Why Don’t Many Physicians Believe in Chronic Lyme Disease? The Sociological and Psychological Impact This Places on Patients and the Need for Higher Sensitive Testing

Jocelyn Jernegan

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Dr. Jareb and Dr. Moras
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Introduction

Lyme disease has increased rapidly, and it continues to generate concern as more than 476,000 cases emerge every year in the United States alone (Bay… 2021). However, not only is this disease prevalent in the United States, but it also remains a large issue throughout North America and Europe (Liu et al. 2018). Lyme disease is a bacterial disease caused by various *Borrelia* species that is transmitted to humans through a tick bite (Boudreau et al. 2018; Bay... 2021). With early diagnosis through the recognition of a rash called erythema migrans, or what is commonly known as a bull’s eye on the skin, Lyme disease can be easily treated with antibiotics (Rebman et al. 2017; Boudreau et al. 2018; Bay... 2021). However, it is not always easy to diagnose Lyme disease, which leads to a chronic condition (Rebman et al. 2017; Boudreau et al. 2018; Bay... 2021). The chronic form of Lyme disease can lead to the persistence of symptoms such as fatigue, pain, mood changes, as well as neurologic, cardiovascular, and musculoskeletal complications (Rebman et al. 2017; Shah et al. 2018). Symptoms also often overlap with other conditions, which highlights the importance of effective and accurate testing (Shah et al. 2018; Bay… 2021). However, while this disease is very prevalent within the population and negatively impacts the daily functions and lives of the individuals affected, chronic Lyme disease remains a highly controversial topic in the medical community (Davidsson 2018; Shah et al. 2018; Bay… 2021). With a lack of efficient testing and treatments and unexplained symptoms which continue to present themselves in an individual, the medical community has become divided on whether this disease truly exists (Davidsson 2018; Shah et al. 2018; Bay… 2021). The current standard of testing that is in place to diagnose Lyme disease, while it continues to be used, has been proven to be insufficient in detecting Lyme cases and has thus influenced physicians to question a patient’s true diagnosis (Liu et al. 2018). However, the longer the diagnosis of this disease is prolonged, the more the physical health of patients declines, as symptoms persist with no administered treatments (Rebman et al. 2017; Bay... 2021). Without proper understanding of this disease, healthcare professionals, and eventually society, belittles patients, which places more burdens on these individuals as they struggle financially and mentally to overcome their condition (Gasmi et al. 2017; Rebman et al. 2017; Boudreau et al. 2018; Davidsson 2018; Hundersen et al. 2021). Therefore, there is a need for higher sensitive testing to efficiently diagnose Lyme disease (Embers et al. 2017; Liu et al. 2018; Shah et al. 2018; Fesler et al. 2020). The lack of knowledge around chronic Lyme disease places a stigma and financial burdens on patients which negatively impacts their mental and physical health, thus emphasizing the need for implementation of higher sensitive testing for correct diagnosis.

Current Standard of Testing for Lyme Disease

The Centers for Disease Control and Prevention (CDC) currently has a two-tiered test designed to detect the presence of Lyme disease in patients (Liu et al. 2018; Shah et al. 2018). This includes an ELISA, or enzyme-linked immunosorbent assay, or an IFA, or immunofluorescence assay, which is first used to detect for antibodies to *B. burgdorferi*, a specific species of the *Borrelia* group of bacteria that cause Lyme disease (Liu et al. 2018; Shah et al. 2018; Bay… 2021). If this first test is found to be positive, it is followed by a Western blot test for confirmation of this disease (Liu et al. 2018; Bay… 2021). A Western blot is used to detect antibodies to multiple proteins in the cells of the *B. burgdorferi* bacteria (Liu et al. 2018; Bay… 2021). While originally thought to be specific due to the inclusion of a second method of testing, the two-tiered method continues to miss infections (Liu et al. 2018; Bay… 2021). Lyme disease is caused by various species and strains within this group and this test is not specific enough to account for all this variability (Embers et al. 2017; Liu et al. 2018; Bay… 2021). The

