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## Lyme Disease in Kentucky: Prevalence, Awareness, and Diagnosis in a Conventionally Low-Endemic Area

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EASTERN KENTUCKY UNIVERSITY

Lyme Disease in Kentucky:  
Prevalence, Awareness, and Diagnosis in a Conventionally Low-Endemic Area

Honors Thesis  
Submitted  
In Partial Fulfillment  
of the  
Requirements of HON 420  
Fall 2020

By  
Rachel Lyn Carden

Mentor  
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Biological Sciences

## Lyme Disease in Kentucky:

### Prevalence, Awareness, and Diagnosis in a Conventionally Low-Endemic Area

Rachel Lyn Carden

Dr. Marcia Pierce, Biological Sciences

#### **ABSTRACT**

Lyme Disease is the fastest-growing vector-borne illness in the United States – including in low-endemic states, such as Kentucky; given Kentucky’s low Lyme disease incidence in prior decades, it has since experienced an increase of cases despite a lack of discussion on the condition and its implications on patient health and wellbeing. To measure current levels of knowledge and awareness of Lyme disease in Kentucky residents, a survey was distributed to Microbiology and Honors Program students at Eastern Kentucky University, and its results were discussed. While Lyme disease cases do continue to rise, the general public of Kentucky lacks in substantial discussion on the implications of this health condition. Lyme disease is an uncommon condition, an invisible illness, and a complex infection that mimics myriads of other illnesses, which effectively contributes to low levels of public awareness of the condition. This consideration can directly impact patient experience during Lyme disease infection, and contribute to lower patient quality of life, mental strain, lack of support and negative patient experience during the course of Lyme disease infection.

**Keywords and phrases:** Lyme disease, epidemiology, microbiology, bacteria, vector-borne, tick-borne, awareness, Kentucky, *Borrelia burgdorferi*, diagnosis, treatment, tick.

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I would also like to send the biggest thank you to my parents Carol and Mike, the rest of my family, and my roommates as well. This thesis idea has been close to home because I had late-stage Lyme disease throughout much of high school, and my parents and family witnessed every high and every low of that period of my life. My family supported me, comforted me, and were with me every step of the way during that period of my life and are there with me through this new period, where I can use that past part of my story to create and hopefully impact others through this thesis. They were the ones that encouraged me to pursue this topic start to finish, along with my ECU mentor who helped me make it a reality. My roommates encouraged me in the entire process of planning, writing, finishing, and celebrating this thesis. Without all of these people in my circle this thesis, and the past that led to it, would have been much harder.

## **Lyme Disease in Kentucky:**

### **Prevalence, Awareness, and Diagnosis in a Conventionally Low-Endemic Area**

#### **BACKGROUND AND RATIONALE**

In the autumn of 1975, a cluster of children and adolescents residing in and around the area of Old Lyme, Connecticut displayed a mysterious and prevalent outbreak of what was assumed to be juvenile rheumatoid arthritis (1). Doubting that a widespread occurrence of juvenile rheumatoid arthritis was the sole etiology behind the childrens' symptoms, a handful of the patients' mothers sought medical aid from the Connecticut State Department of Health, and from Yale School of Medicine; within a short time, this scenario would ignite a full investigation by Yale School of Medicine's Dr. Allen Steere, MD, and Dr. Stephen Malawista, MD, into what is now identified as Lyme disease (1).

As time passed into the following year, this team of researchers discovered an association between the occurrence of these arthritis-presenting symptoms and a bullseye-shaped skin lesion known as erythema migrans (EM), as well as acknowledging a link between this specific skin rash and recent tick bites (1). In 1982, the scientist Willy Burgdorfer began to study Lyme disease, and correctly identified the infective agent of Lyme disease as a spirochete bacterium (2). This bacterium, named *Borrelia burgdorferi* after this researcher, was the missing piece of the puzzle past research had not been able to identify. With new knowledge of how tick bites caused people to fall ill, these researchers and the Connecticut State Department of Health concluded that the high population of ticks in the vicinity of Old Lyme, Connecticut translated into a high number of human residents in the area receiving tick bites, and that some form of

bacterium within these ticks was migrating into these people and presenting as a systemic and multi-stage illness that most commonly presented a round skin lesion, arthritis, fatigue, pain, flu-like symptoms, a stiff neck, and headaches (3) – Lyme disease.

As of now, Lyme disease is a much more readily-recognized bacterial infection that has since expanded from this small Connecticut township to affect – in some capacity, be that great or small – every contiguous U.S. state. Our society's, and the United States', medical understanding of Lyme disease is much more concrete and well-developed as of today, and Lyme disease research has continued and vastly expanded since the initial exploration of this illness in the late 1970s. This thesis focuses largely on said research concerning Kentucky.

This being said, there is a substantial amount of background information that is essential for a reader to understand in order to fully engage with the rest of this thesis. Lyme disease is a complex infection that includes multiple stages and, in many cases, presents symptoms of seemingly every common medical ailment. Due to the very nature of this condition, it is worthwhile to explore the pathology, mechanism of infection, clinical symptoms and stages of infection, effects on quality of life, and current treatment protocol for Lyme disease before discussing the medical and societal implications of this condition in Kentucky.

To begin, Lyme disease is a bacterial infection that has the ability to affect every human bodily system. The causative agent of Lyme disease is the spirochete bacterium *Borrelia burgdorferi*, which resides in the midgut of multiple tick species found in the contiguous United States. By far, the most common vector of Lyme disease in the United States is the blacklegged tick, (*Ixodes scapularis*) also referred to as the deer tick. This

species of tick is the most common transmitter of Lyme disease, and is found in the eastern half of the United States, which includes the northeast, much of the mid-west, eastern, south, and southeastern regions. In the western United States, the western blacklegged tick (*Ixodes pacificus*) is closely related to the deer tick and is another known vector of Lyme disease (1).

These tick species are also known to transmit numerous other tick-borne bacterial infections, such as Babesiosis, Anaplasmosis, Ehrlichiosis (4). As this thesis will expand on, it is possible that multiple bacterial infections can be transmitted into a patient from one tick bite, and multiple tick-borne comorbid infections (often abbreviated as “co-infections”) can occur at the same time in one patient. These comorbid infections are often transmitted to a person at the same time, as ticks can harbor many different bacterial infections simultaneously.

These tick species can be infected by *Borrelia burgdorferi* at any point in their lifespan. Their two-year long lives include three different stages of development – larvae, nymph, and adult – which each require the tick to feed a blood meal from an animal host to mature to their next life stage. Each time a tick feeds on a host, the tick transmits multitudes of bacteria, including *Borrelia burgdorferi*, into that host. While these blood meals allow the ticks to mature and sustain themselves, they simultaneously nourish the multitudes of bacteria commonly found in the ticks’ midgut after the tick’s initial infection.

Both species of blacklegged tick feed off varying species of mammals during their different life stages; tick larvae hatching in the summertime feed on small animals such as robins and other birds, chipmunks, and most markedly, the white-footed mouse. These



animals (especially white-footed mice) do not present Lyme disease symptoms, but are often incessantly infected with *Borrelia burgdorferi* and other bacterial infections through continual tick feedings, and therefore commonly serve as a continuous reservoir for Lyme and other tick-borne bacteria (5). Thus, many black-legged ticks generally acquire multiple bacterial infections through feeding on these animals, and then transmit these same infections back into these same reservoir species during their second blood meals to create a cycle that keeps *Borrelia burgdorferi* bacteria alive.

As these ticks mature into nymphs, they feed on these small animals again. This nymphic stage of the tick's life is also most commonly when ticks feed on, and transmit tick-borne infections to, humans as outdoor activity in people increases at the same season that these ticks generally seek a host. Nymph ticks are incredibly small and can easily avoid human detection while they can continuously feed, being only the size of a poppy seed (5). As these ticks grow once again into their adult life-stage, they seek a third meal from larger mammals, such as white-tailed deer, dogs, and cattle. These animals – most notably the white-tailed deer – serve as means of transportation to surrounding areas, a meal source, and a breeding ground for adult ticks (5).

Noted explosions in deer populations – as well as the expanded presence of deer, mice, and robins in suburban areas – have been thought to be partially responsible for the upturn in recent Lyme disease cases (1). Increased presence of these animal hosts in close proximity to people and their land allows for more frequent opportunities for ticks to land on and feed off people and their pets (such as dogs and horses) – and thus allows for greater incidence of tick bites on humans, and rising incidence of tick-borne illnesses. This is not necessarily the only cause for the recently increasing incidence Lyme disease

cases, but it could very likely be a partial reason and explanation, of many, as will be expanded on shortly.

As it is hopefully apparent, it is important to discuss blacklegged ticks as a means of transmission of *Borrelia burgdorferi* so that Lyme disease's mechanism of infection and pathology can be understood, within the context of its being a tick-borne illness. Thus, it is also worthwhile to briefly examine the bacterium *Borrelia burgdorferi* so that the clinical symptoms and effects of Lyme disease infection can be most clearly understood.

As noted by various researchers, *Borrelia burgdorferi* is a spirochete (i.e. corkscrew-shaped) bacterium; this is a class of bacteria distinguished by their cylindrical shape, and includes various bacteria such as the pathogens that cause syphilis, tick-borne relapsing fever, dysentery, and leptospirosis (6). Spirochete bacteria are particularly resilient as their shape allows them to 'walk' along the bloodstream of an infected host (in this case, a person) – akin to a child on monkey bars – through a series of broken and re-joined chemical bonds (6). Furthermore, the Lyme disease-causing bacteria has demonstrated an ability to mask themselves from the immune system via the use of biofilms (7). As researcher Eva Sapa of the University of New Haven suggests, biofilms are colonies of bacteria that aggregate together, attach to a surface, and then blanket themselves with secreted polymers. This allows the bacteria to effectively hide from immune system detection (8).

Furthermore, unlike many other types of bacteria, spirochetes' (including *Borrelia burgdorferi*) cylindrical shape allows them to 'screw' their way into tissue; due to this ability, Lyme disease can affect all parts of the body and is not limited to the circulatory

system. Once these bacteria have escaped the host's bloodstream and have infected various organs and/or tissues, they are then able to evade the body's natural immune system (which is limited to the bloodstream) and can replicate freely. This curious ability of spirochetes is a large part of why such infections were so hard to understand in the past, and still complex to fully understand today.

This all considered, the symptoms of Lyme disease directly reflect the unique way *Borrelia burgdorferi* migrates and affects the human body. Lyme disease has three distinct clinical stages: early localized or stage one, early disseminated or stage two, and late stage or stage three (9). The first stage of Lyme disease is the early localized stage, when *Borrelia burgdorferi* has not yet exited the patient's bloodstream and has not migrated into various parts of the body (9). This stage is defined as lasting one to four weeks, and is the most crucial time for Lyme patients to be diagnosed and to receive antibiotic treatment as the bacteria have not yet disseminated throughout the body.

