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REVIEW

# Increasing Actual and Perceived Burden of Tick-Borne Disease in Maine

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**Introduction:** The burden of tick-borne diseases (TBDs) in Maine has steadily increased since the first case of Lyme disease was reported in the late 1980s. Five different agents of TBDs have emerged in Maine, challenging clinicians and the public .

**Methods:** We reviewed the ecology of emerging TBDs as well as the risk factors for tick bites and TBDs in Maine. We then evaluated the burden of TBDs versus comparable community-acquired infections in terms of hospitalizations, deaths, and media attention.

**Results:** In Maine, the risk of exposure to bites from the vector blacklegged or “deer tick”, *Ixodes scapularis*, is a reality in most of the state. In New England, the deer tick’s range has expanded from relict populations in southern New England northward due to reforestation, resurgence of white-tailed deer (*Odocoileus virginianus*), suburbanization, and climate change. In Maine, TBDs have emerged as a significant health burden, but they receive disproportionately high media attention compared with other infections important to public health. Measures of TBD severity provide a necessary context for individual and public health decision-making. Mass media reports and social networking inform much public debate regarding TBDs, but in many instances, they do not accurately reflect their actual prevalence or expected outcome.

**Conclusions:** Reducing actual and perceived risks associated with TBDs will require well-supported information and an appreciation for how interpersonal communication and social media drive community perceptions and responses to the emergence of TBDs.

**Keywords:** deer tick, Lyme disease, *Ixodes scapularis*, tick-borne disease

Since the first reports of Lyme disease in Maine in 1986, tick-borne diseases (TBDs) have assumed an increasingly high profile in the state’s public health reports<sup>1</sup> and in public attention. The deer (blacklegged) tick (*Ixodes scapularis*), now widespread across Maine, carries up to five different human pathogens. The recent emergence of this tick and the diseases it can transmit represent a remarkable occurrence in the regional annals of infectious diseases.<sup>2</sup>

Case reports of Lyme disease rose from a few per year in the late 1980s to more than a thousand per

year during the past five years. These reports are likely a significant underestimate of actual cases. Geographic risk increased from a few southern and coastal counties to nearly all areas of the state.<sup>1,3</sup> Anaplasmosis and babesiosis cause serious infection in the elderly or immune suppressed,<sup>4</sup> and cases of both infections increased sharply from 2013 to 2017 [605% (94 to 663) for anaplasmosis and 69% (36 to 118) for babesiosis].<sup>1</sup> These ticks also can transmit a virus (Powassan virus or “deer-tick virus”) that can cause a devastating encephalitis, an effect underscored by the death of a Maine resident from this agent in 2013.<sup>5</sup> To add to the complexity, another species of *Borrelia* (*B. miyamotoi*), which differs in some aspects from *B. burgdorferi*, causes a febrile illness similar to anaplasmosis. If untreated, it can occasionally cause relapses of fever.<sup>6</sup> The full

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spectrum of disease caused by Powassan virus and *Borrelia miyamotoi* is still under study.

This article first reviews what we know about the ecology of emerging of TBDs. Then it reviews risk factors for tick bites and TBD in Maine. We discuss this phenomenon in the broader context of public-health threats in Maine through data we gathered on hospitalizations and deaths attributable to TBDs, which we compared to conditions such as influenza. We also assessed the volume of news coverage of TBDs versus comparison conditions. In doing so, we revealed a disconnect between standard measures of the burden of TBD versus the burden implied by the frequency of media coverage. We also addressed causes and consequences of public misperceptions of disease prevalence and outcome.

### **Review: Ecology of emerging TBD in Maine**

Progressive expansion of deer ticks across the northeastern United States and the upper Midwest reflects widespread ecologic changes.<sup>7,8</sup> The rising incidence of human TBD is due to the geographic range expansion of deer ticks and increased human encounters with ticks in residential areas.<sup>3,8,9</sup> However, enhanced clinical recognition and availability of improved diagnostic tests may also contribute to the increase in case reports.

