Making Diagnostic Testing for Lyme Disease More Approachable

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Lyme Disease: Confusing Tests; Confused Patients

- Even without diving into the scourge of “chronic Lyme,” understanding the diagnosis and treatment of Lyme disease can be difficult for patients and healthcare providers alike.
- The two-step testing recommended by the CDC may not seem straightforward without some understanding of:
  - What is being analyzed in the blood sample
  - Why the sensitivity/specificity of these tests is important
- Many of the resources available to patients and healthcare providers are either too technical or too basic.
- No single resource was identified that provided enough detail without becoming too confusing.
The Cost of Tests and Medications

- One retrospective cohort study found that in California <20% of all tests for Lyme disease were ordered because the disease was actually suspected in the patient.¹
  - 35% were requested by the patient based on undue clinical suspicion
  - 41% were ordered as part of “screening tests” for nonspecific findings

- A study at Yale found that of ~200 patients referred for the presumptive diagnosis of Lyme disease >60% had no evidence of current or past infection yet had received an average of:³
  - 4 serologic tests
  - 7 office visits relating to Lyme disease
  - 42 days of antibiotics
  - 1 death related to inappropriate treatment⁴

- While no research has shown resource overutilization in Vermont, subjective evidence from clinicians is abundant
Community Perspectives

• JD (anonymized) presented to the clinic after being diagnosed with “chronic Lyme” at a holistic health center
  – She was placed on a “Lyme diet” of red meat and berries that was giving her diarrhea and making her feel “awful”
  – She claimed that her ELISA results were “equivocal,” was told that she “definitely had chronic Lyme disease”
  – She didn’t understand what the test results meant and didn’t understand what the test was even analyzing

• Victoria Sheehan, a staff nurse at the clinic, expressed some frustration with explaining intricacies/complexities of Lyme testing to patients during triage
  – Details of IgM/IgG seroconversion and duration of immune response
  – When re-testing is indicated and if previous exposure = false positive
  – What duration of tick bite warrants testing
How Can We Help?

• Educating patients and clinicians about the recommended guidelines for testing, interpretation of test results, and the basic-science immunology behind Lyme disease may prove to be an inexpensive and easy intervention

• An educational document for use as an in-office guide and digital distribution was created using simple language to illustrate the sometimes complex concepts of:
  – The CDC’s testing guidelines for when Lyme disease is suspected
  – The rationale behind two-tier testing relating to sensitivity/specificity
  – The roles/time-course of IgM and IgG in Lyme disease

• The hope is that this document can be distributed or referred to as a starting point for any conversations concerning the sometimes confusing diagnosis of Lyme disease
Patient and Clinician Response

• Subjective responses from patients presented with information related to the previously mentioned education goals were positive:
  – “I never new any of this before. I wish someone had just taken the time to explain it to me.”
  – “I know that I shouldn’t trust all the crap on the internet… This makes a lot more sense.”

• Clinicians, unfortunately, didn’t have the opportunity to present any of the information to patients face-to-face or via phone triage, but thought that “it could be really helpful when I’m trying to jump between calls of a pregnant lady bleeding and someone who thinks that they maybe might have found a tick on their leg.”
Effectiveness and Limitations

• The educational document explains testing guidelines into easy to understand pieces with accompanying visual guides
  – One page (front and back) provides a single discrete page that can be distributed to patients and easily referred to
  – Digital format allows for distribution to patients during phone triage
  – Document addresses common concerns raised by clinicians and patients

• The document does not cover all concerns that might be raised by patients
  – Much of the complexity and subtlety of testing can not/was not conveyed given the length/wording of the document
  – “Chronic Lyme Disease” was found to be a very common concern amongst patients and was intentionally NOT addressed in this document
Future Ideas

• Keep the document in digital form to allow for easy updating if there are any changes in testing guidelines.

• While this document does a good job of covering information in an appropriate level of depth it is not especially pretty and could use additional work to allow for greater legibility.

• Create a separate document to cover “Chronic Lyme Disease”
  – Major area of concern to many patients
  – Sometimes very difficult to talk about with patients
  – Information to act as a starting point for conversations with patients

• Receive more feedback that might be used to further update the document to ensure that it covers key areas of concern to patients that it might currently be missing.
References


INTERVIEW CONSENT FORM

Lyme Disease
Jacob A. Korzun
3/1/2017

Thank you for agreeing to be interviewed. This project is a requirement for the Family Medicine clerkship. It will be stored on the Dana Library ScholarWorks website. Your name will be attached to your interview and you may be cited directly or indirectly in subsequent unpublished or published work.

The interviewer affirms that he/she has explained the nature and purpose of this project.

The interviewee affirms that he/she has consented to this interview.

Yes  
Name:  Victoria V. Sheehan
Name:  

If not consenting as above: please add the interviewee names here for the Department of Family Medicine information only.

Name:  
Name:  
Name:  

If you received informed consent, please upload this page as a separate document entitled: "Name of Project/Interview Consent Form".

If an informed consent was not received, please do not upload this page to ScholarWorks. However, you should include this consent page when submitting your PowerPoint to the Family Medicine Department.