The erythema migrans (EM) skin lesion is defined by the CDC as a red, bullseye shaped skin rash that occurs 3 to 30 days after an initial tick bite, with an average latency period before rash formation being around seven days (9). A present lesion is identified to be one the first identifying markers for Lyme disease by the CDC. However, it is noted that this rash may not occur at all in 20-30% of cases, and can also form misshapen instead of in its typical bullseye pattern, or simply may not be detected in a timely manner. Despite these factors, a present EM lesion is a major telltale symptom of early Lyme disease, and should still be regarded as an indicator of possible stage one Lyme disease. Other early Lyme disease symptoms may include various flu-like symptoms, fatigue,

headache, inflammation, muscle, joint pain and swelling, a stiff neck, fever, chills, and swollen lymph nodes (9).

Beginning early on, Lyme disease has a certain aptitude for mimicking many other serious diseases such as mononucleosis, influenza, chronic fatigue syndrome, arthritis, lupus, Multiple Sclerosis, various cognitive disorders lupus, and even Alzheimer's disease, among others. For this reason, Lyme disease is sometimes nicknamed the 'great imitator' because its manifestations mimic the symptoms of many other medical conditions. Lyme disease symptoms can also often appear to be many vague, randomized symptoms affecting the entire body. Aside from the erythema migrans rash and certain qualities about Lyme-specific joint pain and arthritis, most symptoms seem to be imprecise and systemic symptoms, and no one symptom can be utilized for diagnosis as a surefire symptom of Lyme disease infection.

The second stage of Lyme disease, the early disseminated phase, can begin after the first thirty days of infection and last up to four months (9). This stage's symptoms generally include a more severe version of stage one symptoms as the bacteria further spread throughout the body and affect multiple regions of the body. In this stage, if the *Borrelia burgdorferi* bacterium comes into contact with nervous system tissue, inflammation of said tissue may cause an onset of mild to moderate neuro-cognitive symptoms (9). The bacteria may invade the tissues of the heart and cause pericarditis, also referred to as Lyme carditis, and interfere with normal electrical signaling. This can cause palpitations, or may progress into an atrial-ventricular block in up to 80-90% of all patients with Lyme carditis (10). If Lyme carditis progresses into a heart block, the hearts beats too slowly due to electro-signaling being blocked between the heart's atria and

ventricles. Thankfully, this condition usually resolves with antibiotic therapy to treat Lyme disease as a whole. Patients also may notice additional EM rashes on completely different parts of their body than the initial rash, as the bacteria still circulates through the bloodstream. Other notable symptoms include migratory arthritis (which usually occurs in a large joint, can switch between joints frequently, and is not caused by any other type of arthritis), Bell's palsy, meningitis, mental 'fogginess' (clouded mental functioning and mental fatigue), and even ocular inflammation (9). By this stage, patient quality of life can be moderately reduced, depending on individual patient experience, contextual factors, presence or lack thereof of treatment, and illness progression (11).

If Lyme disease stays untreated or is otherwise unresolved for many months or even years, it can progress to leave patients with serious symptoms and lasting damage on a person's joints, muscles, central nervous system, and other bodily functions during the late disseminated stage. By late-stage Lyme disease, *Borrelia burgdorferi* bacteria have spread across the body, and its major symptoms primarily concern joint and muscle pain and neurological manifestations. Part of what makes late stage/disseminated Lyme disease so particularly complex is that the bacteria can spread throughout the entire body, including all major organs, and there is no way to contain infection to just one part of the body because of bacterial access to the bloodstream. Symptoms of stage three Lyme disease include moderate-to-severe fatigue, severe arthritis and swelling in joints, sleep issues, Lyme carditis, Bell's palsy, additional EM rashes on the body, severe headaches and neck stiffness, cognitive difficulties such as memory loss and forgetfulness, inflammation of the central nervous system, musculoskeletal and joint pain, bone pain, dizziness, shortness of breath, flu-like symptoms, and peripheral neuropathy (11).

Additionally, up to 40% of Lyme disease patients may also develop neuropsychiatric disorders – such as various forms of depression or anxiety, mood disorders, panic disorders, and et cetera – during or after active Lyme infection (12,13); this is likely attributed to the great deal of mental stress an infection such as Lyme can cause in patients, as well as the high levels of inflammation *Borrelia burgdorferi* can cause to the nervous system (14). Lyme disease affecting the central nervous system has been observed to cause Lyme-related meningoencephalitis, brain infarction in small blood vessels, and inflammation in the body and central nervous system (13). Any concurrent physical, cognitive, intellectual, or psychiatric health conditions can cause further mental and physical strain in patients.

Within medical circles, there is subjective uncertainty on if Lyme disease can progress into a chronic form, even after normal antibiotic treatment for a standard thirty day period. Ideas revolving around chronic Lyme disease generally involve two camps, with one group of researchers claiming that some Lyme disease infections are able to ‘persist’ in the body and evade antibiotic treatment through the utilization of bacterial biofilm creation (14), while others claim that in some cases (termed Post Treatment Lyme Disease Syndrome or PTLDS) damage can be so greatly done to the body during active infection that some effects, such as joint pain, may still linger even if active Lyme disease is successfully treated (15).

The CDC currently supports investigation into PTLDS and acknowledges this syndrome as a form of long-lasting Lyme disease effects; it also seems to be the most medically-probable option for explaining long-lasting Lyme disease symptoms. Concurrently, new research is emerging about this first camp of ideas concerning Lyme

disease's ability to evade detection in the body, and more researchers seem to acknowledge that all stages of Lyme disease may not respond so quickly and responsively to a standard dose of antibiotics. Long-term antibiotic therapy generally seems to do more harm to the body than good and is not recommended for most bacterial infections and individual circumstances, but the question has been raised of if a standard-length antibiotic course for Lyme disease treatment may not fully cure, for example, infections that have been in their late disseminated stage for months to years. Both sides are worth investigation into as more research emerges, as the idea of long-lasting Lyme disease effects have generally not been heavily researched until as of late.

Thankfully, Lyme disease infection is generally responsive to treatment via antibiotics, and in early cases a standard one-to-four week course of antibiotics prescribed by a physician (after confirmation procedures for diagnosis) should clear up infection. As no single drug, combination of drugs, will treat all cases of Lyme disease with certain 100% effectivity, treatment is generally individualized based on the patient's stage of infection and dissemination, presence of other tick-borne co-morbid infections, and patient response to treatment (16). The specific antibiotic a patient is prescribed is based on factors such as level of dissemination, presence of CNS-related symptoms, with the most common drugs prescribed for Lyme disease being doxycycline, amoxicillin, cefuroxime, as well as the recommendation of using non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen for pain management (17).

A part of the treatment process for some patients with spirochetal infections (such as Lyme disease and syphilis) includes a temporary worsening of symptoms and general pain, known as a *Herxheimer reaction* (18). Lyme disease patients whose infection is

disseminated may notice that their symptoms seem to flare up and intensify upon the patient's starting an antibiotic course; common to all spirochetal infections, a *Herxheimer reaction* is a systemic bodily response that begins when medication effectively kills infective bacteria – such as *Borrelia burgdorferi* – and inflammatory cytokines are released. In response to these protein cytokines, the body launches an inflammatory response one to three days after an initial antibiotic dose, causing fever, cognitive functioning difficulties, stiffness, headache, pain, tachycardia, and a general worsening of the patient's infection-related symptoms (18). Counterintuitively, the presence of such a reaction can indicate that an antibiotic course is successfully clearing bacterial infection, and its symptoms differ from those of both allergic reactions and adverse drug reactions (18).

Overall, Lyme disease is a complex bacterial infection that can affect a patient physically, mentally, and therefore functionally. While it has and can affect patients from all regions of the United States (and in a vast list of countries), this thesis will focus on the effects of Lyme disease on Kentucky residents. This is because Kentucky is a state that is generally not heavily researched when it comes to Lyme disease incidence, and the aim of this thesis is largely to incite and contribute to discussion of Lyme as it impacts Kentuckians. While Lyme disease is not relatively common in Kentucky, it does occur in the state, and cases have increased over time while many members of the general public and some healthcare professionals are not familiar with tick prevention strategies or Lyme disease symptoms. This being acknowledged, there is little-to-no substantial research being done on the health condition as it exists and impacts people specifically in Kentucky, which may contribute to continuing disregard of the condition by Kentucky and United States



residents. Lyme disease is by no means endemic in Kentucky, but this does not mean that the condition is not worth researching, preventing, and being knowledgeable of. This thesis will explore past and current trends in Lyme disease diagnosis, and how this may be reflected in current levels of knowledge of the condition in Kentucky residents. With this discussion, this thesis will also explore how these two factors can impact timely diagnosis and treatment outcomes in patients with Lyme disease, as well as the effects of this illness on a patient's health, wellbeing, and functional ability in order to assess exactly how Lyme disease impacts Kentuckians medically, perceptually, and in terms of wellbeing and ability post-diagnosis.

While Lyme disease is much more relatively uncommon in Kentucky than it is in other regions of the United States, cases are still significantly rising each year, while Lyme disease still goes under-discussed and under-researched in Kentucky despite its very real potential to impact patient quality of life. This serves as a reminder that Lyme disease, however low-incidence it may be, is present in Kentucky, and that alone is enough reason to more frequently discuss Lyme disease in academia and simply in common conversation. To build upon this, as a survey of Eastern Kentucky University students suggests, even many Kentucky residents likely do not find themselves to be knowledgeable about Lyme disease to the point they could reliably notice symptoms and distinguish them from other infections if they fell ill. Overall, the general public of Kentucky does not seem to be particularly knowledgeable about Lyme disease and its transmission and symptoms, nor do Kentucky residents have a working awareness of tick prevention strategies or tick-borne illnesses.

Discussion of these two factors also has implications concerning diagnosis, as low levels of awareness and general knowledge of Lyme disease can significantly impact timeliness of Lyme disease treatment in patients. Every person living in Kentucky has the potential to experience the multiple effects Lyme disease themselves, be that through firsthand experience or through knowing another person with this health condition. Either way, it is an increasingly relevant topic that truly does have meaningful and important implications.

