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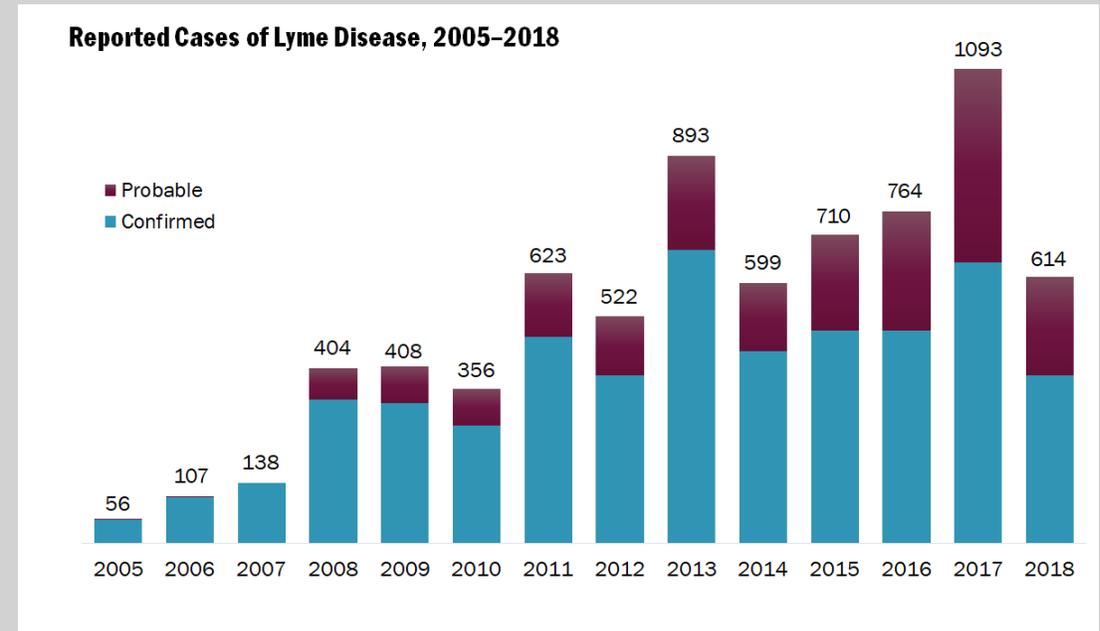
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Improving Community Understanding of Lyme Disease Prevention and Treatment in the Age of Misinformation in Digital Media

Olivia Quatela & Samuel Raszka, MS3s

Problem Identification

- While approximately 30,000 cases of Lyme disease are reported to the CDC annually, the CDC estimates approximately 300,000 individuals in the US become infected
 - Incidence of Lyme disease has risen significantly in the past decade
- Vermont has the second-highest 3-year incidence rate of Lyme disease in the United States
- Treatment with extended courses of antibiotics for nonspecific symptoms of post-treatment Lyme disease syndrome has increased from 29.9% in 2004-2006 to 49.9% in 2010-2012
- A small group of providers (roughly 3%-4%) were responsible for >20% of the patients who were prescribed extended antibiotic treatment for post-treatment Lyme disease syndrome
 - Over 5 randomized controlled trails have not demonstrated any benefit in prolonged antibiotic therapy for Lyme disease even in patients with persistent symptoms



Public Health Cost

- A 2014 study estimated the cost of testing alone to be approximately \$492 million annually in the US
- A 2015 report estimates of the average cost of Lyme disease to be ~\$3,000 per patient over the course of the disease costing the US healthcare system approximately \$1 billion per year (\$712m – \$1.3b)
- Post-Treatment Lyme Disease Syndrome costs the healthcare system an additional \$3798 per case
- Prolonged antibiotic courses and associated healthcare visits in the year following a Lyme disease diagnosis cost the healthcare system an additional \$1 billion annually

