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Original article

U.S. public's experience with ticks and tick-borne diseases: Results from national HealthStyles surveys

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ABSTRACT

Surveillance data indicate that tick-borne diseases (TBDs) are a substantial public health problem in the United States, yet information on the frequency of tick exposure and TBD awareness and prevention practices among the general population is limited. The objective of this study was to gain a more complete understanding of the U.S. public's experience with TBDs using data from annual, nationally representative HealthStyles surveys. There were 4728 respondents in 2009, 4050 in 2011, and 3503 in 2012. Twenty-one percent of respondents reported that a household member found a tick on his or her body during the previous year; of these, 10.1% reported consultation with a health care provider as a result. Overall, 63.7% of respondents reported that Lyme disease (LD) occurs in the area where they live, including 49.4% of respondents from the West South Central and 51.1% from the Mountain regions where LD does not occur. Conversely, in the New England and Mid-Atlantic regions where LD, anaplasmosis, and babesiosis are common, 13.9% and 20.8% of respondents, respectively, reported either that no TBDs occur in their area or that they had not heard of any of these diseases. The majority of respondents (51.2%) reported that they did not routinely take any personal prevention steps against tick bites during warm weather. Results from these surveys indicate that exposure to ticks is common and awareness of LD is widespread. Nevertheless, use of TBD prevention measures is relatively infrequent among the U.S. public, highlighting the need to better understand barriers to use of prevention measures.

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Introduction

From 2009 to 2013, over 200,000 cases of tick-borne diseases (TBDs) were reported to the Centers for Disease Control and Prevention (CDC), including cases of anaplasmosis, babesiosis, ehrlichiosis, Lyme disease (LD), Rocky Mountain spotted fever (RMSF), and tularemia (Centers for Disease Control and Prevention, 2010, 2013). LD, caused by *Borrelia burgdorferi* and transmitted by *Ixodes* spp. ticks, leads in number of cases with over 36,000 confirmed and probable cases reported in 2013. Several novel tick-borne pathogens recently have been found to cause human illness in the United States: *Borrelia miyamotoi*, *Ehrlichia* species Wisconsin, and Heartland virus (Krause et al., 2013; Mcmullan et al., 2012; Pritt et al., 2011). In addition, southern tick-associated rash illness (STARI or Masters' disease), which mimics the erythema migrans rash of early LD, is associated with the bite of the *Amblyomma americanum* tick but is of unknown etiology (Wormser et al., 2005). Diverse in their vectors, geographic distribution, and clinical manifestations, TBDs represent a substantial public health problem in the United States.

In the absence of available vaccines (Food and Drug Administration, 2002; Shen et al., 2011) or easily implemented community-wide interventions, prevention of TBDs relies heavily on the consistent use of personal prevention measures and environmental tick controls on personal property (Connally et al., 2009; Curran et al., 1993; Schulze et al., 1994, 1995; Stafford, 2004). Implementation of these measures is largely contingent upon individuals' awareness of TBD risk where they live and recreate. Information on levels of TBD awareness and use of prevention measures among the U.S. public is lacking. In addition, several other important aspects of TBDs such as frequency of tick exposure and health care seeking behavior have not been quantified. Using data from nationwide HealthStyles surveys, this study was undertaken to gain a more complete understanding of the U.S. population's experience with TBDs to guide prevention and control efforts.

Materials and methods

HealthStyles is an annual, cross-sectional, nationwide survey designed to be nationally representative based on U.S. Census

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Table 1
HealthStyles tick-borne disease survey questions and year questions were asked.

1.	"In the last year, did anyone in your household find a tick on their body?" *Select one:* Yes; No; Not sure (2009)
2.	"If yes, did this person consult a health care provider because of finding a tick?" *Select one:* Yes; No; Not sure (2009)
3.	"Have you ever been diagnosed with Lyme disease?" *Select one:* Yes; No; Not sure (2009, 2012)[a]
4.	"If yes, how long were you treated with antibiotics?" *Select one:* 4 weeks or less; 5–8 weeks; Longer than 8 weeks; I did not receive antibiotic treatment (2009)
5.	"Do you personally know anyone who describes themselves as having chronic Lyme disease?" *Select all that apply:* Yes, I know someone; No, I do not know anyone; I suffer from chronic Lyme disease (2011)
6.	"Which of the following diseases spread by ticks occur in the area where you live?" *Select all that apply:* Lyme disease; Rocky Mountain spotted fever; Anaplasmosis; STARI or Southern Tick-Associated Rash Illness; Ehrlichiosis; Tularemia; Babesiosis; Tick-borne Relapsing Fever; None of these diseases occur in my area; I have not heard of any of these (2009)
7.	"Would you use chemical pesticides up to one or two times per year if they would meaningfully reduce the number of ticks in your yard/on your property?" *Select one:* I already use them; Yes, I would consider them; Maybe I would use them; No, I would not use them; Not sure; Don't have a yard/land (2009)
8.	"When the weather is warm in your area, what steps, if any, do you routinely take to prevent tick bites?" *Select all that apply:* I wear repellent; I shower soon after coming indoors; I check my body for ticks when I come in; I take other steps that are not listed above; I do not take any steps to prevent ticks bites (2011)

[a] In 2012, respondents were asked, "Have you ever been diagnosed with Lyme disease?" Response options included: "No; Yes, within the past the past 6 months; Yes, 7–11 months ago; Yes, 1–2 years ago, Yes, 3–5 years ago; Yes, more than 5 years ago." Due to a small number of responses for any of the "Yes" options, these responses were collapsed into a single "Yes" for those who reported ever having been diagnosed with LD.