Lyme disease is undoubtedly such a potentially complex illness with a relatively short time frame between initial exposure and systemic infection, and there is no expectation for every person to be an expert on Lyme disease. While this thesis mentions the importance of awareness again and again, its goal is not to assert that every Kentucky resident must know every clinical detail about Lyme disease there is to know – instead, a healthy level of personal and social awareness of Lyme disease is the first step to prevention and early recognition of symptoms. A knowledge of basic tick prevention and removal and ability to identify an EM rash and Lyme disease symptoms, even with their vagueness and commonality to other illnesses, can prove vital to someone needing timely medical attention for a possible Lyme disease infection. The overarching purpose of this thesis is to initiate conversation about Lyme disease's presence in an area that is not endemic, and a discussion on the medical and social implications of its rising incidence. The research based on awareness this thesis explores will contribute to limited available data regarding Lyme disease as it relates to Kentucky, and hopefully encourage future research as well.

## **RESEARCH QUESTIONS AND THESIS STATEMENT**

Extant literature on Lyme disease's implications and effects in Kentucky raises the following research questions: is Lyme disease incidence increasing over time in Kentucky, even with its past identity as a relatively uncommon region for Lyme disease transmission? If so, what has possibly contributed to this rising incidence? Are current perceptions and knowledge in the general public of Lyme disease congruent with its increasing amount of cases in Kentucky? What is the average level of knowledge concerning Lyme disease in college students at Eastern Kentucky University, and do any of these students have personal or second-hand experiences with Lyme disease? What are the medical, social, and societal implications of low awareness for Lyme disease, and can this effect the timeliness and patient experience in the process of Lyme disease diagnosis in Kentucky residents?

These questions advance the following thesis statement: Lyme disease is a complex bacterial infection that is relatively uncommon in Kentucky; however, its occurrence is increasing in the state while there remains to be a lack of widespread public discussion and awareness of this illness to match this rising incidence. Lyme disease can significantly impact patient health while dually impacting a patient's psychosocial and contextual wellbeing, and this lack of discussion of Lyme disease paired with low-ranking healthcare and low health literacy in Kentucky further disadvantage patients with this condition in the state.

## **LITERATURE REVIEW**

Given all this information, Lyme disease is an infection that has the potential to be either acute or serious, based on patient reaction as well as the timeliness of diagnosis and treatment. Lyme disease is a highly manageable infection with few residual effects if caught, diagnosed, and treated early. However, it can progress to a late-stage infection that

highly impacts the function, ability, and quality of life of patients if it goes untreated. Lyme disease is also increasingly on the rise, both in the United States and in Kentucky specifically, and its past and present incidence trend indicates that it will continue to exponentially increase throughout the next decade and beyond. While the Northeastern and Midwestern regions of the United States are in no doubt hotspots for Lyme disease transmission, and observe much higher rates of Lyme disease cases than Kentucky ever has, this does not negate the fact that Lyme disease incidence is steadily increasing in Kentucky and that it likely will continue rising. Kentucky is also where these two regions meet as Lyme disease cases become increasingly high in southern states. As Lyme disease transmission becomes more and more common and higher incidence rates so-to-speak spread southward, Kentucky finds itself as a unique meeting point between two very high-incidence regions.

In the upcoming sections, the past and current incidence rates of Lyme disease in Kentucky will be analyzed to predict future trends. Later on, the implications of this increasing prevalence will be evaluated – such as what a future with higher incidence of Lyme disease in Kentucky might mean for the general public and how it might impact current levels of awareness. In a brief summary, if the general public has a low to moderate level of awareness of Lyme disease, but the condition's incidence continues to rise, this can negatively impact the health and proactiveness of the general public in terms of prevention and recognition of Lyme disease symptoms and infection.

Additionally, another section will analyze how both of these ideas impact diagnosis and patient experience during active infection. It will also discuss the stages of Lyme disease and how they pertain to diagnosis, the diagnostic process of Lyme disease, and

exactly how it is diagnosed clinically. However, this section will also analyze diagnosis in terms of its effect on patient health, quality of life, functional ability, and how healthcare, socio-economic systems, and resources in Kentucky might support (or provide a lack of support) a patient with Lyme disease. This section will also explore how an individual's patient experience post-diagnosis might be impacted by their pre-infection level of awareness and healthcare knowledge.

### **Prevalence in the United States**

The Center for Disease Control (CDC) now estimates that in the United States as a whole, there are on average around 300,000 diagnosed cases of Lyme disease per year (20). Over 96% of these cases are of people living in the Northeast and Midwest, but over time higher incidence rates have 'migrated' and begun to occur in higher prevalence in other U.S. regions and states. To gauge annual incidence cases in Kentucky, the total numbers of cases in the United States as a whole must be assessed. In the past, (albeit, the CDC only provides data up to 2018), the CDC estimated that 34,971 people were diagnosed with Lyme disease per year (21). This number was based on reported cases made by doctors treating patients with Lyme. However, two new studies launched by the CDC in 2018 aimed to find the actual number of people clinically diagnosed with Lyme disease through laboratory testing, and these studies found that the actual number of cases in the United States per year could actually likely be around 300,000, and may be as high as 444,000 cases per year.

This being said, these two values of 34,971 and +/- 300,000 have a vast disparity between them, and more research is needed to confirm one value over another. The CDC seems to currently favor the larger estimated value, but they do explain that all estimated

incidence rates are best guesses, and rely on doctors actually reporting Lyme disease cases. State-level annual reports are also based on the state and county a person with Lyme disease lives in, and not the state and/or county they may have gotten a tick bite in. Their 2019 and 2020 data on U.S. and state Lyme disease incidence is also not currently published on the CDC website and related data banks.

This all being said, their current U.S. incidence rate of 300,000 cases per year does line up with state-level reported cases, and reflects a significantly growing incidence rate every two-to-three years. This estimate raises the question of if all incidence rate reports prior to the 2018 studies were accurate, or if they were “low-balled” and only reflect a fraction of the true number of Lyme disease cases per year. If this is true, past numbers of Lyme disease cases could be much higher than what they were reported to be on both the national and state level, simply because of the surveillance mechanisms used in the past. Conversely, prior average estimates of +/- 34,000 cases per year from 2010-2020 could also be correct if the two 2018 surveys that suggest an estimate of 300,000 cases per year are found to be incorrect. More research into the validity of both estimates would benefit future reporting, prevalence estimates, and general knowledge of Lyme disease prevalence.

Based on past estimates prior to 2018, the CDC reported a total number of 9,465 Lyme disease cases in the U.S. in 1991, and by 2000 this number had nearly doubled at 17,730 annual cases (22). From 2000 to 2010, cases went from the 2000 annual value of 17,730 cases to 30,158 cases, and by 2018 there were 33,666 reported cases nationally. It should be noted that prior to 1998, the CDC notes that reporting for Lyme disease cases was not nearly as common, and this could mean the true number of Lyme disease cases is higher than what yearly estimates show. It is also noteworthy that in 2008, the means of

nation-wide surveillance and reporting for Lyme disease was reformed, and the category of ‘probable case’ was added for reporting purposes. These two time periods and events brought on subsequent surges in reporting Lyme disease diagnoses.

### **Prevalence Rates in Kentucky**

In order to evaluate the effects of Lyme disease on Kentucky residents, the incidence of past, present, and predicted future trends of Lyme cases in the state must be assessed. To gauge past incidence of Lyme disease, statistical records from the Center for Disease Control (CDC) will be evaluated. All considerations and trends from these past and present time periods will be utilized to form an estimate about future trends we might see about Lyme disease in Kentucky (i.e., if it appears that Lyme disease cases in the state will likely increase, plateau, or decrease within future decades). The past section on United States Lyme disease incidence rates, including the newer increased estimates included in 2018, is important to consider in relation to Kentucky’s past and current trends of Lyme disease cases.

In terms of specific case numbers, state-specific reports are listed on the Morbidity and Mortality Weekly Report (MMWR), a now-subset of the CDC that releases weekly and annual reports on transmittable illnesses present in the United States, including Lyme disease. Lyme disease reporting data for Kentucky is included in this report, starting at 1990. Over the 1990-2000 decade, Kentucky observed a fluctuation of cases, with the lowest being 16 and a peak being 44 cases. The average incidence rate for this time period was .3 cases per 100,000 residents. From 2000 to 2010, the average incidence rate for the state was .2, with a peak of .4 in 2013.

In terms of specific case numbers, Kentucky has observed a substantial increase in Lyme disease cases just in recent years (23). From the year 2009 to 2011, there were five or less reported cases of Lyme disease in all of Kentucky (2009 having one case, 2010 having five cases, and 2011 having three cases). However, 2012 saw an increase in both nationwide and Kentucky cases, with a 18% increase in cases nationally, and a 366% jump in Kentucky (23). While the overall numbers are still low, the rapid increase in cases in just one year is notable, especially for a non-endemic state. Following this trend, numbers of cases in Kentucky spiked again from 14 cases in 2012 to 40 cases in 2013, 44 cases in 2014, and 49 cases in 2015 (24). Compared to the three cases recorded in 2011, this is a recognizable spike. Future trends for both Kentucky and the greater United States will likely include a continuation of the increasing Lyme disease cases. It is worthwhile to note that improving and consistent reporting strategies (as are encouraged now) in medical professionals may contribute to a spike in national incidence rates, but this is not so much a spike in the development of future cases as much as it would be increased documentation and medical reporting of Lyme disease and guideline-following treatment of infection. However, this is not the sole reason for case spikes and actual increases diagnosed cases should still be acknowledged.

A notable consideration in terms of incidence rates is that the CDC only takes confirmed cases into account when calculating incidence rates per year, and excludes probable cases altogether. In terms of a functional example, the CDC estimates that the 2018 incidence rate of Lyme disease in Kentucky is .1 cases per 100,000 people (26), based on four confirmed diagnoses in the state in 2018. However, there were 18 probable cases in the state that were excluded from incidence reports (27). Probable cases are defined in



the 2017 CDC Lyme disease case definition as a physician-diagnosed case of Lyme disease that is laboratory-confirmed, with the exclusion of a present EM rash. Probable cases obviously do not come with the same diagnostic ‘weight’ as confirmed cases, but they are nonetheless still valid and medically-confirmed cases. If the 2018 report included these cases, the incidence rate would jump from .1 to nearly .6 percent – again, not near endemic, but this is a sizeable jump considering the state’s past rates. Continuing on this, if this consideration was employed, 2016’s 33 cases in the state would observe a .9 incidence rate instead of a .4 rate. Increased numbers of cases, both in Kentucky and nationwide, are likely due to rising numbers of Lyme disease vectors and ticks in Kentucky and across the country, increased tick exposure in humans, lack of tick prevention strategy use by the general public, and may be associated with better reporting strategies within healthcare professionals.

