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Healthcare access and burden of care for patients with Lyme disease: A large United States survey.

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Abstract

OBJECTIVE: To evaluate the challenges faced by Lyme disease patients in obtaining adequate healthcare.

METHODS: A web-based survey conducted over nine months was analyzed for the study. The survey focused on medical status, access to healthcare, and burden of illness. For inclusion in the study, survey respondents had to reside in the United States, be more than 10 years old, and have clinically diagnosed Lyme disease with chronic symptoms and positive laboratory testing.

RESULTS: Responses from 2424 patients were included in the study. Half of the respondents reported seeing at least seven physicians before the diagnosis of Lyme disease was made. Nearly half had Lyme disease for more than 10 years and traveled over 50 miles to obtain treatment. Most respondents experienced symptoms lasting six months or more despite receiving at least 21 days of antibiotic treatment. A quarter of respondents had been on public support or received disability benefits due to Lyme disease symptoms, and over half had visited an emergency room at least once as a result of these symptoms.

CONCLUSIONS: Lyme disease patients frequently endure extensive delays in obtaining an initial diagnosis, have poor access to healthcare and suffer a severe burden of illness.

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