

The Road to Lyme Disease is Paved with Missed Opportunities

A July 22, 2018 column in the StarTribune discussed one Minnesota legislator's struggle with Lyme disease. While ongoing news coverage of tick-borne diseases is a welcome sign, it is discouraging to know that his is just one in the several thousand cases that occur annually in Minnesota.

The financial and health related costs of the disease are significant for individuals and society. Approximately 380,000 new cases of Lyme disease are diagnosed each year in the US (unfortunately, only 10% are actually reported to and officially counted by the CDC). A 2015 Johns Hopkins study estimated the average expense of direct medical costs to be \$3000 per case, totaling \$1.2 billion annually. While that alone is staggering, adding indirect costs such as missed wages, medical travel expenses, and the need to pay for goods/services typically provided by patient or their family raises the average expense to \$11,248 (in 2015 dollars). Most cases treated early in the illness cost far less, it's the 10-20% that produce prolonged illnesses that drive up costs. The attendant suffering of prolonged disease is impossible to calculate.

That's why public health officials, physicians and the public must take every opportunity to actively encourage/engage in prevention practices. In the course of my work on tick-borne diseases, I provide accredited continuing medical education for physicians and speak to a range of public audiences; I've published papers in peer-reviewed medical journals and recently served on a subcommittee of the congressionally mandated Tick-borne Disease Working Group. Here are some suggestions:

- The Minnesota Department of Health should develop a year-round media campaign on the dangers of tick-borne diseases that runs across all popular platforms. It should include messaging for the general public and targeted information for high-risk groups such as campers, hunters, people with occupational exposure, residents of wooded housing developments, and people whose risk is often unrecognized, such as golfers who spend time in the rough. Equating risk only with "the woods" is a mistake.
  - The campaign should advocate strongly for the use of permethrin on clothing and gear by everyone with potential tick exposure as this insecticide is highly effective, long-lasting, safe, inexpensive and easy to use.
  - The messaging needs to invoke some degree of fear regarding the potential for a prolonged illness as fear is a strong motivator for behavioral changes.
- Each Minnesotan must identify and minimize potential sources of risk in their life by avoiding tick
  habitat whenever possible, using permethrin and repellents, performing careful tick checks and
  promptly reporting known bites and/or symptoms of Lyme disease to their doctor. Given that
  patients with late disease do worse than those treated for the telltale erythema migrans rash (EM)
  or the flu-like symptoms of early disease, he who hesitates may indeed be lost.
- Clinicians need to improve their diagnostic and therapeutic skills. Serologic testing, while highly
  specific, is insufficiently sensitive to rule out Lyme. This is true for early disease and neurologic
  presentations. The serology module on LymeCME.info lays out the details. Lyme disease is a multi-

- systemic illness producing a wide array of symptoms. Clinicians who only seek swollen joints, AV conduction defects, facial nerve palsies and bull's-eye rashes are, in many cases, missing the target.
- Clinicians should not be overly reliant on trial findings while caring for individual patients as Cochrane and GRADE analyses of the therapeutic evidence determined it is of low/very low quality.
  - Single dose doxycycline is ~ 50% effective for primary prevention of Lyme disease;
     therefore, high-risk bites may deserve a 10-day course.
  - More aggressive management of early disease may reduce the risk of a prolonged illness (secondary prevention). Most US trials for EM patients used 20 days of a first-line agent, not 10. Given that certain presentations multiple EM lesions, the presence of neuro symptoms, more severe illness and ongoing symptoms at the end of active therapy were associated with a higher risk of long-term failure, it seems prudent to consider extending the duration of treatment in these groups.
  - The goal of antibiotic stewardship isn't to simply limit antibiotics, it's to employ them appropriately in a given situation.
- The scientific understanding of tick-borne diseases has evolved substantially over the 10 years that I've been writing and teaching about these illnesses. Yet, vaccines for this group of infections are still a long way off. In the interim, an ounce of permethrin is worth a pound of antibiotics use it.