When considering Kentucky specifically, it is also important to acknowledge the climate and culture of the state in the context of illness; the state has a temperate climate with predominantly rural areas that fosters Lyme disease vectors such as the black-legged tick, whitetail deer, white-footed mouse, and various bird species. These animal vectors are all ‘edge creatures’ that tend to live just on the outskirts of human settlement where nature meets development (such as farms and suburbs). White-tail deer and birds frequently make their way into yards and farms of people in more rural areas, which thus brings the black-legged tick into close proximity with humans. Kentucky also has a culture that generally values time spent outdoors and nature, and this promotion of time spent outside does unfortunately increase a person’s proximity to ticks – and thus their risk of Lyme disease and other vector-borne illnesses. According to the state’s official website and

journalist Barbara J. Fox, “tick season” – or the time period where tick bites in humans are most common – runs from mid-March throughout August in Kentucky (25). This is a time when Kentucky residents spend much time outside in various activities and occupations, and stretches for a majority of the year as well as the state’s most temperate months.

To reiterate, these values do not put Kentucky near the category of being endemic, but this increase is indicative that Kentucky residents are likely being exposed to Lyme disease vectors and falling ill with Lyme disease more frequently than just a decade or two ago – which is still the recent past. This implies that while Kentucky may not be a high-incidence state, its incidence of Lyme disease has increased significantly just since 2000, and an increasing amount of Kentuckians are contracting this condition each year.

Building on this, Lyme disease has the potential to develop into a late-stage condition if not carefully managed and treated, and can even develop into ‘Post-Treatment Lyme Disease Syndrome’ (PTLDS) well after active infection is cleared with antibiotic treatment; this illness can in turn affect individual patients’ functional ability, quality of life, and psycho-emotional wellbeing at any illness stage. If more and more people are diagnosed with Lyme disease each year, this obviously alludes to the fact that a greater amount of people are experiencing a conventionally uncommon disease; any uncommon or long-term illness can have an impact on a person’s physical and mental wellbeing that healthy and acutely ill people simply may not (and likely do not) experience. According to a literature review of illness experiences in rare disease patients by Charlotte Lippe et al, people with relatively uncommon illnesses such as Lyme disease often face psychosocial difficulties such as stress, social isolation, lack of social support, social stigma surrounding their health condition, altered self-concept, perceived difference from the social norm, lack

of autonomy, emotional distress, and prolonged pain (28). If an increasing amount of patients are being treated for Lyme disease each year, then an increasing proportion of Kentucky's population is concurrently in need of support that goes beyond the standard biomedical model of treatment during the course of their illness. The individual patient's perception of healthcare and illness, contextual and environmental factors, and demographic are also important considerations in terms of how an illness such as Lyme disease will affect them in this way. This goes for any illness, but for the sake of this thesis only Lyme disease will be discussed.

This all is an important consideration in terms of incidence rates and Lyme disease occurrence in Kentucky because if an increasing number of people are being diagnosed over time, then that same increasing amount of people will be seeking healthcare for an uncommon disease, and thus a greater proportion of Kentucky residents will likely need external support due to these diagnoses. Consequently, as the rest of this thesis will evaluate, a rising incidence of Lyme disease in Kentucky assumes that more Kentuckians will come into first-hand or distant contact with the effects of Lyme disease, how people perceive it, current levels of knowledge of the illness, how public awareness of the condition affects patient experience and perception of diagnosis, and the general ideas of health management and even of disability in relation to Kentucky culture.

### **Awareness of Lyme Disease in Kentuckians**

With this consideration, the question was brought to mind of if Kentucky's past history of low Lyme disease incidence has an impact on current levels of awareness in the general public. While there is a growing incidence rate of Lyme disease cases in Kentucky, are awareness levels in the state also increasing to match this growing incidence? If there

is low awareness of Lyme disease in the general public despite climbing Lyme disease cases in Kentucky, this has the potential to affect patient outcomes – if Kentucky residents are not knowledgeable, at least to a degree, of tick prevention strategies and early Lyme disease manifestations, they may not be able to distinguish the vague and flu-like early Lyme disease symptoms from other common illnesses that usually reside on their own with time. However, if Lyme disease is not promptly caught and treated, patients can quickly begin to experience much more severe and limiting symptoms – thus, personal misconception of Lyme disease for another illness can prove painful in the long-run. Additionally, health literacy – the ability to understand and apply healthcare information to one’s life and make informed health decisions – plays a role in health awareness in the general public, which Kentucky is lacking in. As will be discussed later, low health literacy rates correlate with public awareness of health conditions; if someone is not able to fully understand and apply information pertaining to their health, they likely also may not have a working knowledge of various health conditions and how to tell when they should see a medical professional. Health awareness in the general population drives health literacy, health outcomes, promotes the use of medical resources and care, and leads to an informed patient that is able to make knowledgeable medical decisions and understand their own health.

There is no significant amount of statistical data available in terms of public awareness of Lyme disease, and no data available concerning Kentucky residents and Lyme disease knowledge. However, available data on health literacy, healthcare quality in the state, and Lyme disease incidence can be used to predict what Lyme disease awareness might be like in Kentucky. This being said, more research is heavily needed on this topic. In terms of

what is researched already in Kentucky, the state routinely ranks low in both health literacy and in healthcare access and outcomes, which seems to allude to public knowledge about Lyme disease likely being low. If the general public in Kentucky has already been found to have low health literacy even on acute illnesses – especially in rural areas – and poor access to reliable and effective healthcare, it would make sense that public awareness of Lyme disease (a relatively uncommon illness with many vague and systemic symptoms) is likely also low. Logically speaking, a low public awareness of Lyme disease in the state would make sense, given Kentucky's low rankings in health literacy, health outcomes, healthcare access, high rates of poverty, and its many rural and Appalachian communities.

To further investigate this, one component of this thesis was to create a survey of Eastern Kentucky University students of various majors, backgrounds, demographic groups, and interests to gauge their level of knowledge about Lyme disease. The data from this survey will generate an evidence-based analysis on Kentucky residents and their awareness of Lyme disease. A survey of college students is beneficial to observing awareness levels concerning Lyme disease as these students come to ECU from so many different backgrounds and place in Kentucky – they include people from large cities, people from tiny mountain communities, students from multitudes of academic fields, students with great amounts of healthcare knowledge and students who have never taken any courses concerning health, and survey participants represent multiple demographics.

## **Methods**

This survey was generated through Eastern Kentucky University Qualtrics XM, a research and survey generation website. It was approved for use by the Eastern Kentucky University Institutional Review Board on June 24<sup>th</sup>, 2020 and overseen by Dr. Marcia

Pierce, the mentor for this thesis. This survey included 19 multiple choice questions, and asked participants about their basic demographic, college major, and questions about their knowledge of Lyme disease. These knowledge-based questions asked participants about their knowledge on Lyme disease solely as a health condition, such as what kind of infection it includes (i.e. viral, fungal, or bacterial), what manifestations it produces, its transmission, their personal awareness and knowledge of Lyme disease, how they perceive Lyme disease to impact Kentucky, and if they have ever experienced Lyme disease first- or second-hand. In the latter section of the survey, participants were questioned on how much they agreed with a given statement that related to Lyme disease incidence in Kentucky, and were also questioned on how weakly or strongly they knew about Lyme disease, its symptoms, and the course of a typical Lyme disease infection.

The survey was split into two sections with each section receiving the same unchanged survey – one section being BIO 111 Microbiology students in the College of Science, and one being Honors students of any major. The goal of this division was to investigate if knowledge of Lyme disease differs across academic areas, as every student enrolled in BIO 111 is a science major in some aspect, while the Honors program is multidisciplinary. The surveys were sent out on the same day; the survey was provided to BIO 111 students on their class Blackboard page, and provided to Honors students through the Eastern Kentucky University Honors social media page (managed by the Honors Program's Assistant Director Katie Patton), as well as being posted at the ECU Library's Noel Studio. All students were provided the survey by an Eastern Kentucky University faculty member, and no identifying personal information was provided. Every person the survey was provided to belongs to one of the two focus groups (i.e. Microbiology or Honors), and participants

were given a password-encrypted survey link to prevent non-EKU affiliated responses. The surveys were opened to students on September 11<sup>th</sup>, 2020 and responses were collected up until November 1<sup>st</sup>, 2020. In total, there were 78 responses, with 60 participants being BIO 111 students and 18 responses being in the Honors Program.

**Table 1** Survey Questions and Responses by Academic Area

<b>Question</b>	<b>Total Responses</b>	<b>Science Majors (BIO)</b>	<b>Honors Program</b>
Gender:	M: 18 F: 58 Nonbinary: 1	M: 17 F: 41 Nonbinary: 1	M: 1 F: 17 Nonbinary: 0
Race:	White: 73 Black: 3 Asian: 1 Indigenous: 0 Other: 1	White: 55 Black: 3 Asian: 1 Indigenous: 0 Other: 1	White: 18 Black: 0 Asian: 0 Indigenous: 0 Other: 0
Majors Represented:	English, Undecided, Computer Science, Environmental Health, Biomedical, Accounting, Exercise Science, Elementary Education, Pre-Medical, Occupational Therapy, Forensic Science, Biology, Honors Program (unspecified), Graduate Student (unspecified), Child and Family Studies, Medical Laboratory Sciences, English Teaching, Psychology, Digital Forensics, Emergency Medical Care, Chemistry, Animal Studies, Wildlife Management	Undecided, Computer Science, Environmental Health, Biomedical, Exercise Science, Pre-Medical, Forensic Science, Biology, Medical Laboratory Sciences, Psychology, Digital Forensics, Emergency Medical Care, Chemistry, Animal Studies, Wildlife Management *ALL enrolled in BIO 111 (Microbiology)	Social Work, Forensic Psychology, Biomedical Sciences, Biology, Accounting, Elementary Education, Child and Family Studies, Pre-Medical Sciences, Occupational Therapy, English Teaching, Graduate Student (major unspecified), English, Honors Program (major unspecified)

