for their physicians' appointments.

The burden of education does not fully rest on the patients' shoulders. The Take a Bite Out of Lyme Disease challenge began on March 1, 2015, to raise money for ILADS and to raise awareness for the disease.⁷⁶ The premise of the campaign is that people photograph or record themselves taking a bite out of a lime and post the footage to social media. Participants include a fact about Lyme disease in their post and tag friends and family members to also participate. Additionally, participants are asked to make a donation to ILADS' non-profit educational fund.

The purpose of a social media campaign like this is to modernize Lyme disease, making it relevant to today's popular forms of communication and making it entertaining to learn about. A similar movement called the Ice Bucket Challenge became globally popular in 2014. This campaign raised 21.7 million dollars for the Amyotrophic Lateral Sclerosis Association.⁷⁷ The Ice Bucket Challenge thus set a hopeful precedent that the Take a Bite out of Lyme Disease challenge will succeed in raising both funds and awareness to help reduce bias and confusion and reach people across the country.

Controversy Three: Chronic Lyme Disease

Level One: Personal Level

Regardless of the terminology used to define chronic Lyme disease, it is undeniable that some people who have been diagnosed with Lyme disease are experiencing chronic symptoms long after they stop treatment. These chronic symptoms that are in some cases debilitating can have an extremely negative influence on patients' quality of life. S1 recalls when "it was so bad that I was at a grocery store and I couldn't get through the store. I would have such bad fatigue and pain that I couldn't get through the store."

Because of the confusion over the pathology behind chronic symptoms, patients can be left confused about their disease status and future treatment options. Once S2 had completed all logical treatments for Lyme disease, she was diagnosed with fibromyalgia as an explanation for persistent body pain and fatigue. This update in her diagnosis brings a personal change in disease identity.

Identifying oneself with a certain disease entails accepting new attitudes or ways of thinking. First, patients identifying with chronic Lyme disease must accept new identity goals.⁷⁸ S3 recognized the need for new identity goals when she acknowledged that she cannot do everything at once. When she is taking care of her children, she has to plan time to take a nap and rest when possible. This embracing of

chronic Lyme to describe her symptoms consequently changed her maternal identity.

Second, patients with chronic Lyme must embrace a “loss of self.”⁷⁹ Because there is no conclusive explanation of or treatment for chronic Lyme, patients must become content with living in a medical mystery. Contentment does not imply complacency. Patients can continue to seek the best possible care and to educate themselves and others. However, patients will best adapt chronic Lyme as their disease identity if they view it as “life transforming, and they [experience] a sense of progress and [feel] empowered.”⁸⁰ S2 demonstrated this positivity when she acknowledged that her chronic Lyme experience has given her a sense of empathy and a desire to help other sick kids by working as a nurse. By embracing chronic Lyme rather than rejecting it, patients can best assimilate it into their personal identity.

Patients of chronic Lyme disease tend to live in cycles. They will treat the disease with antibiotics for a period of time. When the treatment ends, the patients usually stop taking medication for a period of time, often feeling better during this time. When patients’ health status starts to decline, they will seek treatment again. This cycle continues, usually based on how the patients feel rather than on what their tests for active Lyme disease say.

With each new cycle, there is the potential for a Jarisch-Herxheimer reaction (a.k.a. Herx reaction). As applied to Lyme disease,

Herx reactions are immunological reactions to the lipoproteins released by dying spirochetes within 24 hours of antibiotic treatment.⁸¹ While the specific science behind Herx reactions is still not known, understanding that symptoms can worsen when initially taking antibiotic treatment can help a patient be more prepared for the influence that this never-ending cycle of chronic pain will have on the patient.

Level Two: Relational Level

In order to advocate for themselves in communication with healthcare providers and with others, it is important that patients understand their identity and power. According to patient testimony, it is not uncommon for other people to respond to chronic symptoms by saying that the patients are imagining things or are heretical. Over time, patients can absorb these views as their own, no longer recognizing their influence or the importance of their experiences. How quickly or to what degree this happens depends on the patient's identity, described above, and the influence of people around him.

Patients are “more than the sum of their symptoms; they are also and always cultural products as well as being shaped by political economies and historical contingencies.”⁸² Some chronic Lyme patients are particularly vulnerable because of these cultural, political, and historical influences. In a web-based survey of 2,424 patients with chronic Lyme symptoms who were clinically diagnosed with Lyme disease and had positive testing, over 50 percent of respondents reported that

they saw more than seven physicians between the onset of symptoms and the diagnosis of Lyme disease. Over 60 percent of respondents reported traveling 51 or more miles for treatment of Lyme disease.⁸³

Visiting this many physicians and at this distance is an inconvenience to any patient, especially to one with functional limitations related to chronic Lyme symptoms. Therefore, these data represent a barrier to healthcare faced by Lyme patients. Because of the controversies discussed in this paper, Lyme disease is improperly recognized, diagnosed, and treated in many instances. These challenges thus keep patients from being diagnosed in a timely and convenient manner.

