Chronic Lyme Disease

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KEYWORDS

• Lyme disease • Chronic Lyme disease • *Borrelia burgdorferi* • Chronic fatigue • Chronic pain • Antibiotics

KEY POINTS

- There is no accepted clinical definition for chronic Lyme disease.
- Most patients with a diagnosis of chronic Lyme disease have no evidence of Lyme disease.
- Persistent subjective symptoms during recovery from Lyme disease are not active infection.
- Prolonged antibiotic courses are ineffective and unsafe patients for patients with prolonged symptoms after Lyme disease.

THE CHRONIC LYME DISEASE CONTROVERSY

Chronic Lyme disease (CLD) is a poorly defined term that describes the attribution of various atypical syndromes to protracted *Borrelia burgdorferi* infection. These syndromes are atypical for Lyme disease in their lack of the objective clinical abnormalities that are well-recognized in Lyme disease and, in many cases, the absence of serologic evidence of Lyme disease as well as the absence of plausible exposure to the infection. The syndromes usually diagnosed as CLD include chronic pain, fatigue, neurocognitive, and behavioral symptoms, as well as various alternative medical diagnoses—most commonly neurologic and rheumatologic diseases. Perhaps the most recognized and contentious facet of this debate is whether it is effective, appropriate, or even acceptable to treat patients with protracted antibiotic courses based on a clinical diagnosis of CLD.

The dialogue over CLD provokes strong feelings, and has been more acrimonious than any other aspect of Lyme disease. Many patients who have been diagnosed

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with CLD have experienced great personal suffering; this is true regardless of whether *B burgdorferi* infection is responsible for their experience. On top of this, many patients with a CLD diagnosis share the perception that the medical community has failed to effectively explain or treat their illnesses. In support of this patient base is a community of physicians and alternative treatment providers as well as a politically active advocacy community. This community promotes legislation that has attempted to shield CLD specialists from medical board discipline and medicolegal liability for unorthodox practices, to mandate insurance coverage of extended parenteral antibiotics, and most visibly to challenge legally a Lyme disease practice guideline. The advocacy community commonly argues that Lyme disease is grossly underdiagnosed and is responsible for an enormous breadth of illness; they also argue that the general scientific and public health establishments ignore or even cover up evidence to this effect. A large body of information about CLD has emerged on the Internet and other media, mostly in the forms of patient testimonials and promotional materials by CLD providers. For a medical consumer and for the physician unfamiliar with this subject, this volume of information can be confusing and difficult to navigate.

The CLD controversy does not, however, straddle a simple divide between 2 opposed scientific factions. Within the scientific community, the concept of CLD has for the most part been rejected. Clinical practice guidelines from numerous North American and European medical societies discourage the diagnosis of CLD and recommend against treating patients with prolonged or repeated antibiotic courses.[1–21] Neither national nor state public health bodies depart from these recommendations. Within the medical community, only a small minority of physicians have accepted this diagnosis: 1 study found that only 6 of 285 (2.1%) randomly surveyed primary care physicians in Connecticut, among the most highly endemic regions for Lyme disease, diagnosed patients with CLD and still fewer were willing to prescribe long courses of antibiotics.[22,23]

THE CONFUSING TERMINOLOGY OF CHRONIC LYME DISEASE

The mere name “chronic Lyme disease” is in itself a source of confusion. Lyme disease, in conventional use, specifically describes infection with the tick-borne spirochete *B burgdorferi* sensu lato. The diagnosis “chronic Lyme disease,” by incorporating that terminology, connotes a similar degree of microbiologic specificity; the addition of the word “chronic” further implies that there is some distinction between “chronic” Lyme disease and other manifestations of the infection. This distinction in itself is problematic because several manifestations of Lyme disease may indeed present subacutely or chronically, including Lyme arthritis, acrodermatitis chronicum atrophicans, borrelial lymphocytoma, and late Lyme encephalopathy.

“Chronic Lyme disease,” however, has no clinical definition and is not characterized by any objective clinical findings. The only published attempt to define CLD provisionally produced a description too broad to distinguish CLD from myriad other medical conditions, and the case definition did not mention evidence of *B burgdorferi* infection (**Box 1**).[24] The absence of a definition makes it impossible to investigate whether a patient population with putative CLD has evidence of infection with *B burgdorferi*; this would seem to be a basic requirement to include a syndrome within the term “Lyme disease.” It stands to reason that it is impossible to even posit a well-designed antibiotic trial when the study population is undefined.

In the absence of a definition, it is instructive to examine the circumstances under which patients receive a diagnosis of CLD. These circumstances can be