

NEWS

Combatting Lyme disease myths and the “chronic Lyme industry”

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Medical organizations are developing tools to help Canadian doctors talk to patients about Lyme disease at a time when many front-line physicians report feeling ill-prepared to counter misinformation about the condition and pressured to send patients for Lyme testing and prescribe antibiotics when they aren't warranted.

When Dr. Lynora Saxinger, an infectious disease specialist and associate professor at the University of Alberta's medical school, recently conducted an informal survey of mostly primary care physicians, 30% said they have been pressured to give antibiotics and almost 90% said they didn't feel they had appropriate educational resources to offer patients. (She posed the questions to a group of Canadian doctors online

and 71 responded.) Health providers in Reddit chats share concerns and frustrations about patients overly concerned about Lyme, often in cases of extremely low possibility.

“It is difficult to counter some of the misinformation about Lyme, because it's spread on websites that actually look very legitimate and very professional and there's enough misinformation out there that it kind of cross-references itself,” says Saxinger.

Some of the common misconceptions include that there's a high likelihood of getting Lyme from tick bites everywhere (not just in endemic areas), and that doctors lack up-to-date information about Lyme disease's spread. (Across Canada, public health scientists conduct surveys every year).

Meanwhile, patients are getting more concerned about Lyme because of horror stories of “chronic Lyme.” Some advocacy groups argue that Lyme-causing bacteria continue to wreak havoc after treatment, but this position isn't backed by evidence or supported by mainstream medical organizations. “There is an increasing number of people who have bought into the chronic Lyme industry,” says Saxinger.

When Dr. Michelle Cohen started practising in eastern Ontario in 2012, “people would come in with ticks attached but they weren't pushing for treatment. They weren't as upset about what that might mean.” These days, however, patients bitten by ticks often panic and request antibiotics right away. “People have heard these horrible stories about how



Many people bitten by ticks panic and request treatment for Lyme disease prematurely.

Lyme is so awful and you suffer for years and years and nobody knows what's wrong with you."

This year, for the first time, her local public health department sent pamphlets for patients that included step-by-step charts of what to do after finding a tick, including which symptoms to look for and when to test. "Up until then, I'd only seen very clinical-facing guidelines and we're supposed to explain that to patients and it's confusing to explain all the complexities."

Doctors have to communicate why it takes at least 24 hours of a tick being attached for the bacteria to be transmitted, why testing isn't accurate in early stages, why Lyme is unlikely to be acquired from tick bites in most parts of Canada, and more.

The Centre for Effective Practice is developing clinician toolkits to help providers recognize and treat early Lyme disease, as well as patient-facing information to communicate the risks

and effectiveness of testing and treatment. Dr. Todd Hatchette, president of the Association of Medical Microbiology and Infectious Disease, is a member of a working group involved in the development of the toolkits. He says that counselling patients about Lyme disease can take more time than physicians have in a busy clinic.

Testing is an option for patients with symptoms consistent with Lyme for four or more weeks, but "diagnosing early infection is more of a challenge," he says, especially when patients can't identify an expanding rash. "There are a lot of things that can cause nonspecific febrile illness."

Another common misconception is that Lyme disease snowballs unless treated early, so it can be difficult to convince patients to wait several weeks to see if symptoms resolve before taking tests, says Hatchette. It can be reassuring to reiterate, however, that waiting doesn't increase the low risk of

post-Lyme disease syndrome. "There are no data I'm aware of that waiting for four weeks and treating at that time if the symptoms are positive means that antibiotics are any less effective."

Although it can be tempting to allay patients' concerns by providing prophylactic antibiotics after tick bites, if the practice becomes widespread, "the accumulated antibiotic risk exceeds the potential benefit by quite a bit; even though it's a single dose of doxycycline, people can have severe drug reactions and it feeds an error-based myth as well," says Saxinger.

To help combat myths about Lyme, future patient-facing pamphlets and campaigns should address the misconceptions directly, says Saxinger. "Patients may feel the information they themselves found, which always seems to be especially noteworthy if you've found it yourself, is not being accounted for."

Wendy Glauser, Toronto, Ont.