In the late 1980s, deer ticks appeared in Maine in a discontinuous distribution that included sites in southern coastal York and Cumberland Counties, as well as Acadia National Park and remote islands, such as Monhegan Island.<sup>3,10,11,12</sup> This patchy pattern of initial colonization of Maine by *Ixodes scapularis* is best explained by passerine birds that introduce the tick while they migrate during the spring, as shown by studies on migrating birds banded on Appledore Island.<sup>13</sup> Once dispersed by birds, larval and nymphal ticks feed upon small rodents, and to a lesser extent, larger mammals and birds. Adult ticks feed on large mammal hosts, particularly white-tailed deer. White-tailed deer are the key large mammal involved in the tick's life cycle, as a large number of ticks feed and mate on them.<sup>14</sup>

Why the relatively recent dispersal of deer ticks by migrating birds? The most compelling explanation is the increase in white-tailed deer abundance in the northeast United States. Deer ticks were once isolated to relict populations in southern New England. They have expanded geographically

during the 20th and 21st century, due to resurgence of white-tailed deer populations, reforestation, and suburbanization of the landscape.<sup>7,15</sup> Abundant deer support focal concentrations of deer ticks as they are dispersed by migratory birds from endemic areas to new ones.

In the early 1900s, deer populations were sparse in much of Maine, gradually increasing over the following decades. Through the late-1980s and 1990s, Maine's deer population increased 65%, rising from ~200,000 deer in 1990 to a high of 331,000 in 1999.<sup>16</sup> This occurred mainly in the central and southern tiers of the state, increasing the odds that tick populations would establish in regions where most of the human population lives. Tick abundance is correlated with measures of deer abundance in Maine.<sup>17</sup> Removal of deer from Monhegan Island with subsequent disruption of the deer tick life cycle there provided a proof of principle of the white-tailed deer's critical role.<sup>17,18</sup>

In addition to an increased number of deer, a warming climate confers survival advantages to deer ticks in northern areas of Maine and adjacent areas of Canada.<sup>19,20</sup> Climate change is also facilitating the movement of other tick vectors northward, with reports of *Amblyomma americanum*, the lone star tick, now established in areas of southern New England.

### **Review: Risk factors for deer-tick bites and TBD in Maine**

In the northeastern US, exposure to deer-tick bites occurs primarily in the peri-domestic environment (i.e., yards and other areas around residences).<sup>9</sup> This exposure is a product of the time spent in activities outside on home properties, and the presence of suitable habitat and tick hosts, such as rodents and deer, next to households.<sup>9,15,21</sup> In Maine, Lyme disease incidence varies from lower in the northern tier to higher in the southern tier of the state (Table 1) likely due to variations in suitable climate, bloodmeal-host communities, and habitats.

In addition to the peri-domestic environment, human risk of infection varies with outdoor recreational or work activities.<sup>9</sup> Though early studies demonstrated focal risk in the southern and mid-coast counties, exposure to deer ticks now occurs in all areas of Maine, with the exception of higher montane elevations.<sup>3</sup> Within counties, there are areas of high risk and areas of low or negligible risk. In open fields

**Table 1.** Five-year average incidence (cases per 100,000) of the three most common tick-borne diseases vectored by *Ixodes scapularis* in Maine (2013–2017)\*.

State/County	Anaplasmosis	Babesiosis	Lyme disease
Maine	22.6	5.0	110.5
Androscoggin	14.3	2.8	75.8
Aroostook	0.6	0.0	5.5
Cumberland	17.0	4.6	109.0
Franklin	3.3	0.0	38.5
Hancock	17.6	1.5	256.0
Kennebec	20.2	3.3	156.0
Knox	138.0	31.7	287.6
Lincoln	133.0	17.0	236.1
Oxford	9.8	2.4	76.9
Penobscot	1.4	0.9	46.4
Piscataquis	2.4	1.2	15.3
Sagadahoc	67.1	11.4	184.3
Somerset	3.1	1.6	75.1
Waldo	29.6	1.5	211.4
Washington	1.3	0.0	63.1
York	27.5	9.2	105.3