Agree/Disagree: “I have heard of the term Lyme disease before”.	Strongly Agree: 11 Agree: 43 Somewhat Agree: 23 Disagree: 1	Strongly Agree: 8 Agree: 33 Somewhat Agree: 18 Disagree: 1	Strongly Agree: 3 Agree: 10 Somewhat Agree: 5 Disagree: 0
Knowledge: Lyme disease is spread by ____?	Mosquitoes: 7 Genetic: 3 Ticks: 72 Person-to-Person: 3	Mosquitoes: 6 Genetic: 0 Ticks: 56 Person-to-Person: 2	Mosquitoes: 1 Genetic: 3 Ticks: 16 Person-to-Person: 1
Awareness: Do you know if Lyme disease is a condition present in Kentucky?	Yes, KY is high risk: 20 Yes, moderate risk: 38 Low risk: 18 I don’t know: 1	Yes, KY is high risk: 13 Yes, moderate risk: 31 Low risk: 14 I don’t know: 1	Yes, KY is high risk: 7 Yes, moderate risk: 7 Low risk: 4 I don’t know: 0
Awareness: How many cases of LD do you think Kentucky has per year?	No cases: 0 A small amount: 18 A moderate amount: 41 A high amount: 13 A very high amount: 2 I am not sure: 3	No cases: 0 A small amount: 15 A moderate amount: 34 A high amount: 6 A very high amount: 2 I am not sure: 2	No cases: 0 A small amount: 3 A moderate amount: 7 A high amount: 7 A very high amount: 0 I am not sure: 1
Knowledge: Which season is ‘tick season’ in Kentucky?	Winter: 1 Spring: 10 Summer: 51 Fall: 7	Winter: 0 Spring: 8 Summer: 40 Fall: 5	Winter: 1 Spring: 2 Summer: 11 Fall: 2
Knowledge: Lyme disease is a ____ condition.	Viral: 20 Bacterial: 47 Genetic: 3 Fungal: 7 I don’t know: 15	Viral: 14 Bacterial: 38 Genetic: 1 Fungal: 7 I don’t know: 11	Viral: 6 Bacterial: 9 Genetic: 2 Fungal: 0 I don’t know: 4
Knowledge: Do Lyme disease symptoms stay the same or worsen over time if a person is not treated?	Stay the same: 4 Worsen: 73	Stay the same: 2 Worsen: 57	Stay the same: 2 Worsen: 16
Knowledge: Lyme disease can affect a person’s ____.	Joints: 31 Muscles: 31 Brain: 9	Joints: 23 Muscles: 22 Brain: 5	Joints: 8 Muscles: 9 Brain: 4



	Heart: 9 None of the above: 0 Whole Body: 41	Heart: 5 None of the above: 0 Whole Body: 30	Heart: 4 None of the above: 0 Whole Body: 11
Knowledge: Do you associate Lyme disease as being a physical or cognitive condition?	Physical: 41 Cognitive: 4 Both: 32	Physical: 36 Cognitive: 2 Both: 21	Physical: 5 Cognitive: 2 Both: 11
Awareness: Do you know anyone with Lyme disease?	Yes, I've had it myself: 1 Yes, another person: 22 No: 54	Yes, I've had it myself: 0 Yes, another person: 12 No: 47	Yes, I've had it myself: 1 Yes, another person: 10 No: 7
Agree/Disagree: Has popular media increased your knowledge of Lyme disease:	Strongly Agree: 3 Agree: 7 Somewhat Agree: 4 Neutral: 12 Somewhat disagree: 7 Disagree: 20 Strongly Disagree: 24	Strongly Agree: 3 Agree: 4 Somewhat Agree: 1 Neutral: 8 Somewhat disagree: 5 Disagree: 17 Strongly Disagree: 21	Strongly Agree: 0 Agree: 3 Somewhat Agree: 3 Neutral: 4 Somewhat disagree: 2 Disagree: 3 Strongly Disagree: 3
Awareness: Have you learned about Lyme disease in any college class?	Strongly Agree: 1 Agree: 3 Somewhat Agree: 9 Neutral: 3 Somewhat disagree: 5 Disagree: 27 Strongly Disagree: 29	Strongly Agree: 1 Agree: 2 Somewhat Agree: 5 Neutral: 2 Somewhat disagree: 4 Disagree: 22 Strongly Disagree: 23	Strongly Agree: 0 Agree: 1 Somewhat Agree: 4 Neutral: 1 Somewhat disagree: 1 Disagree: 5 Strongly Disagree: 6
Awareness: How would you rate your current of Lyme disease as a health condition?	Expert: 0 Pretty Knowledgeable: 6 Somewhat Knowledgeable: 24 Slightly Knowledgeable: 47 No knowledge at all: 0	Expert: 0 Pretty Knowledgeable: 3 Somewhat Knowledgeable: 19 Slightly Knowledgeable: 37 No knowledge at all: 0	Expert: 0 Pretty Knowledgeable: 3 Somewhat Knowledgeable: 5 Slightly Knowledgeable: 10 No knowledge at all: 0
Awareness: How would you rate your knowledge of Lyme disease in <b>Kentucky</b> ?	Expert: 0 Pretty Knowledgeable: Somewhat Knowledgeable: Slightly Knowledgeable: No knowledge at all:	Expert: 1 Pretty Knowledgeable: 1 Somewhat Knowledgeable: 13 Slightly Knowledgeable: 24	Expert: 0 Pretty Knowledgeable: 2 Somewhat Knowledgeable: 5 Slightly Knowledgeable: 5 No knowledge at all: 6

		No knowledge at all: 20	
Agree/Disagree: After taking this survey, do you want to learn more about Lyme disease?	Strongly Agree: 7 Agree: 27 Somewhat Agree: 27 Neutral: 13 Somewhat disagree: 0 Disagree: 1 Strongly Disagree: 1	Strongly Agree: 5 Agree: 23 Somewhat Agree: 18 Neutral: 11 Somewhat disagree: 0 Disagree: 1 Strongly Disagree: 1	Strongly Agree: 2 Agree: 4 Somewhat Agree: 9 Neutral: 2 Somewhat disagree: 0 Disagree: 1 Strongly Disagree: 0
Have you ever had a Lyme disease diagnosis yourself?	Yes: 1 No: 78	Yes: 0 No: 59	Yes: 1 No: 17

## Results

This survey indicates that there is a mixed level of awareness in Kentucky residents when it comes to Lyme disease knowledge. Participants reported that they had a basic to moderate understanding of information regarding Lyme disease symptoms, and a majority of participants regarded themselves to be fairly knowledgeable on the topic. A moderate majority of participants answered knowledge-based questions on common Lyme disease symptoms and transmission correctly, but dually reported that they felt only slightly to somewhat knowledgeable on Lyme disease (both as a general condition and as it impacts people in Kentucky). Overall, participants seemed like they had a working knowledge of Lyme disease that was at least in part accurate (possibly reflecting a moderate level of health literacy), yet at the same reported that they did not feel confident in their level of awareness of more complex intricacies and manifestations of Lyme disease. This raises the question of if awareness and knowledge have different definitions – and in terms of this thesis, they seem to mean contextually different things. At least according to the results of this survey, knowledge seems to pertain to how much of a working knowledge and the

number of facts a person knows about a thing, while awareness seems to have more social, large-scale, and future-oriented associations. This is an interesting thought that could be more extensively researched outside the bounds of this thesis.

This being said, it can be argued that while participants displayed a working knowledge of ‘textbook’ Lyme disease symptoms and early manifestations, and a majority – but not all, especially among non-science majors – could identify basic information, means of transmission, and manifestations of Lyme disease. However, these same participants were not confident in their own social and perceptual awareness of Lyme disease, and demonstrated a desire to know more about the condition. These students seem to know a limited but correct amount of knowledge on Lyme disease, but were not at all confident in their ability to apply this knowledge in terms of healthcare literacy and social awareness surrounding Lyme disease. This alludes to low public awareness of Lyme disease in Kentuckians, which may be the result of a lacking public discussion and sense of advocacy around Lyme disease prevention.

### **Limitations and Recommendations**

Given the nature of this survey, there are limitations associated with it. Due to this thesis only being written over the course of one semester, the survey was only open to participants for just under two months. Additionally, the survey was limited to only students at Eastern Kentucky University, and there was not a significant amount of participant turnout. There are over one hundred students enrolled in BIO 111, and over 100-200 Honors students at minimum at Eastern Kentucky University, yet the surveys only received 78 responses in total. The survey participants that did respond were predominantly science-related majors, as well – even in participants from the Honors program. The survey

also was fully online due to COVID-19, and this may have discouraged some students from participating.

This being considered, the premise of this survey could be heavily expanded into a more large-scale investigation. Students and/or professors from other academic disciplines outside of Biology and the Honors Program could be included, or the survey could be expanded to other Kentucky colleges. Due to COVID-19 related restrictions and the time constraints of this thesis, the survey was not expanded, but this could be easily made into a much larger project.

## **Discussion**

As mentioned, this survey is limited and is small-scale – however, it does have implications in terms of this greater discussion of Lyme disease that do have substantial implications. As can be observed, Lyme disease is relatively not discussed much in Kentucky, outside of the doctor’s appointments of people that have a Lyme disease diagnosis. In terms of the greater culture of Kentucky, there is no substantial discussion of Lyme disease, and this is reflected in the survey results. In academia, there is minimal discussion of it – where more acute and specific health conditions have chapters dedicated to them, Lyme disease often garners a few paragraphs at most and late-stage Lyme disease may be excluded from that discussion completely. Therefore, this lack of discussion of Lyme disease can promote a lack of awareness in the general public about it.

Furthermore, is an invisible illness – one not immediately recognizable by physical differences. A person with Lyme disease has no one distinguishing symptom that screams, “I have Lyme disease!” – rather, they have multiple, vague, and non-specific yet painful

and draining symptoms that affect multiple body systems. These symptoms can vary day-to-day, appear to be symptoms of fatigue or other more common illnesses such as Influenza, and can vary from patient to patient. This being said, there is no true public discussion in Kentucky on Lyme disease just as there is a lack of discussion of other invisible illnesses – what is not easily recognizable can be stigmatized or ignored by the general public. Lyme disease is dually an uncommon illness, and this too may fuel a lack of public discussion. As mentioned before, the general public seems to have at least a moderately working knowledge of what Lyme disease is, but may lack the understanding, sense of advocacy and discussion that comes with true awareness of what the condition is. In this specific context, awareness seems to be correlated with this perceived lack of discussion; the general public may very well have a basic idea of what Lyme disease is and what its symptoms are – a sort of ‘textbook knowledge’ – but awareness boils more down to a social understanding of patient experience, and an application of that knowledge to fuel discussion and advocacy around research. And, Kentucky and the United States as a whole seem to lack this.

As the next section will discuss, this lack of awareness in the general public can impact the people who do have a Lyme disease diagnosis, and how they experience their illness. If there is no true discussion regarding your illness in your area (in this case, that would be Lyme disease patients living in Kentucky), this can hinder the social support, biomedical support, and contextual support that helps a patient recover.