Western blot involves an SDS PAGE technique for investigation and determination of protein identities based on molecular weight or size of the protein; however, proteins can have similar sizes and thus will travel along the gel together and cause uncertainty in verifying the identification (Liu et al. 2018). In addition to the varying species and strains which cause this two-tiered testing method to be insensitive and inefficient, bacteria also have evolved mechanisms to be undetected by the body's immune system so they can continue to thrive in the host environment (Embers et al. 2017; Liu et al. 2018; Bay… 2021). *Borrelia* exhibit low numbers in the body, as they are not actively dividing and spreading and are instead immersing themselves in the tissues (Embers et al. 2017). In addition, these bacteria induce mild inflammation responses from the body which allows for them to avoid recognition and destruction by the human body (Embers et al. 2017). Thus, when patients go to be tested, the body has not produced enough antibodies to be detected (Shah et al. 2018; Bay…2021). Due to the lack of active bacteria observed in the body and the lack of detectable antibodies after infection, testing for Lyme disease is often ineffective, thus negatively impacting the lives of many patients (Embers et al. 2017; Shah et al. 2018; Bay… 2021).

Sociological Impact

Without the support of the medical community, patients with chronic Lyme disease struggle to find the support they need to overcome this illness and struggle to find their role they must play in society (Rebman et al. 2017; Hundersen et al. 2021). The structure of society becomes impaired in terms of the treatment of Lyme disease (Gasmi et al. 2017). General practitioners lack the knowledge to properly prevent and treat Lyme disease (Gasmi et al. 2017). With misdiagnoses, use of unjustified preventative treatments, and failure to administer proper testing, society is not educated enough on patients with this illness (Gasmi et al. 2017). Gasmi et al. (2017) note the unjustified use of prescriptions merely to attempt to provide the patient with some answer they hope to achieve. Here, this emphasizes the lack of seriousness about this disease and the drive to simply remove the patient from their care (Gasmi et al. 2017; Boudreau et al. 2018).

Stigma centered around Lyme disease has resulted in patients feeling the effect of discrimination and isolation (Boudreau et al. 2018). Even when patients attempt to find new medical practices, physicians may deny treatment, as they fear the consequences and what other medical professionals will think (Boudreau et al. 2018). Physicians may also deny treatment simply because they do not understand the cause of symptoms and assume the patient's condition is psychologically caused (Boudreau et al. 2018; Hundersen et al. 2021). The lack of concern exhibited only leads to more tension between the medical professional and the families involved (Gaudet et al. 2019). Families have stated that symptoms of their children were dismissed, and instead healthcare professionals blamed the parents and said those parents were not doing enough (Gaudet et al. 2019). Physicians also have accused parents of abuse or accused parents of placing a disease on their child due to their own mental health issues (Gasmi et al. 2019). As a result, patients and families feel pressured to leave the conventional medical system to attempt to avoid stigma (Gaudet et al. 2019).

With so much uncertainty and stigma that is placed on patients with Lyme disease, patients are not given relief and it becomes hard for them to understand their place in society (Rebman et al. 2017). Their illness is questioned because it is not clear to everyone that chronic Lyme disease is a real illness and that someone may be suffering from it (Rebman et al. 2017). Symptoms remain invisible to many in society which makes it more difficult for people to understand the severe impact of Lyme disease on the lives of these individuals (Rebman et al.

2017). Society also assumes Lyme disease is just a tick bite and that they will overcome it; however, it is different for everyone (Rebman et al. 2017). Unlike typical healthcare issues like a common cold, or a broken bone, with chronic Lyme disease there is no clear trajectory of this disease and its outcomes, which can be frustrating (Rebman et al. 2017). Patients thus feel pressured to "go home and live with it" which further creates a sense of disconnectedness from the rest of the world and prevents one from receiving the help one would normally receive from a conventional illness (Boudreau et al. 2018).

As society fails to acknowledge and accept this disease, the more symptoms persist, and the more patients can no longer function in society as they normally would (Rebman et al. 2017). Patients see themselves as a completely different person as their social life and career goals change (Rebman et al. 2017). They do not engage in the same activities and cannot attend social events or work as they suffer with fatigue and pain throughout the body (Rebman et al. 2017). The neurological damage that results can even impair one's confidence to fulfil their duties (Rebman et al. 2017). Without known treatment, patients might strive to interact less with the outside world as they fear the consequences of inhabiting new illnesses (Rebman et al. 2017). Individuals with this disease must once again learn their capabilities and limitations; they must learn what their new body can do (Rebman et al. 2017).

