

RESEARCH REPORT



Characterizing the Symptoms of Patients with Persistent Post-Treatment Lyme Symptoms: A Survey of Patients at a Lyme Disease Clinic in Rhode Island

original research by

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WHAT IS POST-TREATMENT LYME DISEASE SYNDROME?

An estimated 20% of people who take antibiotics for Lyme have persistent symptoms including fatigue, pain, and impaired thinking more than 6 months after treatment without any continued clinical findings such as Lyme rash. These persistent symptoms are known as post-treatment Lyme disease syndrome, or PTLDS. Studies funded by the National Institutes of Health have found no benefit to continued antibiotic treatment for persistent symptoms. Without a known cause or cure, PTLDS treatment focuses on managing symptoms.

WHAT WAS THE RESEARCH QUESTION?

How severe is fatigue, pain, impaired thinking, and sleep disruption among patients with persistent post-Lyme treatment symptoms at the Rhode Island Lifespan Lyme Disease Center? Are there differences in symptom severity ratings by gender, age, or time since the onset of post-treatment Lyme disease symptoms?

HOW DID WE GET THE DATA?

Patients at the Lifespan Lyme Disease Center were approached by study staff while attending an appointment at the Center and asked to complete a series of symptom rating questions if they were: 1) 18 years of age or older and 2) had a history of Lyme disease with persistent symptoms after antibiotic treatment. The questions were from publicly-available Patient-Reported Outcomes Measurement Information System (PROMIS®) surveys assessing fatigue, pain intensity, pain interference, impaired thinking, sleep disturbance, physical functioning, social functioning, anxiety, depression, and ability to participate in social roles and activities.

WHAT DID WE LEARN?

Compared to healthy people and people with other chronic illnesses, patients with persistent post-Lyme treatment symptoms had:

MILD impairments in...	MODERATE symptoms of...
<ul style="list-style-type: none">• Sleep• Physical & Social Functioning• Depression & Anxiety	<ul style="list-style-type: none">• Pain Interference• Fatigue

Consistent with other findings, women reported higher levels of fatigue than men.

Studies like this help clinicians and researchers identify and address the needs of patients with PTLDS.