### **Illness Course and Diagnosis**

Taking this all into consideration, it is important to consider how Lyme disease’s unique position as an uncommon disease in Kentucky that is dually on the rise, yet not

commonly known about, impacts the individuals who do have a diagnosis and are living with Lyme disease in Kentucky. This section will explore what diagnosis looks like, how patient experience is an important consideration in terms of living with and treating Lyme disease, and what lived experience of Lyme disease diagnosis might be like for someone with the condition – all taking in the context of someone living in Kentucky, and also with the context of how Lyme disease is perceived in Kentucky.

Lyme disease generally comes with pain, fatigue, flu-like symptoms, and potential cognitive difficulties. Symptoms vary by stage and can progressively worsen if not treated in the early stage of illness. During early infection (stage one), a patient may have the ‘bullseye’ erythema migrans rash, muscular and joint pain, flu-like symptoms and malaise, fatigue, and headaches. Generally, over the progression of Lyme disease these manifestations worsen and bring on severe symptoms. By late-stage (stage three) Lyme disease, the infection is disseminated and *Borrelia burgdorferi* affects multiple body systems, which brings on more severe symptoms and neurological concerns. The stage-one symptoms may still be present, but later-stage Lyme disease can prove to be very painful and potentially cause an impairment on the patient’s functional ability.

Later on, stages two and three of Lyme may come with Bell’s palsy, cardiac problems and palpitations, muscle weakness, swelling, migratory arthritis (arthritic pain that moves from joint to joint, as *Borrelia burgdorferi* often harbors in joint capsules and connective tissue), nerve pain, “brain fog” or cloudy mental state and other cognitive difficulties such as memory problems, apraxia and trouble with coordination, and encephalopathy (28). These manifestations can be debilitating and mentally draining. Depending on the patient’s functional ability pre-infection, reaction and perception of

illness, overall health, support, and independence, any of these symptoms can potentially limit a person's ability to fully be independent and do the activities they want to each day without restriction. Lyme disease can prove to be a painful, limiting, and uncomfortable condition.

Before looking at Lyme disease diagnosis on an individual and lived basis, one must consider what criteria must be met for a Lyme disease diagnosis. The diagnostic criteria for this illness is provided by the CDC, which has two case definitions – one for a confirmed case, and one for a probable case. Both are laboratory-confirmed and clinician-approved active cases of Lyme disease, with a confirmed case having a present erythema migrans (EM) 'bullseye' rash, among other criteria that a probable case does not meet. A probable Lyme disease case is defined by the CDC as “a case of physician-diagnosed Lyme disease that has laboratory evidence of infection” (28), while a confirmed case is described as having: (1) an EM rash in a high incidence state, (2) an EM rash and laboratory confirmation, as well as known exposure in a low incidence state, or (3) any case that has a late manifestation (severe symptoms in the musculoskeletal, neurological or cardiac systems) with laboratory confirmation.

Going off of this, a laboratory confirmation includes: (1) a positive culture for *Borrelia burgdorferi*, (2) a positive two-tier test consisting of a positive enzyme immunoassay (EIA) or immunofluorescent assay (IFA) test in tier one, followed by a positive Immunoglobulin M (IgM) or Immunoglobulin G (IgG) western immunoblot (WB) test in tier two, or (3) a positive Immunoglobulin G (IgG) western immunoblot (WB) test (28). In brief, a positive Lyme disease test includes positive laboratory tests that either look for *Borrelia burgdorferi* or human antibodies to it, and certain symptoms related to active

infection. The diagnostic criteria is not stage-specific and is used for every stage of Lyme disease infection. Diagnosis has considerations surrounding the laboratory tests, such as the fact that they search for antibodies that people with certain immune conditions may not make, that Lyme-specific antibodies form slowly (which can cause false negatives if a person is tested during the period when antibodies have not formed yet).

Lyme disease is treated with antibiotics, given its basis of a bacterial infection. The exact choice of antibiotic will depend on the doctor, patient, and illness stage -- however, common antibiotics used in treatment of Lyme disease are Doxycycline, Amoxicillin, or Cefuroxime. One side effect of taking antibiotics – and in this case especially Doxycycline because its class as a tetracycline – for Lyme disease in many patients, regardless of the stage of infection, is a *Herxheimer reaction*. This is a cytokine-driven (inflammatory) bodily reaction to the dying off of spirochete bacteria, such as *Borrelia burgdorferi*, and also in some gram-negative infections. It is an uncomfortable sign that antibiotics are successfully working, and generally comes on a patient within a few hours of their first antibiotic dose. It brings on flu-like symptoms with fever, chills, malaise, fatigue, headache, fast heartbeat (tachycardia), and anxiety (29). While this reaction can be very uncomfortable and make a patient seem more ill, it is a bittersweet sign that antibiotics are working and generally will subside with time. Not all patients will have this reaction, but it is a well-documented and known reaction to antibiotic treatment of spirochetal infections.

### **Effects of Diagnosis and Illness Stage on Patient Wellbeing**

While discussing the symptoms that come with Lyme disease is imperative to understanding it, this thesis is just as largely concerned with discussing the implications of those symptoms on the patient's wellbeing, quality of life, and ability. The symptoms



themselves of Lyme disease are painful, uncomfortable, and can be very severe. They should in no way go unacknowledged. However, there is a part of having a painful and potentially severe illness that can go unacknowledged in terms of biomedical care – the effects of that illness on the rest of a person’s life. Lyme disease can affect a person’s outlook on life, view of themselves, their mental wellbeing, ability to do the things they want to do freely, how that person is perceived in their culture and society, and multitudes of other factors. This section will discuss the effects of Lyme disease on patients’ health and wellbeing, but also in terms of a condition with potentially long-lasting and severe effects on health and wellbeing, and as an uncommon illness in Kentucky,

After diagnosis, every patient has a different experience that is partially dependent on which stage of Lyme disease (early to late) their infection is in. Lyme disease diagnosis finds itself in a unique position – if a patient is seen by a physician within the first thirty days of symptoms, and they have no other pre-existing conditions, then that patient will likely be prescribed a course of antibiotics, and once they finish that course they will likely be cured from active infection and have no major residual effects. This follows an allopathic approach to medicine and patients receiving treatment for early-stage Lyme disease will likely recover fully; they may have concurrent health conditions, tick-borne illnesses, or negative emotional reactions to infection that may prolong sickness or make their subjective experience worse, but in the case of an otherwise healthy patient with a localized infection, the patient should fully recover relatively quickly. However, as will be discussed later in this section, Lyme disease is an uncommon illness regardless of if the individual infection in a person is acute or late-stage, and there are stresses and experiences

that come with this in any stage of Lyme disease that healthy people may not fully understand or be able to empathize with (30).

However, when a person infected with Lyme disease is no longer in the early, localized stage one infection, their prognosis may not be so readily bright. Especially when a patient has untreated or otherwise late-stage Lyme disease, they may have more severe symptoms such as migratory arthritis (arthritic pain that moves from joint-to-joint frequently), neuromuscular, and neurological symptoms that are not so easily cured quickly (28). This stage patient obviously still has the same health condition someone with an earlier stage infection has, but later-stage Lyme disease comes with more severe manifestations that can cause serious damage to a person's health and wellbeing that someone with a localized/early infection may not yet experience. Lyme disease that is later-stage or has gone untreated for an extended period of time can be treated with antibiotics just as early-stage Lyme disease can, but the symptoms and manifestations that come with later-stage Lyme are often more severe, and may have longer-lasting damage to the body and patient wellbeing.

There comes a point the progression of Lyme disease infection (in cases of patients with a later-stage or untreated infection) that a person's quality of life and functional ability may have an observable decrease, even after a standard antibiotic course. Even if active infection is cleared, in many late-stage patients there still may be residual joint pain, muscle pain, neurological and nerve-related symptoms, and many other painful symptoms that may continue on despite no longer having an active Lyme disease infection due, or these symptoms may persist through treatment of active late-stage Lyme. This is thought to be attributed to the amount of wear and tear the body goes through during active Lyme disease

infection, and after prolonged or late-stage infection with severe manifestations the infection simply can take a toll on the patient's body that can last after the infection itself is resolved. There is currently developing research on this also being a potential result of Post-Treatment Lyme Disease Syndrome (PTLDS) – but this area does not have a significant amount of research around it, and it is very much worth investigating in the future.

Thus, a patient with stage two or stage three Lyme disease can fall into a grey area – what once used to be an acute infection is no longer easily and quickly manageable, and often comes with physical pain but also long-lasting mental stress. The diagnosis of any illness such as Lyme disease can increase stress – it is an illness that is downright painful, may change the way the person does things and lives, and comes with an altered part of life that the average person likely does not live with or experience. These patients have what is normally an illness that can be quickly treated, yet their body isn't seeming to follow those guidelines due to later-stage or prolonged infection. This puts late-stage Lyme disease and Post-Treatment Lyme Disease Syndrome patients at risk for developing concurrent psychiatric disorders, such as anxiety, depression, panic disorders, and an altered self-concept (31). This is congruent with myriads of long-lasting and/or chronic illnesses and the higher risk of mental conditions associated with them (30). This is not to say Lyme disease is a psychiatric condition, but rather is a result of the sheer stress that often comes with Lyme disease infection.

### **Psychological Manifestations From or Concurrent with Lyme disease**

In short, patients with any stage of Lyme disease run the risk of developing comorbid mental disorders simply due to its nature as an uncommon, painful, and

potentially long-term illness; however, as seen in many long-lasting illnesses, when a condition has severe symptoms and the patient may have been sick for an extended period of time, the prolonged stress and/or even chronic pain can put a patient at a higher risk for developing a concurrent psychiatric condition (32). Development of a psychiatric condition can happen simply due to the mental strain of being ill, but this is not something every patient will experience. It is a possibility, but in no means a certainty. Neurological manifestations of Lyme disease can impact cognition in later-stage cases, but this is not to be confused with a separate psychiatric condition.

Lyme disease is known to affect the central and peripheral nervous system, but this consideration should serve as a reminder that while Lyme disease patients obviously need biomedical support throughout their illness, their emotional wellbeing should be just as highly regarded as their physical wellbeing. This does not mean Lyme disease is a psychiatric disorder or simply ‘in the patient’s head’ as many patients report being told – but actually that it is the opposite; it is a physical, bacterial infection that has the potential, if not treated promptly and effectively, to impact a person’s brain and emotional wellbeing just as it impacts the patient’s muscles and their ability to function. This is not a result of weakness or poor emotional regulation but is the result of physiological changes in the body.