To attempt to find some relief and success, many individuals will leave the conventional medical practices and find alternative medicinal therapy and guidance (Boudreau et al. 2018). At these outside practices, patients have found physicians to be more receptive and supportive, as they believe Lyme disease could be the responsible factor of their symptoms (Boudreau et al. 2018). Patients felt relieved from stigma, which further highlights the negative sociological impact of Lyme disease and how changes must be made to the traditional healthcare system to provide every patient with fair and optimal treatment services (Boudreau et al. 2018).

Financial Implications

The poor healthcare response to Lyme disease leads to many financial stressors (Boudreau et al. 2018). With a lack of support from the conventional healthcare system, people feel pressured to leave and find guidance elsewhere even though they face burdens of travel costs, costs for consultations and medications, and treatment costs (Boudreau et al. 2018). Patients have noted how they must find ways to obtain medications and treatments on their own, as it is not covered or made readily available by the current system (Boudreau et al. 2018). Patients on average seek out eight physicians, thus highlighting the burden of traveling to seek each of these different medical practices as well as the costs to meet and receive help from these physicians (Hundersen et al. 2021). For those who have children suffering from Lyme disease, parents must take off work to be able to care for them and provide transportation to the necessary doctor appointments (Gaudet et al. 2019). The mother of a patient with Lyme disease reported that she had to plan out a whole day to travel (a total of ten hours to and from another state) just to speak to a physician clinically trained to handle cases with chronic Lyme disease and diagnose her daughter with this disease (J. Jernegan, phone call with author, November 5, 2021). Not only must she travel to get a diagnosis, but she must also travel an additional three hours to receive a type of therapy which can remove the toxins this bacterial disease causes (J. Jernegan, phone call with author, November 5, 2021). Between the lost pay from taking off work with the added costs to figure out what is wrong and find available treatments, it becomes difficult to provide for the family (Gaudet et al. 2019). One mother in the study by Gaudet et al. (2019) revealed she spent nearly $20,000 to $25,000 to address the symptoms and find help. In addition, Hundersen et al.

(2021) reported that less than half of the subjects were able to receive a diagnosis in the first five years of the appearance of their symptoms. This further emphasizes the drastic financial burdens one must endure as it takes a great amount of time to be able to even identify the cause of one's illness as well as the insufficient support the medical system has on patients (Hundersen et al. 2021).

While patients are suffering with the symptoms of this disease, they also find themselves unable to keep their jobs, which results in further difficulties in keeping up with their medical bills (Boudreau et al. 2018). Most patients in the study by Hundersen et al. (2021) reported they had to pay parts of the costs for antibiotic treatment themselves and antibiotic treatment is very expensive (Davidsson 2018). Due to the highly expensive treatment options for this disease, insurance companies do not classify Lyme disease as a real illness and thus are able to deny services to patients and their families (Davidsson 2018). However, this does not just place a financial burden on the lives of families, it also provides a great financial cost to the government (Davidsson 2018). When people are pushed out of their jobs, they lose a great amount of income which causes the government to suffer as this causes a loss in tax revenue (Davidsson 2018). Davidsson (2018) reported that in 2018 the loss of income for chronic Lyme patients in the United States was 16.1 billion dollars. As society fails to give out the necessary treatment patients need, it only leads to accumulating cases and thus longer treatments and greater payments for both patients and the government (Davidsson 2018). More people will suffer financially the more society demonstrates a lack of concern and support for these victims (Davidsson 2018).

Psychological Impact

The negative view on chronic Lyme disease and thus the financial implications that arise, provides further burdens on a patient's mental health status (Gaudet et al. 2019; Hundersen et al. 2021). Rebman et al. (2017) illuminate how psychological symptoms have appeared not from the manifestation of the disease but from the illness experience. With the misdiagnoses, ineffective conventional healthcare system, lack of knowledge and stigma centered around this illness, it only leads patients and families to develop feelings of desperation (Boudreau et al. 2018). From an article published in Lyme Times Children's Treatment Issue, Berenbaum (2012) further emphasizes the concerns about achieving an accurate diagnosis and being able to afford the treatment. Patients and family members experience struggles of facing endless negative tests (Gaudet et al. 2019). A parent noted how she was striving for a test to come back positive to better understand her child's condition (Gaudet et al. 2019). At least if a diagnosis was achieved, treatments could begin to be administered and the patient could begin their road to recovery (Gaudet et al. 2019). However, this willingness for a test to come back positive does not improve the mental health of these parents, as it further makes them feel worse and hopeless, especially for a parent who is unable live up to their duties as a parental figure to cure the child and protect them from this illness (Gaudet et al. 2019).

