

# Should Patients Infected with *Borrelia burgdorferi* No Longer Be Referred to as Having Lyme Disease?



In 1977, a seminal paper described what was subsequently called *Lyme arthritis*.<sup>1</sup> The name 'Lyme' originated from the initial investigation of the disease that was conducted in the Connecticut towns of Lyme, Old Lyme, and East Haddam.<sup>1</sup> As more of the clinical manifestations of this illness were discovered, the condition became referred to as Lyme disease.<sup>2-4</sup> In 1983, the principal etiologic agent for Lyme disease in North America was identified in patients.<sup>3,5</sup> The etiologic agent became known as *Borrelia burgdorferi* and until fairly recently was the only species of Lyme *borrelia* identified to cause Lyme disease in the United States. Now it has been established that a few cases have been caused by *Borrelia mayonii*, but these have only been identified in the north-central region of the United States.<sup>6</sup> In Europe, several other *Borrelia* species cause Lyme disease, and indeed, *B burgdorferi* is not the principal etiologic agent of Lyme disease there.<sup>7</sup> With the discovery of these European species, Lyme *borrelia* were then generically referred to as *B burgdorferi* *sensu lato*, with the original species discovered in the United States identified as *B burgdorferi* *sensu stricto*. Also, it became understood that some of the clinical features caused by infection with Lyme *borrelia* had been recognized in Europe well before 1977. In Europe, the infection is referred to as Lyme borreliosis rather than Lyme disease. In addition, due to the different etiologic agents, certain clinical manifestations, such as acrodermatitis chronica atrophicans and borrelial lymphocytoma, principally or exclusively occur in Europe.<sup>4,7</sup>

Medically unexplained subjective symptoms are a common reason for doctor visits. In 1973, in his book *The Effective Clinician*, Tumulty<sup>8</sup> wrote that medically unexplained subjective

symptoms are responsible for at least 25% of visits to primary care practitioners. Fatigue is often the centerpiece of medically unexplained subjective symptoms, along with joint pain, muscle pain, and memory and concentration difficulties. Similar symptoms not infrequently accompany objective diagnoses such as culture-verifiable infections, including Lyme disease,<sup>9</sup> autoimmune diseases, and neoplastic conditions; however, in those settings, the symptoms are medically explained, not medically unexplained.

Unexplained chronic fatigue may be referred to as chronic fatigue syndrome or myalgic encephalitis when certain diagnostic criteria are satisfied.<sup>10,11</sup> Looking at chronic fatigue syndrome from a historical perspective, it is clear that there has been intense interest in identifying the etiology (or etiologies). Putative causes have included Epstein-Barr virus, *Candida albicans*, and a murine retrovirus. For the most part, these infectious causes have disappeared from the radar, as they were debunked by scientific data.<sup>12</sup>

However, chronic fatigue syndrome and medically unexplained subjective symptoms are now increasingly referred to as Lyme disease or as chronic Lyme disease (interchangeable terms), which triggers certain clinicians to initiate long-term antibiotic therapy often using simultaneous administration of multiple antimicrobials thought to be directed to *B burgdorferi* bacterial cells, *B burgdorferi* cyst forms, and to putative 'coinfections' with *Babesia microti* and *Bartonella henselae*.<sup>12,13</sup> There is no requirement to establish that the patient was ever actually infected with *B burgdorferi* *sensu lato*, *B microti*, or *B henselae* using laboratory assays (reliable or otherwise), or ever had an objective clinical manifestation of Lyme disease.<sup>14-16</sup> Indeed, *B henselae* has not been established to be an *Ixodes scapularis*-transmitted pathogen.<sup>13</sup> The key presumption is that serologic testing for antibodies to *B burgdorferi* *sensu lato* is too insensitive to exclude *B burgdorferi* infection despite weeks to months of symptoms.<sup>15,16</sup> This perspective on Lyme disease (or chronic Lyme disease) has been widely endorsed by Lyme disease activists, support groups, and politicians. Consequently, there is increasing confusion about what Lyme disease is, or is not, for both patients and health care practitioners.<sup>14-16</sup> Apparently, there is no way to exclude Lyme disease (or chronic Lyme disease) as the diagnosis for a given patient. No diagnostic testing is required to establish the

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Requests for reprints should be addressed to Gary P. Wormser, MD, Division of Infectious Diseases, New York Medical College, 40 Sunshine Cottage Road, Skyline Office #2N-E14, Valhalla, NY 10595.

