

Impact of Lyme disease on working and caregiving

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“The impact of Lyme disease on work and caregiving activities emerged as a salient theme for participants, impacting patients prior to treatment and, in some cases, even after treatment,” [writes Hirsch and colleagues in the *British Medical Journal*](#). [1]

The authors identified 26 patients who were diagnosed with Lyme disease between 2014 and 2017 and had a positive IgG western blot test. All the participants were patients at Pennsylvania-based Geisinger, an integrated health system.

The qualitative study used in-depth telephone interviews with patients to help understand what occurs between the onset of Lyme disease symptoms and treatment. Although it was not included in the study's design, the authors found that a “detrimental impact of Lyme disease on the ability to work and fulfill caregiving roles emerged as a common theme among participants.” Patients describe their frustration in losing their ability to be productive workers or caregivers at home.

In one case, the tables are turned after a woman develops Lyme disease and her 92-year-old mother must begin caring for her.

“I couldn’t function, and I’m a care-taker for my mother, although she’s a good 92 now... She took care of me, but I could not function. I lived on the sofa or in bed. That’s how tired I was. If I tried to do a little bit of anything, I would have to get back down, because I couldn’t handle it.”

A man describes his struggles with continuing to manage his own business.

“I’d never sit down at work ever. I have my own machine shop. And I like nobody ever sees me sit. ... like it came to the point where I was sitting and then actually at lunchtime and stuff I would actually lay on the bench.”

Other participants express frustration with how the disease has impacted their work and caregiving abilities even after treatment.

“I own my own business, I’ve been in business since 1990. It is definitely not the same. I have a hard time spelling words. I mean you got to go in, you got to sell yourself, you got to get all the work and, it’s just tough anymore. I just don’t have the... it’s hard to put things together, you know what I mean, like on the fly. Like with words and everything. You seem to lose that edge and I don’t know how to explain it. You know and everybody says, ‘Oh you got old’, but it just like changed instantly...”

The [cost of Lyme disease](#) for workers and caregivers is not well understood. “Prior studies that focused

on productivity loss and activity limitations in Lyme disease have been confined to individuals reporting symptoms [persisting for more than 6 months.](#)” writes Hirsch.

But these studies do not examine the costs associated with delayed treatment -- what occurs between infection and treatment – and are therefore “likely underestimating costs.”

“A comprehensive study of indirect and direct costs across the full spectrum of Lyme disease, before and after treatment, would give a more complete picture of the individual and population-level burden of this disease,” the authors state.

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[Case report: Persistent pain and fatigue after treatment for Lyme disease](#)

References:

1. Hirsch AG, Herman RJ, Rebman A, et al. Obstacles to diagnosis and treatment of Lyme disease in the USA: a qualitative study. *BMJ Open*. 2018;8(6):e021367.

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