Historically, medicine is built around lasting relationships between patients and providers.⁸⁴ These relationships are imperative in order to build trust. Trust and an atmosphere of quality care can be strengthened by better management of chronic symptoms. Dissatisfied patients will break existing relationships and search for providers who will better serve them. This is an example of the patient power that is necessary for self-advocacy.

The data presented above indicate this patient power. While a majority of patients surveyed had the power to test different providers and travel to do so, this power comes with several expenses. The time spent visiting different providers delays access to treatment. Due to the controversies surrounding Lyme disease, these different providers will

inevitably have differing opinions. Inconsistent information breeds patient confusion and distrust of providers. Also, it is impossible for patients to develop lasting relationships with their providers if they are constantly searching for a new one. For these reasons, patients should seek the highest quality of care available within financial reason, but not at the expense of developing enlightening, trusting relationships with providers and not at the expense of access to treatment.

Level Three: Population Level

In an analysis of the effects of chronic disease, defined as conditions lasting more than a year and limiting daily activity or requiring medical attention, four out of every five healthcare dollars in 1998 were spent on chronic conditions.⁸⁵ Per this definition, chronic Lyme disease, or at least the conglomeration of chronic symptoms experienced by some patients previously diagnosed with Lyme, is classified as a chronic disease. Therefore, helpful methods being used to reduce the burden of more prevalent chronic diseases can be applied to reduce the burden of Lyme disease.

Three ways to reduce these burdens are by preventing the disease, detecting it early, and minimizing symptoms.⁸⁶ Prevention efforts for chronic Lyme will follow directly from prevention efforts for Lyme disease. S3, when asked what she would say to educate her family members or the public about Lyme, said she would “urge the public to use natural-based insect repellants and to perhaps avoid certain areas in the

outdoors around peak breeding seasons.” Simple methods like this can be used to reduce exposure to ticks.

Detecting Lyme disease early requires effort on the part of individuals and healthcare providers. Individuals need to be more diligent about recognizing ticks quickly and removing them appropriately. Community health education or education on the part of school nurses could help further this knowledge. Additionally, healthcare providers need to be more educated on the testing and diagnosis of Lyme disease, eliminating any uncertainties.

Until there is a specific treatment for chronic Lyme, it is important that patients try to manage their symptoms. This could range from allopathic to homeopathic care. S3 minimizes her symptoms through diet modification and use of essential oils. Additionally, S2 and S3 both said that they have utilized acupuncture to try to reduce pain. These methods allow patients to normalize Lyme disease and to be in a better position to continue working and maintaining relationships.

CHAPTER FOUR

Implications and Agenda for Action

Chapter Overview

Action on the part of many different groups of people is necessary in order to address the controversial challenges that currently present barriers to the quality of life of Lyme disease patients.

Effects of Controversies

Debates over the accuracy of testing and which diagnostic method is appropriate negatively harm patients by delaying diagnosis. This can have serious economic and physical impacts. As Lyme disease goes into its second and third stage, the symptoms become increasingly debilitating and the cost of treatment increasingly expensive.

While these debates are currently necessary because the underlying issues have not been resolved, the persistence of these debates without resolution serves only to harm patients' personal well-being and their ability to acquire effective treatment. Additionally, they create a large imbalance of power between patients and providers. This contributes to patient distrust and confusion. The debates also influence the reliability of data regarding Lyme disease. The data currently available reflect diagnoses made following the IDSA guidelines.

This means that diagnoses made by providers following the ILADS guidelines are not included in the reportable diseases data.

Misinformation among healthcare providers and particular communities contribute to patients feeling harassed when they express their symptoms. Patients are thus forced to hide their health status or reveal it but with potential consequences in their relationships and workplace. This makes it challenging for patients to normalize their Lyme disease situation. Uncertainties can also lead physicians to diagnose patients with Munchausen's or Munchausen's by Proxy. These controversial conditions assert that patients are manifesting or feigning symptoms in order to receive attention. This creates distrust in the patient/provider relationship and can make finding a physician more challenging. At the population level, these uncertainties and biases can negatively influence how patients are viewed in the workplace and in their social circles.

Lastly, the polarizing differences in opinions over chronic Lyme disease can severely harm patients. While some physicians embrace chronic Lyme as a disease that needs continued treatment, others reject it completely, denying treatment.