Community Perspective

- Observed obstacles to prevention & diagnosis
 - Misunderstanding of when and how to perform tick checks
 - Public knowledge of preventing tick bites (ie. appropriate dress, repellent)
 - Public misunderstanding of tick bite timing and disease transmission
 - Patient knowledge of symptoms of Lyme disease (what to look for, when to call)
- Obstacles to appropriate management of Lyme disease
 - Lyme disease misrepresentation in the media
 - Vtlyme.org compiled over 40 instances of media sources in VT publishing misinformation about tick bites and the Erythema Migrans rash from 2017-2019
 - Misinformation and mismanagement of Post-treatment Lyme Disease Syndrome
 - “Lyme literate” providers treat patients with non-specific symptoms with extended courses of antibiotics despite repeated randomized controlled clinical trials indicating that this treatment course has no benefit and can lead to complications related to prolonged antibiotic use such as opportunistic infections

Community Perspective

- On detection & prevention of Lyme disease

“People are not aware of the wide range of symptoms of tickborne illnesses, and that weeks, months or years can pass between a tick bite and symptom onset.”

- – Rebecca Zelis, founder & content creator of VT Lyme.org

- On obstacles to appropriate management of Lyme disease

“Particularly in children, the diagnosis of the vast majority of Lyme disease cases, with appropriate consultation with an expert if needed, can often be fairly straightforward. But there is no shortage of irresponsible practitioners of all stripes who are willing to make diagnoses and offer treatments completely outside the boundaries of accepted medical practice, for those who are motivated to seek them out.”

- – Dr. Benjamin Lee, pediatric infectious disease specialist, UVMMC

Intervention and Methodology

Generation of a pamphlet/education handout with information on:

- Techniques for Lyme disease prevention and detection
 - When and where to use protection against
 - How to effectively check yourself and others for ticks
 - How to identify different types of ticks
 - How to properly remove a tick
 - When to call your doctor or be seen for a tick bite
 - Symptoms to look out for
 - Appearance of rash that can appear with Lyme disease
- Evidence-based information about treatment
 - Common misconceptions about Lyme disease treatment that result in inappropriate use of prolonged antibiotic courses to treat persistent and non-specific symptoms attributed to Lyme disease
 - Risks of prolonged antibiotic use especially when there is no evidence of symptom improvement
- Credible sources on Lyme disease prevention, diagnosis, and treatment
 - Provide information about accessing the CDC website and Vtlyme.org
 - Emphasis on the frequent misrepresentation of Lyme disease in the media
 - Cautioning against following recommendations made by the media

Methodology

- Information for the aforementioned pamphlet was accumulated from a literature review of databases including PubMed, the CDC, interviews with infectious disease specialists and community members, as well as programs aimed at community education including VT Lyme.org
- Distribution of the pamphlet to be available to patients and visitors of Colchester Family Practice and handed out to patients that may be at higher risk

Effectiveness and Limitations

- The effectiveness of this intervention cannot be specifically measured at this time but is one of many efforts to increase awareness and methods of presentation and diagnosis of Lyme disease
- Goal of long-term reduction in rates of Lyme disease in the community would be difficult to attribute to any one of many preventative initiatives
 - However, surveying patients and visitors to Colchester Family Practice as well as groups in the community such as schools, day cares, and summer camps on their basic knowledge of Lyme disease and proper prevention could be influential
- Limitations include:
 - Limited size of the patient population at Colchester Family Practice
 - Distributing information in a medical setting is less likely to reach those most susceptible to Lyme disease misinformation
 - Distribution of this pamphlet would be more beneficial in neutral settings such as community centers and summer camps
 - Lack of a method to assess whether the pamphlet has improved community understanding of Lyme disease

Recommendations

- Awareness of the common misconceptions and basics of Lyme disease is still an ongoing issue and more can be done to increase the understanding in our community
- Further distribution of this pamphlet in neutral environments such as community centers and camps
- Include Lyme disease reading in the After Visit Summary of patients, especially families with children and during months of high incidence
- Proactively ask patients and families thought to be at higher risk what they know about ticks and Lyme disease during annual visits
- Generate a survey for patients and visitors asking basic of Lyme disease in order to more closely understand where there are gaps in knowledge

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