E-mail address: [gwormser@nymc.edu](mailto:gwormser@nymc.edu)

diagnosis. If the patient improves on treatment, that validates the diagnosis, whereas if the patient worsens on treatment, that similarly supports the diagnosis, as this is attributed to the symptomatic effects of destroying *B burgdorferi* cells.<sup>15</sup>

As scientific evidence is not persuasive in this matter, perhaps an approach that would enable clinicians and patients to better understand what was originally intended with the term *Lyme disease* would be to change the name of the illness using a name that conveys that the condition is not solely a clinical diagnosis but instead is a clinical and a microbiological laboratory diagnosis. To this end, we propose the name *B burgdorferi* sensu lato infection, or Bbsl infection for short, instead of Lyme disease. Because most patients with erythema migrans cannot be readily proven to have laboratory evidence of *B burgdorferi* infection, such cases would be counted as possible Bbsl infection. However, encouraging data suggest that it may be possible in the future to validate the diagnosis of erythema migrans using a novel laboratory assay on serum.<sup>17</sup> Microbiology taxonomists, coincidentally, are arguing that Lyme *borrelia* should be referred to as *Borrelia*, reserving the term *borrelia* for relapsing fever type *borrelia* strains (eg, *Borrelia hermsii*). This change would be expected to cause even more confusion in the Lyme disease field and not benefit in any way clinicians, clinical microbiology laboratories, or patients.<sup>18</sup> The name change proposed here, however, may be immensely helpful to patients and health care practitioners interested in evidence-based medicine and thus should be a topic for future discussions.

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Gary P. Wormser, MD  
 Division of Infectious Diseases,  
 New York Medical College,  
 Valhalla

## References

1. Steere AC, Malawista SE, Snyderman DR, et al. Lyme arthritis: an epidemic of oligoarticular arthritis in children and adults in three Connecticut communities. *Arthritis Rheum.* 1977;20:7–17.

2. Steere AC, Malawista SE, Hardin JA, Ruddy S, Askenase W, Andiman WA. Erythema chronicum migrans and Lyme arthritis. The enlarging clinical spectrum. *Ann Intern Med.* 1977;86:685–698.
3. Steere AC, Grodzicki RL, Kornblatt AN, et al. The spirochetal etiology of Lyme disease. *N Engl J Med.* 1983;308:733–740.
4. Wormser GP, Dattwyler RJ, Shapiro ED, et al. The clinical assessment, treatment, and prevention of Lyme disease, human granulocytic anaplasmosis, and babesiosis: clinical practice guidelines by the Infectious Diseases Society of America. *Clin Infect Dis.* 2006;43:1089–1134.
5. Benach JL, Bosler EM, Hanrahan JP, et al. Spirochetes isolated from the blood of two patients with Lyme disease. *N Engl J Med.* 1983;308:740–742.
6. Pritt BS, Respicio-Kingry LB, Sloan LM, et al. *Borrelia mayonii* sp. nov., a member of the *Borrelia burgdorferi* sensu lato complex, detected in patients and ticks in the upper midwestern United States. *Int J Syst Evol Microbiol.* 2016;66:4878–4880.
7. Stanek G, Wormser GP, Gray J, Strle F. Lyme borreliosis. *Lancet.* 2012;379:461–473.
8. Tumulty PA. *The Effective Clinician: His Methods and Approach to Diagnosis and Care.* Philadelphia: WB Saunders; 1973.
9. Tibbles CD, Edlow JA. Does this patient have erythema migrans? *JAMA.* 2007;297:2617–2627.
10. Caruthers BM, van de Sande MI, De Meirleir KL, et al. Myalgic encephalomyelitis: International consensus criteria. *J Intern Med.* 2011;270:327–338.
11. Fukuda K, Straus SE, Hickie I, et al. The chronic fatigue syndrome: a comprehensive approach to its definition and study. International Chronic Fatigue Syndrome Study Group. *Ann Intern Med.* 1994;121:953–959.
12. Feder Jr HM, Johnson BJ, O'Connell S, et al. A critical appraisal of "chronic Lyme disease". *N Engl J Med.* 2007;357:1422–1430.
13. Lantos PM, Wormser GP. Chronic coinfections in patients diagnosed with chronic Lyme disease: a systematic review. *Am J Med.* 2014;127:1105–1110.
14. Auwaerter PG, Bakken JS, Dattwyler RJ, et al. Antiscience and ethical concerns associated with advocacy of Lyme disease. *Lancet Infect Dis.* 2011;11:713–719.
15. Halperin JJ, Baker P, Wormser GP. Common misconceptions about Lyme disease. *Am J Med.* 2013;128:e1–e7. <https://doi.org/10.1016/j.amjmed.2012.10.008>.
16. Shapiro ED, Baker PJ, Wormser GP. False and misleading information about Lyme disease. *Am J Med.* 2017;130:771–772.
17. Molins CR, Ashton LV, Wormser GP, et al. Development of a metabolic biosignature for detection of early Lyme disease. *Clin Infect Dis.* 2015;60:1767–1775.
18. Stevenson B, Fingerle V, Wormser GP, Margos G. Public health and patient safety concerns merit retention of Lyme borreliosis-associated spirochetes with the genus *Borrelia* and rejection of the genus novum *Borrelia*. *Ticks Tick Borne Dis*, provisionally accepted.