While there are worries centered around the inability to achieve a diagnosis, the caring of a child with this disease contains its own worries and psychological distress (Berenbaum 2012; Gaudet et al. 2019). In the study by Gaudet et al. (2019), one parent reported the difficulty in seeing her child go from being healthy and possessing the ability to walk, to falling ill and needing to be pushed in a wheelchair in just a short amount of time. Parents become more concerned as they fear their children will not meet or experience milestones that every child should experience (Gaudet et al. 2019). While families are filled with many concerns as their loved ones battle Lyme disease, parents never want their children to see they are concerned or worried, instead they strive to protect their children (Berenbaum 2012). However, as parents hold in their stress, it takes a toll on one's mental health and negatively impacts their life and their child, as their child can sense the tension that exists in the house (Berenbaum 2012). The whole family dynamic changes (Gaudet et al. 2019). Families feel truly isolated as they lack support medically and financially and are immersed in fear that their children may never recover or never return to what used to be considered their normal (Berenbaum 2012; Boudreau et al. 2018; Gaudet et al. 2019).

While it is important to understand the psychological distress parents exhibit over the care of children with chronic Lyme disease, it is also important to note the psychological symptoms patients come to possess during their experience with this illness (Rebman et al. 2017; Gaudet et al. 2019; Hundersen et al. 2021). Patients have been found to experience symptoms such as anxiety, depression, mood swings, and problems with sleep, thinking, and concentration (Rebman et al. 2017; Hundersen et al. 2021). Depression appears to be a direct consequence of chronic Lyme disease, as these symptoms have been found to improve after the administration of treatment (Hundersen et al. 2021). As others do not understand their illness and what the patients must endure, patients also face feelings of frustration and loneliness (Rebman et al. 2017). The symptoms make patients feel insecure about themselves and only make them more upset when handling this illness, for they do not know how long this disease will last or how long symptoms will have to be endured, and they face fears about what their future will entail (Rebman et al. 2017; Hundersen et al. 2021). Without treatment, symptoms and the condition of patients worsen, and patients experience a reduced quality of life (Boudreau et al. 2018; Hundersen et al.

2021). Hundersen et al. (2021) revealed in their study that the quality of life was worse in patients with Lyme disease than the control group without Lyme disease. Patients with Lyme disease feel as if they will have to suffer forever, and with the current healthcare system practices, they never find a sense of security and safety (Boudreau et al. 2018).

To improve the psychological conditions of patients with Lyme disease, researchers have proposed several mechanisms which should be implemented (Rebman et al. 2017; Boudreau et al. 2018; Hundersen et al. 2021). Rebman et al. (2017) found the importance of validation and connectivity in improving one's health. In addition, Hundersen et al. (2021) emphasize how treatments and resources for psychological issues should be provided to patients with Lyme disease. While the conventional healthcare system fails many patients, Boudreau et al. (2018) reveal alternative medicinal practices can provide patients with more relief. When someone possesses more support and feels heard, psychological symptoms can improve and the path to recovery can become easier (Rebman et al. 2017; Boudreau et al. 2018; Hundersen et al. 2021).

Newer Testing Methods and the Importance of Implementing these Methods in Society

As patients and families experience heavy burdens due to chronic Lyme disease, there is a need for more efficient testing to accurately diagnose one's condition (IgeneX [date unknown]; Liu et al. 2018; Shah et al. 2018; Fesler et al. 2020). In the study by Shah et al. (2018), a Lyme multiplex PCR-dot blot assay (LM-PCR assay) was developed to better detect the presence of this bacteria, *Borrelia burgdorferi* (BB), in blood and urine samples. The LM-PCR assay uses magnetic beads that contain streptavidin which will bind to labeled BB capture probes (Shah et al. 2018). These capture probes bind to the DNA of these bacteria which allows for researchers to identify that this bacterium is present in the body and collected samples (Shah et al. 2018). Once bound to the targeted DNA, or BB DNA, the beads in the assay are washed to remove debris, inhibitors, and any substance that is not specifically the BB DNA, which highlights how this method is efficient in extracting specific DNA (Shah et al. 2018). Amplified DNA was supported to be derived from this bacterium causing Lyme disease (Shah et al. 2018). While inhibitors typically interfere with the results of PCR testing and therefore raise concerns for the use of this type of test, this assay removes these inhibitors, thus allowing for higher sensitivity, which is crucial due to the small number of bacteria present in a patient's blood and urine samples (Liu et al. 2018; Shah et al. 2018). Ultimately, this testing method resulted in higher positive samples than the currently approved CDC test results, which further emphasizes that without efficient testing, many cases will go undiagnosed (Shah et al. 2018).

