At least 50% of patients with Lyme neuroborreliosis remain ill years after treatment

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There are doctors who continue to question the existence and severity of chronic manifestations of Lyme disease (LD), despite a growing number of cases described in leading medical journals. [1,2] The cases include chronic neurologic Lyme disease, [3] Lyme encephalopathy, [4,5] neuropsychiatric LD, [6] post-treatment chronic Lyme disease, [7] post-Lyme disease [8] and post-treatment Lyme disease syndrome. [9] The severity of chronic manifestations of LD includes a poor quality of life, profound fatigue and chronic pain. [5,7,8]

A study by Dersch and colleagues described 30 adults with 'definite' Lyme neuroborreliosis (LNB), who were treated at the Medical Center, University of Freiburg between 2003 and 2014. [10] These patients had to have compatible neurological symptoms, CSF pleocytosis, antibodies against Borrelia burgdorferi in serum and CSF and a CSF/serum antibody index >= 2.

There was a broad spectrum of LNB conditions with 50% of patients diagnosed with polyradiculoneuritis, 6 with isolated cranial nerve disorder, 4 with meningitis, 2 with encephalomyelitis, 2 with myelitis, and 1 with vasculitis. [10]

The 30 subjects were treated an average of 4.1 weeks after onset of symptoms with either ceftriaxone, doxycycline or subsequently with both antibiotics. [10] The duration of antibiotics was not described.

Out of the 30 subjects, 17 (57%) reported residual symptoms an average of 5.7 years after antibiotic treatment. The residual symptoms consisted of pain (n = 6), ataxia (n = 6), sensory disturbances (n = 4), cranial nerve disorder (n = 2), spastic gait (n = 2), fatigue (n = 2), and micturition disorder (n = 1). [10] The patients could have more than one residual symptom. The 17 patients presented with severe fatigue an average of 5.7 years after antibiotic treatment. The average Fatigue Severity Scale (FSS) score was 4.29. [8] Krupp defined severe fatigue >= 4.0 in her NIH sponsored clinical trial. [8]

The 17 LBN subjects with residual symptoms also presented with a poor quality of life. "Patients with residual symptoms had statistically significantly lower measures of quality of life, as measured with the physical component summary of the SF-36 compared to patients without residual symptoms," according to Dersch.

"The proportion of patients with residual symptoms is similar to proportions reported in other studies of antibiotically treated patients with LNB," states Dersch. According to the study, the 17 LBN subjects did not present with depression or global cognitive impairment.

“Our results do not support the hypothesis that a considerable proportion of patients with antibiotically treated LNB develop a ‘post Lyme syndrome’ consisting of debilitating fatigue or cognitive impairment or have severe limitations of quality of life.” [10]

However, the investigators did not assess for the broader range of cognitive symptoms as described in Fallon’s National Institutes of Health (NIH) sponsored trial of Lyme encephalopathy. [5]

Dersch may have overlooked the severity of fatigue and poor quality of life by pooling the results of the 17 patients with persistent symptoms with the 13 patients without persistent symptoms.

Instead, the Dersch data demonstrated that at least 50% of patients with antibiotically treated LNB develop a ‘post Lyme syndrome’ consisting of debilitating fatigue and poor quality of life.

Two retrospective cohorts in the U.S. had described persistent symptoms in 34% to 62% of antibiotically treated patients years after treatment. [11,12] Meanwhile, 28% of patients with LNB remained ill years after treatment in a systematic review of 48 clinical trials. [13]

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