This being said, patients with any stage of Lyme disease have to emotionally process their diagnosis. This is an important factor of patient wellbeing and can include the realization of the patient having a relatively uncommon illness (especially in terms of Kentucky residents), a grieving process surrounding their health, anxiety or uncertainty, denial or emotional numbness, can genuinely not affect the patient much emotionally, or

can fall somewhere in between. Each person processes their diagnosis differently; some people may not think much of it, some may completely disregard it, others will experience mild stress, and still other groups of patients will experience emotional distress and worry. Diagnosis of any condition, no matter how acute or chronic, can come as a shock, with level-headedness, with a turn to outside support or religion, with grief, with apathy, with a can-do attitude, and a multitude of other outlooks on their life. Much of this revolves around the individual patient's reaction to illness, environmental support, past experiences and medical history, perception of illness and cultural factors, emotional outlook (optimism/pessimism/realism), and their knowledge of what Lyme disease entails.

### **Contextual Impacts on Patient Experience**

These many factors that are mentioned above directly influence how a patient experiences being ill and their attitude throughout their being sick, consequently impacting patient outcomes. Of course, being an optimist or being health literate will not cure a patient. However, positive support and healthy perceptions of what their illness is and will entail can help a patient get through their time being sick and support them through their illness more than someone who does have the same level of support in their life.

In the same way, various cultural and religious groups may attribute illness to different causes or may perceive sickness differently (this is called an illness narrative), and this impacts how a patient might view their own illness. Demographics, the patient having a first language that is not English, other comorbid conditions and/or disabilities, economic status, access to healthcare, the way the person was raised, social determinants

of health (anything outside of a person that directly impacts them and their health), past medical history, health literacy, preconceptions about doctors, and attitudes about healthcare can also impact how a patient experiences being ill (33). Obviously, the first goal of healthcare is for the patient to recover and be free of pain and limitation.

However, what happens while they are ill and how the experience that illness can directly impact that patient's health and end outcome. Patient experience directs how fast a patient recovers, how they experience being sick and their attitudes through it, and their willingness to seek and follow healthcare plans.

Concurrently, this is also why the idea that no two patients will have the same experience is so important and should be strongly emphasized surrounding Lyme disease. Every patient has a different outlook on life, illness narrative, contextual factors, and outlook on life that impacts how they experience a condition such as Lyme disease. Someone that is an optimist, has a supportive home environment, social support, or a positive outlook on medical professionals may have a very different experience with Lyme disease than someone who may not be so optimistic about their prognosis, has a family that will not support them while they are ill, or unemployed could experience outside stress that directly impacts their experience of personal illness – despite both of those people having Lyme disease. Dually, someone who is young versus someone older, or someone with stage one Lyme disease versus stage three, will have two different experiences despite having the same diagnosis. Even two patients within the same stage or even the same symptoms of Lyme disease can still have very different reactions and experiences during their illness.

### **Experience of having Lyme Disease in Kentucky**

Building on this consideration, the specific culture, healthcare system, public awareness levels of Lyme disease, and incidence rates present in Kentucky combine to impact how patients with Lyme disease perceive illness in general, their diagnosis, their health, and how they experience being ill. In terms of multiple health-based statistics, Kentucky has routinely worse rates of health literacy, healthcare access, chronic and serious conditions, substance use, and low physical activity than the national U.S. average. According to the Foundation for a Healthy Kentucky, 67% of all Kentuckians are overweight, 28% smoke tobacco, and 30% of Kentuckians report getting no physical activity: frankly, these are terrible health statistics (34). In 2019, Kentucky was ranked by the Courier Journal as the 7<sup>th</sup> worst state in the country in terms of healthcare, community and environmental support, public and health policies, clinical care, and health outcomes (35). And as University of Kentucky reporter Laura Wright notes, “In the Appalachian region – where the population, in general, is chronically underemployed, less educated, and has limited access to resources like affordable transportation or healthy foods – the situation is even more dire: the largest decreases in life expectancy in the U.S. are currently in eight eastern Kentucky counties” (36). The odds of getting sick with any health condition in Kentucky are stacked against the state’s residents, and when a Kentuckian does get sick or experience disability they may struggle finding healthcare resources, making their own informed healthcare decisions, routinely getting access to healthcare, and becoming and staying healthy again. Furthermore, much of Kentucky is rural or even Appalachian, and this decreases access to routine and quality healthcare, public resources and transportation, and socio-cultural support to people needing medical care.

### **Importance and Implications of Low Health Literacy**

Kentucky also suffers in terms of health literacy, which is defined by WHO's Healthy People report as the "degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others" (37). At least half of Kentucky's counties report residents as having only 'below basic' to 'basic' health literacy, which impacts their ability to apply and understand information regarding their health. Someone with a basic health literacy may be able to locate clear information in a document, such as their next appointment time or a laboratory score, but likely will not be able to apply it and understand what a medical professional is trying to convey about their health. According to a report by the University of North Carolina, some counties in Kentucky report up to 45% of their residents having only basic or below basic health literacy, with the state average hovering around 33% of residents having basic health literacy proficiency or below (38). If a person does not or cannot understand information regarding their own health, their health may suffer because they may not be able to make healthy choices in their personal life, understand Lyme disease (or for any illness) prevention measures, make informed decisions and follow healthcare protocols for their health.

This affects a person's ability to understand and manage their own health, be informed about their own healthcare, and understand terminology and information surrounding diagnoses. This obviously applies to a Lyme disease diagnosis as well as any other health diagnosis. In terms of Lyme disease, low health literacy impacts Kentucky residents' knowledge of tick bite prevention, recognition of early Lyme disease symptoms, ability find resources and appropriate medical care pertaining to Lyme disease (ex. many people with low health literacy go to the emergency room for non-emergency medical



care), how to read medication bottles and understand treatment methods, and an impact on health outcomes and recovery.

Taking this all into consideration, many factors combine to impact the patient experience of someone with a Lyme disease diagnosis. The person's health prior to diagnosis, their environment, their support system, culture and attitudes surrounding health, the stage of their Lyme disease infection, and access to healthcare can impact anyone's experience with being ill, and Lyme disease has the potential to significantly impact a person's ability to do everything they want to without pain or limitations. Additionally, when considering Kentucky residents specifically, the healthcare system and lack of health literacy in the state further disadvantages patients. If a patient cannot understand information regarding their health, cannot access reliable healthcare (for any reason, be it financial or insurance-related, lack of transportation, personal distrust in medical professionals, poor quality healthcare services, or lack of services in rural areas), or otherwise faces an obstacle to healthcare, it disadvantages their ability to get effective, quality, and reliable healthcare. This obviously is said in terms of care for Lyme disease, but this can be broadened to have implications for all Kentucky residents with health conditions.

### **Stigma Surrounding Lyme Disease and Invisible Illness**

In our society, there are pre-conceived social stigmas and biases surrounding many health conditions and disabilities. These stigmas are negative attitudes and preconceptions about people with various illnesses that (sometimes unconsciously or even consciously) portray people with those illnesses as lesser than, weak, inherently different, or otherwise out of the social norm. This is evident across multiple health conditions and illnesses, as

seen in the use of the ‘R-Word’ (this thesis will not be mentioning the full word as it is offensive) to reference people with cognitive disabilities, the popularity of the words ‘handicappers’/‘handicapped’, ‘psycho’ or ‘mental’ to reference people with various disabilities and conditions, medical disparities in the care of People of Color versus the care of Caucasian people (i.e., people with dark skin are more likely to get debilitating ulcers as they are not as quickly picked up on), negative perceptions of people with psychiatric conditions as being dangerous, judgement of people using accessible parking spaces that do not have an easily recognizable health condition, and many others.

This being said, there is even more-so a negative stigmatization of people with invisible illnesses in our society – any illness that is not easily picked up on just by looking at a person. This includes Lyme disease, and many other conditions such as cognitive and psychiatric conditions, neuromuscular conditions, chronic pain, conditions involving internal organs, and many more. People with invisible illnesses such as Lyme disease may look completely healthy on the outside, yet are struggling on the inside (39). Common stigmatized or bias-driven remarks people with invisible illnesses often hear from others may include, “you look so healthy though!”, “you’re just tired or not trying hard enough!”, or “are you sure you’re sick?”. This stigma, when paired with concurrent low awareness of a given health condition (in this case, Lyme disease) and negative social reactions and bias against the ill person, can lead to social isolation, anxiety and/or depression, alienation, negative self-image/self-concept, low self-esteem, and further stress (39).

In the unique case of someone with Lyme disease, they are a person that has an illness that other people cannot quickly and effectively identify. In fact, many patients with Lyme disease and other invisible illnesses look healthy on the outside but are hurting on

the inside. Lyme disease is a complex illness with vague and whole-body symptoms that does not have one distinguishing symptom that is unique to solely Lyme disease; the erythema migrans rash does not form in at minimum 30% of patients and is common among many tick-borne infections. In fact, this rash is the only externally recognizable manifestation of Lyme disease – all others deal with neuromuscular pain, fatigue, cognitive manifestations, and et cetera. Furthermore, Lyme disease can progress (if left untreated) to have severe, potentially debilitating, and long-term effects and symptoms that may not simply disappear quickly and totally. However, someone can be in severe pain while still appearing “fine” on the outside.

As well as these considerations, Lyme disease is also an uncommon illness. It is not something like Influenza that most people know the signs, symptoms and preventative measures of; as discussed, Lyme disease does not have high public awareness or advocacy measures surrounding it, and it is not something incredibly rare in the United States or Kentucky. This contributes to negative social stigmas and perceptions of Lyme disease – sadly, if the public does not know much about a condition and it is not easily recognizable to the untrained eye, or if there is just a lack of understanding of the condition, many people are quick to judge and slow to listen. If the public does not know about a condition (such as in Lyme disease’s case of low awareness), and it is hard to conceptualize or understand (such as in Lyme disease’s vague symptoms that are common among other illnesses), there can be a lack of sympathy and overall lack of understanding of the condition as it affects a person.

As many people with invisible illnesses report, lack of social understanding and support can make the affected individual feel unheard, unseen, and pushed aside by society.

This can lead to negative perception of oneself due to stigmas, social isolation or exclusion, mistrust of people's intentions and/or medical professionals, and occupational alienation (prolonged disconnectedness and isolation) in people with various illnesses, and especially in those with Lyme disease. Furthermore, our society and the United States tends to follow identity-first social norms – this is the attribution of one's socio-cultural identities as the forefront of who they are. In terms of illness and disability, this becomes problematic as people with various health conditions are typically defined by their illness or disability as their most definitive and identifying factor (40). This comes from unconscious bias against illness and disability and labelling people with them as their illness being who they are (thus further fueling stigma and stereotypes). Thus, a person that has Lyme disease becomes the Lyme patient or the child that happens to have Down Syndrome becomes the Down Syndrome boy. If this definitive factor or identity is perceived as negative by society, such as having invisible or uncommon illnesses, then that person can often be perceived as lesser than by society. This rings true in the case of many illnesses, disabilities, and minority populations – however, by that point then it is dually applicable to people with Lyme disease.

