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Lyme Disease Awareness in Downeast Maine

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Lyme Disease Awareness in Downeast Maine

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Family Medicine Rotation, R3, July – August 2015

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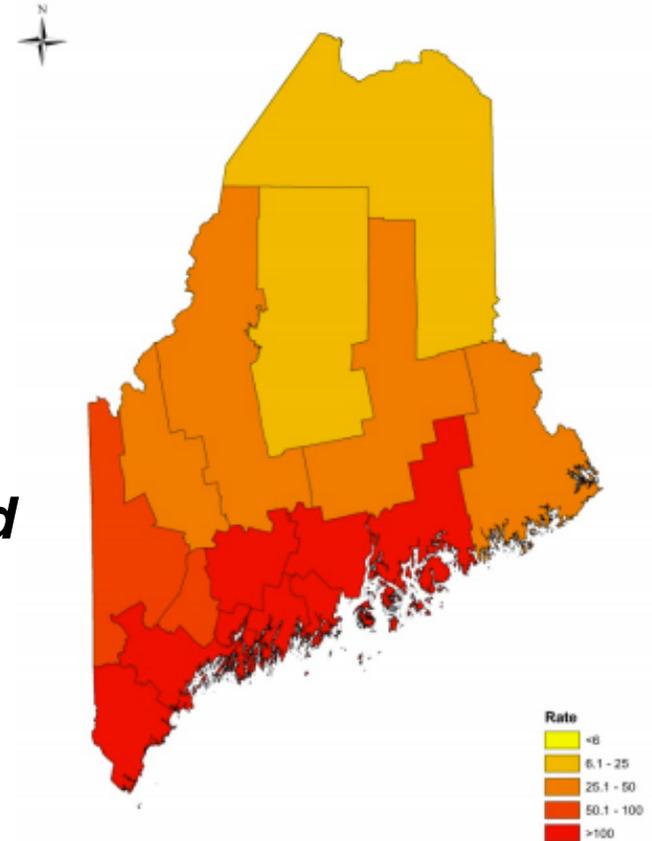
The Problem

Lyme disease is transmitted by the bite of the deer tick, and is endemic in Maine, especially in the coastal counties. After speaking with providers at the EWD Memorial Clinic in Gouldsboro, ME it is evident that many are frustrated with perceived community anxiety around the Lyme disease treatment protocols. This frustration is compounded by patients finding ***false or misleading information on the internet*** about Lyme disease.

It is the primary goal of this project to provide patients with ***concise and accurate*** information about Lyme disease, and to ***direct them to reliable resources***. I also hope to provide clinicians with information that debunks many of the current myths regarding Lyme disease.

Epidemiology & Public Health Costs

In 2014, there were **1,399 probable and confirmed cases of Lyme disease** reported to the Maine CDC. This represents a state case rate of **105.3 cases per 100,000 people**.¹ Hancock County, wherein this project takes place, is one of eight counties where its rate is higher than the state rate. The number of cases reported in Hancock county has **doubled since 2012**. Currently, the rate of infection in Hancock county is the **third highest** in the state of Maine. As of June 2015 **Lyme disease has the highest prevalence** of any reportable infectious disease in the state of Maine.²



2014 Rate by County, Maine DOH

Community Perspectives

“I know Lyme disease is transmitted by ticks, **deer ticks specifically**. I also know that it has to be attached for more than 48 hours in order to actually pass on the bacteria that causes Lyme disease... people can get that bulls eye rash, but not everyone with the disease gets it...I don't think it can be passed person to person – at least I know you can't get it by someone breathing on you...If I need more information on it **I know I can go to the CDC website**...I would like to know when we will have more effective treatment and better detection for the disease.”

Cyndi Wood

Staff member, Downeast Family YMCA, Ellsworth, ME

Reporter, *Ellsworth American & Mount Desert Islander* newspapers

“You can get Lyme disease from tick bites and it can cause fatigue. I think **it's hard to diagnose** because it has a lot of the same symptoms as a lot of other things, but I do know that the bulls eye rash can accompany it. I don't think everyone gets it or notices it...**We never really learned about Lyme disease** when I was in school growing up here in Maine. I am learning a little bit about it in my medical assistant program at Eastern Maine Community College...If I wanted to find out more about it I would start on the internet, looking for websites of some sort of national organization that I've heard of before. I would also look for information that's associated with hospitals' websites.”

Kaitlin Orr

Staff member, Downeast Family YMCA, Ellsworth, ME

Community Perspectives

“**I had Lyme disease** back when I was in 7th or 8th grade. I had that big bulls eye rash on the back of my leg. We went to the doctor, had some blood tests, and got treated with antibiotics for it, but I don’t remember the name of the antibiotics. I cleared up without any problems. I do have a friend’s dad who has **uncurable Lyme disease**...No, we didn’t get any Lyme disease education in school. I know that ticks carry it, but I’m not sure if people can give it to each other...I heard on VPR that you can get it within 30 seconds if you’re bit by a tick that was just feeding off of someone else. But, it seems like the odds of that happening are very low.”

