

Study finds misdiagnosis and delayed diagnosis common for Lyme disease patients

Tuesday, December 04, 2018

<http://danielcameronmd.com/study-finds-misdiagnosis-and-delayed-diagnosis-common-for-lyme-disease-patients/>

[A study published in *Healthcare \(Basel\)* by Johnson and colleagues](#) [1] summarizes information provided by 3,903 individuals registered with MyLymeData.

The participants reported a delay in diagnosis. “More than half (51%) reported that it took them more than three years to be diagnosed and roughly the same proportion (54%) saw two or more clinicians before diagnosis,” says Johnson.

Furthermore, there was a delay in diagnosis even when patients had an early onset of symptoms, Johnson explains. “Diagnostic delays occurred despite the fact that 45% of participants reported early symptoms of Lyme disease within days to weeks of [tick] exposure.”

The reasons for such delays included false negative lab tests (37%) or positive test results “that were dismissed as ‘false-positives’ (13%),” she says.

Also, “the majority of patients (72%) reported being misdiagnosed with another condition prior to their Lyme diagnosis.”

The most common misdiagnosis for those patients included: psychiatric disorder (52%), myalgia (43%) and chronic fatigue syndrome (42%).

“Although misdiagnosis with a psychiatric illness was common (52%),” says Johnson, “only 18% reported psychiatric symptoms as being among their three worst symptoms.”

The symptoms they reported are similar to those in the literature. “Three worst symptoms included neurologic-associated symptoms (84%) and fatigue (62%), followed by musculoskeletal-associated symptoms (57%),” Johnson states.

Neurologic symptoms included cognitive impairment, sleep impairment, memory loss, psychiatric manifestations, headaches and twitching, with cognitive impairment (30%) and neuropathy (29%).

Musculoskeletal symptoms included muscle aches and joint pain.

The [MyLymeData survey](#) results found that patients frequently required symptomatic treatment, Johnson explains.

“Sleep medications [were] taken at higher rates (34%) than the general age-adjusted population (9%).”

“Thyroid medication, which is sometimes associated with managing fatigue, was also much higher (33%) than the general age-adjusted population (8%).”

“Pain-associated symptoms (joint pain, muscle aches, or neuropathy) were common (71%), and prescription pain medication usage (26%) was higher than the age-adjusted rate in the US general population (16%).”

Editor’s note: MyLymeData is a project by LymeDisease.org, which is a grassroots non-profit organization that supports the interests of Lyme disease patients. The organization has been conducting and publishing peer-reviewed big data patient surveys for over 10 years.

Related Articles:

[Six reasons for delayed treatment of Lyme disease](#)

[Video: Are there common misdiagnoses for Lyme disease?](#)

[Impact of Lyme disease on working and caregiving](#)

References:

1. Johnson L, Shapiro M, Mankoff J. Removing the Mask of Average Treatment Effects in Chronic Lyme Disease Research Using Big Data and Subgroup Analysis. *Healthcare (Basel)*. 2018;6(4).

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