

What is a Lyme literate doctor?

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In the Infectious Diseases Society of America (IDSA) guidelines, Wormser and colleagues initially dismissed Lyme disease symptoms as nothing more than the aches and pains of daily living.[2] A Lyme literate doctor would disagree.

That conclusion, however, has been undermined by findings from clinical trials, sponsored by the National Institutes of Health (NIH), which report patients with Lyme disease suffer from severe symptoms, poor quality of life, and a loss of function.

Additionally, other studies indicate patients diagnosed with Post-Treatment Lyme Disease Syndrome (PTLDS) exhibit ongoing pain, impaired cognitive function, severe fatigue, and poor function.

Although they may not agree on the cause, both groups of doctors are beginning to recognize that these patients, whatever they are labeled, continue to suffer from chronic illnesses.

Medically unexplained illnesses are often described as “syndromes characterized by multiple symptoms, significant suffering, and disability that fail to show consistent pathophysiology,” [Dumes writes](#).

Lyme literate doctors have reached the same conclusion. For purposes of transparency, I have been viewed as a Lyme literate doctor.

Dumes describes the divide between doctors over the diagnosis of Lyme disease. Mainstream doctors argue that the diagnosis is usually straightforward. A Lyme literate doctor would maintain that tests are often inaccurate and that chronic Lyme disease is a problem.

[The article also describes the divide between doctors over treatment for Lyme disease](#). While mainstream doctors argue that chronic issues are due to a medically unexplained illness, a Lyme literate doctor would maintain that chronic symptoms may be due to active infection and patients should be treated with additional antibiotics if symptoms persist.

“Mainstream proponents argue that the bacterium that causes Lyme disease, *Borrelia burgdorferi*, does not persist in the body at pathogenic levels after standard antibiotic therapy,” the author writes.

On the other hand, “Lyme literate doctors consider Lyme disease to be a tick-borne pathogen that may require prolonged oral and intravenous antibiotics for a persistent infection.”

Symptom-based diagnosis

Doctors also differ in their approach to symptoms. “For the physicians who diagnose and treat these patients, how they approach their patients’ diagnosis depends in large part on the diagnostic value they

assign to symptoms,” Dumes writes.

Mainstream doctors consider Lyme disease as another controversial diagnosis, such as hypoglycemia, Briquet’s syndrome, chronic fatigue syndrome, multiple chemical sensitivity, Gulf War syndrome, and somatization disorders, Dumes explains.

Mainstream doctors typically rely on objective criteria, such as the presence of an erythema migrans rash, seventh nerve palsy, heart block, Lyme arthritis, or a positive IgG Western blot test.

Meanwhile, “Lyme literate doctors embrace a symptom-based diagnosis at odds with Lyme’s conventional diagnostic paradigm,” Dumes writes.

The author cites a list of symptoms from the [International Lyme and Associated Diseases Society’s \(ILADS\) working group](#): “fatigue, low grade fevers, hot flashes or chills, night sweats, sore throat, swollen glands, stiff neck, migrating arthralgias, stiffness and, less commonly, frank arthritis, myalgia, chest pain and palpitations, abdominal pain, nausea, diarrhea, sleep disturbance, poor concentration and memory loss, irritability and mood swings, depression, [and] back pain.”[3]

Mainstream doctor’s view of symptoms

The author reports two interviews that offer insight into the mainstream doctor’s view of Lyme disease symptoms.

First Interview

“Most Lyme patients are not difficult to diagnose and treat. Do you know the difference between a symptom and a sign? It boils down to subjective symptoms and objective signs. For example, arthralgia is the subjective experience of pain, and arthritis is an objective sign. Chronic Lyme patients only have nonspecific symptoms that are chronic. There’s so much evidence that this is related to psychological factors.”

Second interview

When asked to read a list of symptoms the doctor stopped and concluded: “These are exaggerated, nondescript symptoms that people read about and think, ‘Oh! They’re due to chronic Lyme disease.’ But a number of these symptoms should be put in the MUS [medically unexplained symptoms] category; they’re not due to Lyme or any other infection.”

Lyme literate doctor’s view of symptoms

The author reports an interview that offers insight into the Lyme literate doctor’s view of symptoms.

“It’s actually very easy: Lyme is a multisystemic disorder with a classic constellation of symptoms that include fatigue, headaches, joint, muscle, and nerve pain ([such as] tingling, numbness, burning, and stabbing sensations), and memory and concentration problems, as well as sleep and mood disorders.

"Also, people can feel better with antibiotics but then worse, [which is] called a Herxheimer reaction, when the bacteria is being killed off. And women often notice flare-ups of their disease with their hormonal cycle.

"One of the hallmarks of Lyme disease is that the symptoms come and go without any apparent reason. You have good days, you have bad days. Your joint and muscle pain tends to migrate: one day it hurts in the elbow; two days later, it hurts in your shoulder. ... And the tingling and numbness, if you had carpal tunnel, it stays in your hands, right? ... So migratory tingling and numbness that comes and goes and moves around your body with these migratory muscle pains and joint pains, very specific for Lyme disease."

Divergence over interpretation of symptoms

"While both Lyme literate and mainstream physicians insist that Lyme disease is a clinical diagnosis, they diverge over the diagnostic validity of interpreting symptoms as signs," writes the author. "Lyme-literate physicians embrace a symptom-based diagnosis at odds with the mainstream paradigm."

"Although mainstream physicians criticize Lyme-literate physicians and CAM [complementary and alternative medicine] practitioners for attributing specificity to an ambiguous multitude of symptoms, Lyme-literate and CAM practitioners maintain that they are merely practicing more comprehensive medicine," Dumes writes.

Related Articles:

[What does it take to be a Lyme literate doctor?](#)

[Video Q&A: What is a Lyme literate doctor?](#)

[Yale doctor says children don't have Lyme but medically unexplained symptoms](#)

References:

1. Dumes AA. Lyme Disease and the Epistemic Tensions of "Medically Unexplained Illnesses". *Med Anthropol*. 2019 Dec 20:1-16.
2. Wormser GP, Dattwyler RJ, Shapiro ED, Halperin JJ, Steere AC, Klempner MS, Krause PJ, Bakken JS, Strle F, Stanek G, Bockenstedt L, Fish D, Dumler JS, Nadelman RB. The clinical assessment, treatment, and prevention of lyme disease, human granulocytic anaplasmosis, and babesiosis: clinical practice guidelines by the Infectious Diseases Society of America. *Clin Infect Dis*. 2006 Nov 1;43(9):1089-134.
3. Cameron DJ, Johnson LB, Maloney EL. Evidence assessments and guideline recommendations in Lyme disease: the clinical management of known tick bites, erythema migrans rashes and persistent disease. *Expert Rev Anti Infect Ther*. 2014 Sep;12(9):1103-35.

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by Dr. Daniel Cameron - Daniel Cameron, MD, MPH - <https://danielcameronmd.com>

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