Another improved method of testing is a Lyme immunoblot test (Liu et al. 2018). A Lyme immunoblot uses purified recombinant antigens from several species within the *Borrelia burgdorferi* sensu lato (BBsl) complex which helps identify various antibodies that result from Lyme disease (Liu et al. 2018). As there are many strains of bacteria which cause Lyme disease, it is crucial for a test to be sensitive to each of them (Embers et al. 2017; Liu et al. 2018). Liu et al. (2018) found this test had improved sensitivity and specificity which allowed for no further testing to be done. The ability to recognize proteins from different species is essential for better diagnostic purposes (Liu et al. 2018). In addition, the Lyme immunoblot was able to differentiate samples causing Lyme disease and another disease, tick-borne relapsing fever (TBRF) which possess similar antigens (Liu et al. 2018). Antibodies to the bacteria causing TBRF did not react with the antigens used in the Lyme immunoblot, which again highlights how this test is better for achieving an accurate diagnosis (Liu et al. 2018).

Like in the previous study investigating the use of a Lyme immunoblot, Fesler et al. (2020) developed a modified Western blot procedure known as a line immunoblot which also uses recombinant antigens from strains and species of the bacterial groups that cause Lyme disease and Relapsing Fever (RFB). With this line immunoblot test, positive tests could be detected at a specific species level (Fesler et al. 2020). For instance, the bacteria which causes Lyme disease could be classified as *B. californiensis, B. spielmanii, B. afzelli/B. garinii,* and *B. mayonii* (Fesler et al. 2020). As this bacterium is so diverse, it is important to understand the various species involved in causing disease and to have a test that possesses the ability to detect the diversity (Fesler et al. 2020).

Each of these studies highlight the importance of the implementation of these higher sensitive testing methods into clinical settings, for with these testing methods being administered, patients can achieve an accurate diagnosis (Liu et al. 2018; Shah et al. 2018; Fesler et al. 2020). Therefore, education and awareness of chronic Lyme disease is crucial, especially within the medical community (Gasmi et al. 2017). General practitioners need to be more educated on ticks and the species of ticks, as well as on Lyme disease in general (Gasmi et al. 2019). Physicians need to be knowledgeable on the clinical signs of Lyme disease, optimal testing methods, and available treatments to improve the health of many people (Gasmi et al. 2019).

Conclusion

Hundreds of thousands of people suffer from chronic Lyme disease, and they will suffer more as their diagnosis is prolonged (Rebman et al. 2017; Bay… 2021). Patients experience endless doctor's appointments and treatments all in search of an answer and a cure to their devastating condition (Boudreau et al. 2018; Gaudet et al. 2019; Hundersen et al. 2021). Therefore, physicians need to be educated and have proper resources to diagnose Lyme disease and end this long journey of suffering (Gasmi et al. 2017). As the current standard of testing and treatment fails many people, stigma is placed onto these individuals, however with more education and awareness on this disease, stigma can be diminished, and patients can feel more supported (Gasmi et al. 2017; Boudreau et al. 2018). Medical professionals will understand how to provide care to these individuals and insurance companies could become more open to covering their services (Gasmi et al. 2017; Davidsson 2018). With more support from society, the overall health of patients can improve, as patients feel more confident knowing their diagnosis and knowing the path to recovery will be easier with the help from others (Rebman et al. 2017; Boudreau et al. 2018). When patients have access to higher sensitive testing, sociological, financial, and psychological burdens will be eliminated (Embers et al. 2017; Gasmi et al. 2017; Rebman et al. 2017; Boudreau et al. 2018; Davidsson 2018; Liu et al. 2018; Shah et al. 2018; Fesler et al. 2020; Hundersen et al. 2021).

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