Staff members, Cadillac Mountain Sports, Ellsworth, ME



Maine CDC Lyme Disease Awareness Month Poster 2013

Interventions & Methodology

Intervention: Creation of a simple, two-page handout to accurately inform patients about Lyme disease, its prevention, and where to find reliable information. Distributed hand out to all providers at EWD Memorial Clinic, and posted in the waiting room. Inform physicians of literature that combats Lyme disease myths such as the benefit of pulse therapy³, *B.burgdorferi* morphology⁴, and person-to-person transmission.*

Methodology: A literature search was conducted using PubMed, UpToDate, the CDC, and the Maine Department of Health. Patient-oriented information was synthesized from the above resources to create a patient-information hand out. Interviews were conducted with community members at the Downeast YMCA, Cadillac Mountain Sports, and the EWD Memorial Clinic. Each interview was followed with a short discussion on how Lyme disease is transmitted and treated. Literature and members of the Vermont Lyme Corps were consulted to provide clinicians with accurate information regarding Lyme disease myths*.

*Time constraints prevented the development of a good tool for physicians' reference regarding these myths. However one-on-one discussions were had with individual providers regarding spirochete morphology, transmission, and treatment courses based upon current literature.

Response

The results of this public health initiative will be largely qualitative, namely in the observation of the types of questions and challenges patients propose to their providers regarding cases of probable Lyme disease.

One possible quantitative measure is to **track rates of antibiotic prescription** as related to clinical or laboratory signs of Lyme disease. This would have to be **measured over the course of years** to see if an increase in public education correlates to more effective and efficient use of antibiotics.

In preliminary observations from post-interview discussions, community members appeared to trust the information presented to them by a medical student. They also showed a **sense of relief** after being informed about the significance of attachment time for disease transmission. This could point to a degree of large-scale anxiety and uncertainty about the disease that is **alleviated by accurate information** presented by a healthcare professional.

Effectiveness & Limitations

The effectiveness of these interventions is **dependent upon patients' trust in their providers** – which can be a limiting factor as well. As we've seen with the anti-vaccination movement, patient trust in their physician's opinions is not always a given.

We can measure effectiveness by looking at **rates of infection** in Hancock county. However, **with an increase in awareness comes an increase in reporting**, so this would need to be tracked over several years to help control for that confounding factor. Interestingly, the Maine DOH has recently begun an educational push in elementary schools about tick-borne illnesses. This can play a role in the large-scale awareness of Lyme disease in the community.

Limitations include access to this patient information. Having the information housed at the clinic limits access to this information to the clinic. However, the EWD Clinic does seem to act as a **social nexus for the region**, with regular traffic through the clinic during the summer (which is when Lyme disease is most prevalent). Another limitation is language. Downeast Maine is not typically diverse in its ethnic profile, however there are a number of migrant workers in the blueberry industry who could benefit from having this sort of patient information translated into their primary language.

Future Recommendations

1. **Develop** a plan for distributing patient information to outdoor retailers such as Cadillac Mountain Sports and L.L. Bean.
2. **Assess** knowledge of Lyme disease among park rangers at Acadia National Park.
3. **Distribute** patient information about Lyme disease prevention to seasonal blueberry workers.
4. **Coordinate** with the infectious disease department at Maine Coast Memorial Hospital to develop a concise FAQ for physicians that addresses more complicated concerns and misconceptions about Lyme disease.
5. **Partner** with the Maine DOH to measure impact of increased awareness on disease outcomes.

References

1. Maine Department of Health, *Lyme Disease Surveillance Report – Maine, 2014*, April 2015.
2. Maine Department of Health, *Report to Maine Legislature: Lyme Disease*, February 2015.
3. Halperin JJ. Chronic Lyme disease: misconceptions and challenges for patient management. *Infect Drug Resist.* 2015 May 15;8:119-28.
4. Lantos PM, Auwaerter PG, Wormser GP. A systematic review of *Borrelia burgdorferi* morphologic variants does not support a role in chronic Lyme disease. *Clin Infect Dis.* 2014 Mar;58(5):663-71.

References utilized in building patient hand-out:

- Maine Department of Health, *Lyme Disease: Fact Sheet*
- Center for Disease Control online information: www.cdc.gov/Lyme/
- UpToDate Patient Information: *Lyme disease, Lyme disease prevention, What to do after a tick bite to prevent Lyme disease, Lyme disease symptoms and diagnosis, Lyme disease treatment.*
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