\*There have been six cases of hard-tick relapsing fever caused by *Borrelia miyamotoi*: 2016-2, 2017-6; and six cases of Powassan encephalitis: 2013-1, 2015-1, 2016-1, 2017-3<sup>1</sup>

and drier habitats, bites by other tick species, such as dog ticks (*Dermacentor variabilis*) that do not carry diseases in Maine, are more likely. Of 12 tick species removed from humans in Maine, dog ticks are the second-most common human-biting tick after deer ticks.<sup>3</sup> Habitat studies have shown deer ticks are less associated with fields and softwood (coniferous) forests and more associated with hardwood and mixed hardwood/softwood forests. They are especially associated with dense thickets of invasive plants, such as Japanese barberry or American bittersweet.<sup>22</sup> Higher rates of tick contact near homes also occur at lawn edges bordered by brush or forest.<sup>21</sup>

Reported cases of Lyme disease in Maine have a bimodal age distribution, indicating highest risk in youth (ages 5 to 14) and adults over age 45.<sup>1</sup> However, susceptibility to clinical illness from Lyme disease does not vary with age, whereas diseases such as anaplasmosis and babesiosis occur more often and with greater severity with older age. Illness due to anaplasmosis or babesiosis is uncommon in the pediatric population.<sup>1</sup> While Lyme disease and

anaplasmosis may be acquired by deer tick bites anywhere the tick occurs in Maine, babesiosis risk is more geographically limited, with human cases largely confined to areas with the highest risk of Lyme disease.<sup>4</sup> Asplenia, immune compromise, and age are risk factors for severe babesiosis.<sup>23</sup> Rarer agents of disease, such as *B. miyamotoi* and Powassan virus, only infect a few percent of Maine ticks but are present in deer ticks in most locations studied (Maine Medical Center Research Institute Vector Borne Disease Laboratory; unpublished data).

The ubiquitous presence of ticks in many peri-domestic environments results in a high frequency of tick encounters and bites in the community, heightening concerns about the risk of illness.<sup>9,15</sup> Syndromic surveillance in Maine, based on documentation of visits to Maine urgent care centers and ERs,<sup>24</sup> show peaks of over 100 “tick encounters” per day during peak weeks in early summer (nymphs) and mid-fall (adults). The Centers for Disease Control (CDC) reported that in suburban residences of southern New England, nearly 10% of individuals studied reported peri-domestic tick contact during one summer week of high tick activity.<sup>9</sup> Similar numbers may apply to higher risk residential areas in Maine. The high frequency of tick encounters leads to appropriate public concerns regarding the consequences of tick bites. However, subjective perceptions of the inherent risk of infection from a deer tick bite are often overestimated, as are the expected negative health consequences of TBDs.<sup>25–27</sup>

If a deer tick bite occurs, the objective risk of illness varies with the infectious agent, the time of tick attachment, subject age, immune status, and geography.<sup>15</sup> Well-designed studies demonstrate that transmission of Lyme disease usually requires continuous tick attachment for more than 36–48 hours.<sup>28,29</sup> As many ticks are removed early in their feeding, the objective risk of acquiring Lyme disease after removing an attached deer tick within 72 hours is less than 5%, even though up to 50% of nymphal deer ticks carry *B. burgdorferi*.<sup>15,28–30</sup> Adult ticks are discovered and removed prior to 36 hours of attachment (64%) more often than the much smaller nymphs (40%).<sup>15,31</sup> Data are less robust for other agents. However, most disease transmission requires 24 hours of attachment, with the significant exception that Powassan virus may be transmitted in only 15 minutes of tick attachment.<sup>30</sup> Ticks



feeding to repletion over a longer interval steadily increases the risk of disease transmission.<sup>28</sup> Most cases of Lyme disease occur without a reported tick bite, indicating that the infecting tick is often not found before it finishes feeding.<sup>15</sup> While co-infection of deer ticks with more than one pathogen has been documented in 0–5% of Maine ticks (depending on the location; unpublished data), the vast majority of reported cases of TBD are due to infection by a single agent.