Unfortunately, this is seen in the treatment of people with disabilities and other uncommon illnesses in our country and state, as well as other minority groups. The same stigmas surrounding illness and invisible illness also apply to people with Lyme disease. These patients have an illness that is not common, vague, invisible, and complex – this can lead to social exclusion, misunderstanding, alienation, and perception of these individuals as different, making up their pain, dramatic, or even of the pain being 'in their head' when these patients are fighting against real, valid, and severe pain and symptoms (39). If people

do not easily understand the lived experience of someone or cannot conceptualize what a person is experiencing, they often exclude that person and perceive them as different or lesser than in some way. These biases are often rooted in cultural values, perceptions of illness and disability, and social norms present in the United States and Kentucky.

Overall, people with Lyme disease and their experiences (as well as people with other invisible illnesses and/or disabilities) can be misunderstood, isolated, alienated, marginalized, and biased against by other people – something that people without health conditions may not experience. This is actually a common experience reported among many minority groups, such as People of Color, LGBTQ people, people with disabilities and various disability communities and sub-cultures, and women. However, Lyme disease can be even furthermore misunderstood because it is not only invisible, but uncommon, surrounded by low public awareness, comes with vague symptoms, complex, and potentially long-term and/or debilitating.

## **IMPLICATIONS AND SIGNIFICANCE**

Considering these points, a few main conclusions can be drawn. Lyme disease may be a relatively uncommon illness, especially in a state such as Kentucky, but it can significantly impact patient ability, function independently, wellbeing, produce a negative patient experience, and can produce a mental strain due to its complex and relatively uncommon nature. Lyme disease can progress to become a particularly uncomfortable illness if left unchecked, and can greatly damage a patient's ability and independence. Incidence rates in Kentucky are observably rising over time, while there is a lack of substantial discussion on the topic in both academia and in common conversation. Lyme disease's being uncommon discourages extensive knowledge of the condition in the

general public, and a great deal of research on Lyme disease awareness is needed to further this conversation.

All in all, Lyme disease goes relatively undiscussed in the state of Kentucky, which can therefore impact the people that do have this condition. Lyme disease is an invisible illness that comes with seemingly vague and ignorable manifestations – it is easy to overlook since there is no real discussion on Lyme disease in the state, and those who have the condition are likely not identifiable externally or based off one set of symptoms. This can affect patient experience of Lyme disease diagnosis in Kentucky; if a patient has a negative experience during their being ill, it can impact their end outcome and how quick they recover to a degree. Obviously, antibiotic treatment is what cures Lyme disease infection – but contextual factors, mental support or stressors, your environment, and the level of support a patient has impacts the effectiveness, speediness, mental state of, ability to receive healthcare during, the patient's recovery to mental and physical wellness after Lyme disease infection.

Low awareness and knowledge rates surrounding Lyme disease in Kentucky, paired with a rising incidence rate of Lyme disease, can correlate with low rates of health literacy and a low-ranking state healthcare system to negatively impact health outcomes. With all of the aforementioned factors combined, Kentucky is a state wherein its residents have high rates of chronic and/or severe health conditions, poor health outcomes, low-ranking access to medical care and a low-ranking healthcare system, high unemployment, and a service region in the Eastern sector of the state that routinely is even more-so disadvantaged when it comes to health and health outcomes. On top of this, a Kentucky resident that has Lyme disease is someone with a condition that is relatively uncommon,

observing an increasing number of cases over time, relatively not well-known about in a state with moderately low health literacy, and a condition that can greatly impact a person's ability to do what is meaningful to them with no pain, limitations, or fatigue.

In sum, Lyme disease is an illness that has the potential to significantly impact patient health and wellbeing if not kept in check and caught early. Especially in the context of Kentucky, a rising incidence rate in the state and a lack of public discussion on the illness paired with poor health literacy and poor access to efficient and effective healthcare disadvantages those living in Kentucky with Lyme disease. More research on the illness and stronger awareness campaigns in the state could spark future discussion and promote better access to health promotion programs and health literacy.

## References

1. **Elbaum-Garfinkle, S.** 2011. Bicentennial: Close to Home: A History of Yale and Lyme Disease. *Yale J Biol Med* **84**(2):103-108.
2. **Barbour, A., Benach, J.** 2019. Discovery of the Lyme Disease Agent. *mBio* **10**(5).
3. **Asch, E., Bujak, D., Weiss, M., Peterson, M., Weinstein, A.** 1994. Lyme disease: an infectious and postinfectious syndrome. *Int J of Rheumatol.* **21**(3):454-461.
4. **Goldstein, E., Thompson, C., Spielman, A., Krause, P.** 2001. Coinfecting deer-associated zoonoses: Lyme disease, Babesiosis, and Ehrlichiosis. *Clinical Infectious Diseases.* **33**(5):676–685.
5. **Sandberg, S., Spielman, A., Awerbuch, T.** 1992. A comprehensive multiple matrix model representing the life cycle of the tick that transmits agent of Lyme disease. *J Theor Biol.* **157**(2):203-220.
6. **Halperin, J.** 2010. A Tale of Two Spirochetes. *Neurology and systemic disease.* **28**(1):1-338.
7. **Domenico D., Cavallo, I., Bordinon, V.** 2018. The emerging role of microbial biofilm in Lyme neuroborreliosis. *Front Neurol.* **9**:1048.
8. **Yeung, C.** 2019. Diagnosis and Treatment of Lyme Carditis. *J. Am. Coll. Cardiol.* **73**(6):717-726.



9. **Lorraine, J., Wilcox, S., Mankoff, J., Stricker, R.** 2014. Severity of chronic Lyme disease compared to other chronic conditions: a quality of life survey. *PeerJ*.
10. **Fallon, B., Nields, J., Parson, B., Liebowitz, M., Klein, D.** 1993. Psychiatric manifestations of Lyme borreliosis. *J. Clin Psychiatry*. **54**(7):263-68.
11. **Bransfield, R.** 2018. Neuropsychiatric Lyme Borreliosis. *Healthcare*. **6**(3):104.
12. **Oliveira, C.** 2015. Update on persistent symptoms associated with Lyme disease. *Curr Opin Pediatr*. **27**(1):100-104.
13. **Aucott, J.** 2015. Posttreatment Lyme disease syndrome. *Infect Dis Clin North Am*. **29**(2):309-325.
14. **Fallon, B., Levin, E., Schweitzer, P., Hardesty, D.** 2010. Inflammation and central nervous system Lyme disease. *Neurobiol of Dis*. **37**(3):534-541.
15. **Malawista, S.** 1991. Lyme disease: recommendations for diagnosis and treatment. *Ann Int Med*. **114**:472-481.
16. **Wormser, G.** 2000. Practice guidelines for the treatment of Lyme disease. *Clin Inf Dis*. **31**(1):1-14.
17. **Bryceson, A.** 1976. Clinical Pathology of the Jarisch-Herxheimer Reaction, *J Inf Dis*, **133**( 6):696–704.
18. **Hinckley, A., Connally, N., Meek, J., Johnson, B.** 2014. Lyme disease testing by large commercial laboratories in the United States. *Clin Inf Dis*. **59**(5):676-681.
19. **Centers for Disease Control and Prevention.** 2018. Nationally Notifiable Infectious Diseases and Conditions Annual Tables. CDC WONDER.

20. **Centers for Disease Control and Prevention.** 2017. MMWR Weekly Tables of Infectious Diseases. MMWR Weekly Archive.
21. **Centers for Disease Control and Prevention.** 2018. Reported cases of Lyme disease by state or locality. National Notifiable Diseases Surveillance System.
22. **Adams, D., Thomas, K., Jajosky, R., Foster, L., Sharp, P., Onweh, D., Schley, A., Anderson, W.** 2017. Summary of notifiable diseases and conditions. Nationally Notifiable Infectious Conditions Group Division of Health Informatics and Surveillance.
23. **Fox, B.** 2018. Tick season underway across Kentucky. Commonwealth of Kentucky.
24. **Centers for Disease Control and Prevention.** 2018. MMWR Weekly Tables of Infectious Diseases 2009-2018. MMWR Summary of Notifiable Diseases.
25. **Centers for Disease Control and Prevention.** 2018. Reported Lyme disease cases by region and reporting area. MMWR Summary of Notifiable Diseases.
26. **Centers for Disease Control and Prevention.** 2017. Summary of Notifiable Diseases: 1993-2016. MMWR Summary of Notifiable Diseases,
27. **Centers for Disease Control and Prevention.** 2017. Lyme disease 2017 case definition. National Notifiable Diseases Surveillance System.
28. **Rebman, A., Bechtold, K., Yang, T., Mihm, E., Soloski, M., Novak, C., Aucott, J.** 2017. The clinical, symptom, and quality-of-life characterization of a well-defined group of patients with post-treatment Lyme disease syndrome. *Front Med.* **14**(4):224.
29. **Kollmann, T., Dobson, S.** 2011. Herxheimer Reaction. *Inf Dis Fet.* **7**(1).

30. **Lippe, C., Diesen, P., Feragen, K.** 2017. Living with a rare disorder. *Mol Genet Genomic Med.* **5**(6):758-773.
31. **Paparone, P.** 1998. Neuropsychiatric manifestations of Lyme disease. *J Am Osteopath Assoc.* **98**(7):373-378.
32. **Naylor, C. Parsonage, M., McDaid, D., Knapp, M., Fossey, M., Galea, A.** 2012. Long-term conditions and mental health: the cost of co-morbidities. King's Fund Centre for Mental Health.
33. **Healthy People.** 2020. Health literacy. U.S. Department of Health and Human Services.
34. **Zepeda, S.** 2016. Report: health disparities across groups in Kentucky. Foundation for a Healthy Kentucky.
35. **Austin, E.** 2020. Kentucky is ranked as one of the nation's least healthy states. *Louisville Courier Journal.*
36. **Wright, L.** 2020. Center aims to build a culture of health in Kentucky and beyond. *UKnow.*
37. **Healthy People.** 2020. History of health literacy definitions. U.S. Department of Health and Human Services.
38. **University of North Carolina at Chapel Hill.** 2014. Health literacy data map. University of North Carolina.
39. **Brennan, K., Creaven, A.** 2016. Living with invisible illness. *Quality of Life Research.* **25**(5):1227-1235.
40. **Dunn, D., Andrews, E.** 2015. Person-first and identity-first language. *Am Psych.* **70**(3):255-264.