Patients experiencing chronic symptoms must find ways to cope. To do this, they have to reimagine their future in the context of consistent pain and illness. They also have to mourn the loss of old activities, relationships, and characteristics that are no longer possible.

When their chronic symptoms are ignored, it is more challenging for patients to undergo this process of change.

Patients also spend undue resources of time and money to find physicians who will consider their chronic symptoms. Thus patients are less likely to have lasting relationships with providers because of the resources involved. Again, these shorter-term, long-distance relationships bring a lower level of trust and security.

Implications

Research. In order to reduce the controversy over testing, research needs to be directed toward more conclusive tests and diagnostic methods. Current shortcomings, such as patients experiencing false negatives initially or experiencing false positives after receiving treatment, can make the tests difficult to interpret. More accurate tests would speed up the diagnostic process.

Additionally, the debate over different diagnostic methods needs to be settled. Though the IDSA guidelines are the ones recommended by the CDC and used for reporting, physicians continue to use the ILADS guidelines. Physicians need to consistently use one method in order to eliminate patient confusion and to improve accuracy of diagnoses.

Patients can also respond to the controversy over testing and diagnosis by using more informed methods of self-education. While technology makes self-education easy and accessible, there are few gatekeepers to prevent the dissemination of false information. Thus

patients need to be mindful of anonymity on ESGs so that they are not misguided by people's potentially sensationalized stories and advice. Additionally, they need to educate themselves so that they are empowered and informed, but they still need to maintain a respect for their providers' authority and training.

Education. Uncertainties about Lyme disease can best be addressed through education. Ongoing education for physicians about advances in testing and diagnostic methods could lead to improved diagnostic and reporting accuracy. Additionally, patients could have a better experience if they felt free to express their symptoms and feelings about their diagnosis without the risk of being disrespected or dismissed by their providers.

To ensure the dissemination of accurate information, the ILADS and the IDSA need to collaborate. The current tension between the two groups, evidenced by their competing diagnostic guidelines, creates confusion for patients who self-educate. Collaboration between organizations, physicians, and the government to promote unified information would thus benefit patients by improving their ability to self-educate and by reducing uncertainties in medical and social communities.

Treatment. Regardless of a physician's beliefs about the validity of chronic Lyme disease, he needs to respect the patient's experience. Lyme

disease symptoms influence a patient's quality of life in many ways. Thus, improving the patient's experience necessitates that attention be given to the patient's symptoms. This calls for a more holistic, whole-person approach to care. By considering the patient's physical, mental, and emotional health and by be open to both traditional and alternative medical practices, physicians can better serve their patients' needs.

Concluding Remarks

By rethinking how we address Lyme disease, we can reduce the suffering of Lyme patients and empower them to live without the embarrassment and fear that are bred by biases and misinformation. While these issues pertaining to testing, education, and treatment are important, they are not the only points of tension and conflict in the healthcare field. Areas for additional research include how climate changes influence the breeding patterns of the ticks that carry Lyme disease, the possibility of Lyme disease being passed from a pregnant woman to her fetus, and the prevalence of unreported cases of Lyme disease. Improved knowledge in these areas would allow public health professionals to offer better prevention education and would allow physicians to offer more effective treatment.

APPENDIX

APPENDIX

The following summaries provide background information for the subjects interviewed:

Subject 1: S1

Subject 1 is a middle-aged female patient currently suffering from chronic Lyme symptoms. She was diagnosed with Lyme disease after she began experiencing symptoms similar to those of her twin sister, who also has Lyme disease. She began to feel better after three years of antibiotic treatment, so she ceased treatment. However, her symptoms returned in the fall of 2014, so she began antibiotic treatments again.

Subject 2: S2

Subject 2 is a female patient in her early twenties who was diagnosed with Lyme disease after five years of undiagnosed pain and suffering. She asked to be tested for Lyme though her doctor believed she could not possibly have it. She underwent antibiotic treatment for two years. After these treatments, her neurological symptoms subsided, but her joint pain and fatigue persisted. Because of the continued pain, her physicians diagnosed her with fibromyalgia.

Subject 3: S3

Subject 3 is a middle-aged female patient currently suffering from chronic Lyme symptoms. She sought out a diagnosis after learning about the disease from her husband at the time, who had Lyme disease, and

watching a documentary about the disease. Once diagnosed, she underwent multiple different antibiotic treatments. She now finds that she is best able to manage her symptoms through using essential oils and managing her diet.

Subject 4: S4

Subject 4 is a middle-aged female caregiver whose teenage daughter was diagnosed with Lyme disease. S4 expresses that it was very challenging to watch her daughter suffer for multiple years before being diagnosed. This prolonged lack of diagnosis caused S4 to research many diseases on the internet. She found that doctors were often unreceptive of her personal research and opinions about her daughter's health.

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