### Actual and perceived burden of TBD in Maine

Hospitalization data were obtained from the Maine Health Data Organization using ICD9 and ICD10 codes. For the chronic conditions hepatitis B, hepatitis C, and HIV, hospitalizations were counted on the basis of primary diagnosis. For the acute TBDs and influenza, hospitalizations were counted on the basis of either primary diagnosis or other diagnosis 1 through 8. For endocarditis with drug use, we counted hospitalizations using the codes described by Fleischauer et al.<sup>32</sup> Sources for mortality data included TBD deaths in Maine residents (Robinson S, M.P.H., personal communication, January 8, 2019) and Maine Resident Deaths<sup>33</sup> for non-vector-borne deaths. Deaths from endocarditis with drug use were not available from Maine Resident Deaths, so these deaths were estimated as 19% of hospitalizations (Table 2) based on recent findings.<sup>34</sup> Finally, we conducted a Lexis Uni® database search of media

coverage, specifying coverage between January 1, 2014 and December 31, 2018, the word “Maine”, and the infectious disease conditions described in Table 2.

There were fewer hospitalizations (23.3%) and deaths (0.2%) attributable to TBDs than hospitalizations (76.7%) and deaths (99.8%) due to the other infections examined (Table 2). In contrast, the Lexis Uni® database search of media coverage revealed that 41.4% of news coverage focused on Lyme disease and other TBDs compared to 58.6% for the other infectious diseases that threaten public health.

Combined hospital admissions for TBDs may rival some other individual reportable infections (Table 2), but with far fewer fatalities. Fatalities from Lyme disease have been reported in a small number of patients with Lyme carditis nationwide.<sup>35</sup> These fatalities are exceedingly rare<sup>36</sup> and are quite infrequent with anaplasmosis or babesiosis, despite potentially severe disease in the elderly and immune suppressed.<sup>23</sup> Other community-acquired infections leading to hospitalization more significantly burden public health when measured by mortality (Table 2). Notably, the collateral effects of infections related to the opioid epidemic (i.e., infections associated with use of injected drugs, including hepatitis C, bacterial endocarditis, and osteomyelitis) have rapidly risen in prevalence.

**Table 2.** Frequency of hospitalizations for and deaths from tick-borne diseases and select non-vector-borne diseases or conditions (2013–2017), and frequency of news articles that mentioned Maine and the selected diseases or conditions (January 1, 2014–December 31, 2018).

Disease or Condition	Hospitalizations		Deaths		News Articles	
	Count	% of Total	Count	% of Total	Count	% of Total
Tick-borne						
Anaplasmosis	419	12.3	2	0.1	47	2.9
Babesiosis	116	3.4	3	0.1	34	2.1
<i>Borrelia miyamotoi</i> disease	unknown		0	0.0	6	0.4
Lyme disease*	261	7.6	0	0.0	555	34.0
Powassan	unknown		1	0.0	33	2.0
Total tick-borne	796	23.3	6	0.2	675	41.4
Non-vector-borne						
Hepatitis B,C	344	10.1	223	7.6	174	10.7
HIV <sup>e</sup>	278	8.1	96	3.3	481	29.5
Influenza	1998	58.5	2599	88.9	299	18.3
Endocarditis with drug use	593	17.4	113	3.9	1	0.1
Total Non-vector-borne	2620	76.7	2918	99.8	954	58.5
<b>Total</b>	<b>3416</b>		<b>2924</b>		<b>1629</b>	

\*Lyme hospitalizations included 227 of Lyme, Lyme arthritis, and Lyme meningitis, plus 34 of Lyme carditis

Repetitive coverage of any particular infectious disease by the mass media heightens the public's perceptions of disease risk and severity.<sup>25</sup> This effect can stimulate further media attention in an amplified cycle that increases the public's perceptions of risk even more.<sup>37</sup> In addition, the content of mass media reports on Lyme disease often highlights individual narratives of unusually long or debilitating illness attributed to chronic infection.<sup>25</sup> These reports are frequently re-enforced by interpersonal information from social networks.<sup>26</sup> A survey of residents in two endemic sites in southern New England noted that inaccurate views of the expected clinical outcomes of Lyme disease were based upon shared personal narratives rather than information from physicians, the CDC, or state health departments.<sup>26</sup> Anecdotal reports amplified by social media may result in "information silos" that not only increase the prevalence of unchallenged misinformation, but also appear to fuel distrust of information provided by public health and medical experts.<sup>38-41</sup> Nationally, prevalence of public misconceptions regarding current scientific evidence contributes to incomplete use of proven preventive measures.<sup>27,40</sup> They also contribute to overuse of antibiotic and unproven treatment strategies, including long-term polypharmacy for putative multiple co-infections.<sup>42-46</sup>

The emergence of TBDs in Maine over the past 3 decades represents a substantial challenge in public health. Yet the concomitant perpetuation of disparate beliefs regarding the risks of TBDs complicates both individual decisions regarding treatment and the public health response.<sup>26, 38-40,44-47</sup> There are no published Maine-based surveys that document the current prevalence and the range of knowledge and beliefs regarding the risks and consequences of TBDs. However, the public's high concern is reflected by advocacy for Maine legislative initiatives (i.e., three bills specific to Lyme disease signed between 2013 and 2018), media attention (Table 2), and Maine CDC investment in public educational initiatives as outlined in annual reports to the Maine Legislature.<sup>24</sup>

A limitation to our analysis was an inability to assess chronic disability. With low mortality rates from TBDs, specific measures, such as years of life lost (YLL), will also be relatively low. The years of "healthy life lost", or disability-adjusted life years (DALYS), is a more challenging measurement.<sup>48</sup> Comprehensive YLL and DALYS data for TBDs are not available. Although long-term prospective outcome studies of

Lyme disease do not demonstrate differences from the health of the general population,<sup>49,50</sup> individuals may experience persisting complications. For example, a small subset of patients treated for Lyme arthritis develop a disabling form of autoimmune mono-articular joint inflammation. Neurologic disease (primarily 7<sup>th</sup> nerve palsy and/or Lyme meningitis) was reported in up to 10% of newly diagnosed cases of Lyme disease<sup>1</sup> and is generally slow to resolve after antibiotic treatment. Long-term residual neurologic symptoms are rarely reported. Continuing controversy regarding disease outcomes centers on estimates of the incidence and duration of subjective illness (e.g., fatigue, arthralgias, cognitive symptoms) following antibiotic treatment of documented Lyme disease.<sup>44,51,52</sup> Similar controversies now extend to the full spectrum of possible "co-infecting" TBDs and, surprisingly, even to a group of infectious agents not demonstrated to be transmitted by deer ticks (e.g., *Bartonella* species).<sup>42</sup>

The causes of prevalent misconceptions and controversies regarding TBDs are manifold. These causes are likely related, in part, to the recent emergence of these diseases, the variety of their clinical manifestations, and the near ubiquitous presence of ticks throughout suburban communities in the northeastern United States.<sup>9,39</sup> Both mass-media reporting and social networking contribute to disparate information on these diseases. The degree to which this leads to use of unproven treatment strategies deserves study.<sup>43,45,46</sup> Further studies would assess the volume of social media, content of news and social media, and the use of unorthodox treatments for TBDs.

## CONCLUSIONS

Lessening both the actual risk and perceived risks associated with tick-borne infections represents an ongoing challenge that needs continued attention and effort. As the risk of acquiring TBDs varies regionally, continued epidemiologic research directed toward Maine communities may provide the most accurate data on which to base local initiatives for disease prevention. The recognition of new TBDs and the changing landscape of disease risks with ecological and human dynamics highlight the importance of continuing the scientific and clinical study of these different agents.<sup>2,6</sup> Well-supported information on the risks and consequences of TBD, and their most effective clinical management, optimally informs wise decisions in clinical and

public health.<sup>26</sup> Continued work to enhance disease prevention may include efforts directed at different scales, from individuals to regional or community approaches. For example, new strategies for integrated tick management may lower risk in residential areas. Also, vaccine trials currently underway may lead to new options for individual protection. To impact the burden of TBDs, however, these efforts must consider the role of interpersonal communication and of social and mass media in driving community perceptions and responses to the emergence of TBDs.<sup>26,47</sup> Realization of the benefits of these scientific advances will require effective strategies for public and professional education that are based upon peer-reviewed scientific evidence.

**Conflicts of Interest:** None

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