Bureau demographics. Porter Novelli, a social marketing and public relations firm, has conducted the HealthStyles survey since 1995, and CDC annually licenses results from the survey post-collection. Survey questions aim to assess knowledge, attitudes, and behaviors for various health-related topics and to obtain information on self-reported diseases and conditions (Kennedy et al., 2011; Kobau et al., 2006; Polen et al., 2015). In general, HealthStyles surveys demonstrate reliability and validity, showing concordance with the Behavioral Risk Factor Surveillance System on outcome levels, trends over time, and demographic breakdowns for similar health topics (Pollard, 2007).

HealthStyles survey respondents are randomly recruited each year from a large, nationally representative panel of non-institutionalized adults aged ≥18 years living in the contiguous United States and the District of Columbia. The 2009 HealthStyles survey was administered via mail, and the 2011 and 2012 surveys were administered online (Porter Novelli Public Services, 2009a, 2011a, 2012a). Each survey took approximately 40 minutes to complete. The specific questions regarding awareness of, prevention measures for, and experiences with TBDs are shown in Table 1 (Porter Novelli Public Services, 2009b, 2011b, 2012b). Response data were weighted using several demographic factors to ensure representativeness according to Current Population Survey (CPS) demographic proportions and to reduce potential nonresponse bias (US Census Bureau, 2006). (See Appendix A for details on sampling methodologies and demographic factors used for weighting in 2009, 2011, and 2012.)

For this study, reported frequencies are unweighted and reported proportions are weighted. Geographic regions are those designated by the U.S. Census Bureau (Fig. 1). Statistical analysis was conducted using IBM SPSS Statistics 21 (Armonk, NY: IBM Corp.). Analysis of 2009, 2011, and 2012 HealthStyles data was judged to be exempt from institutional review board requirements.

Table 2
Number of respondents who believe that the indicated TBD occurs in the area where they live (2009).

Geographic region	LD *n* (% within region)	RMSF *n* (% within region)	None or "Have not heard of any of these TBDs"[a] *n* (% within region)
Overall	2943 (63.7)	959 (20.2)	1559 (31.6)
New England	170 (86.1)	18 (11.5)	30 (13.9)
Mid-Atlantic	502 (78.7)	64 (7.6)	146 (20.8)
East North Central	552 (68.6)	89 (10.9)	234 (28.6)
West North Central	242 (77.9)	82 (20.6)	70 (19.3)
South Atlantic	597 (66.2)	265 (28.3)	289 (28.8)
East South Central	206 (63.6)	122 (38.3)	109 (30.2)
West South Central	242 (49.4)	110 (25.8)	236 (45.4)
Mountain	157 (51.1)	148 (48.1)	116 (30.3)
Pacific	275 (38.9)	61 (9.5)	329 (55.1)

[a] The TBDs listed in this survey question were Lyme disease, RMSF, anaplasmosis, babesiosis, ehrlichiosis, STARI, tick-borne relapsing fever, and tularemia (Table 1).

Results

Survey response rates were 73% (4728/6504) in 2009, 69% (4050/5864) in 2011, and 80% (3503/4371) in 2012 ($P < .0001$). For all three samples combined, 51.6% of respondents were female and 68.1% were white. Median respondent age was 51 years. Most respondents had an annual household income ≥$50,000 (55.8%), had some college education or higher (61.4%), and were employed (59.8%). Demographic characteristics of respondents matched the CPS proportions for each year (see Appendix B).

In 2009, 934 (21.0%) of 4728 total respondents reported that a household member found a tick on his or her body during the previous year; of these, 109 (10.1%) reported that a health care provider was consulted as a result of finding a tick on a household member. Respondents living in the West North Central, East South Central, and New England regions more commonly reported tick exposure in the household (36.7%, 32.2%, and 29.8%, respectively) (Fig. 1). Of all respondents reporting tick exposure in the household, health care provider consultation was most common in the New England (17.1%), Mid-Atlantic (17.0%), and Pacific (16.7%) regions and least common in the West South Central (2.4%), East South Central (3.0%), and West North Central (5.0%) regions.

Sixty (1.3%) respondents in 2009 and 43 (0.9%) in 2012 reported having been diagnosed with LD at some time in their lives. The percentage was highest in both years among respondents in the New England (6.5% in 2009, 2.2% in 2012) and Mid-Atlantic (3.0% in 2009, 2.0% in 2012) regions. Among survey respondents in 2009 who reported past diagnoses with LD, the reported duration of antibiotic treatment was ≤4 weeks for 39.0% of respondents, 5–8 weeks for 20.3% of respondents, and >8 weeks for 35.6% of respondents. In the 2011 survey, respondents were asked about "chronic LD"; 17 (0.5%) said they had "chronic LD" and 516 (10.5%) said they knew someone else with "chronic LD."

When asked which TBDs occur in the area where they live, respondents' answers varied by disease and region (Table 2). Overall, 63.7% reported that LD occurs in the area where they live. Many respondents living in regions where LD is not known to occur, such as the East South Central, Mountain, and West South Central regions, reported that the disease occurs where they live (63.6%, 51.1%, and 49.4%, respectively). Overall, 20.2% of respondents reported that RMSF occurs in their area, with highest percentages in the Mountain (48.1%) and East South Central (38.3%) regions. In the New England and Mid-Atlantic regions, areas that have a high incidence of LD as well as anaplasmosis and babesiosis, 13.9% reported that no TBDs occur in their area and 20.8% said they had not heard of any of these diseases. Regardless of region or endemicity, few respondents reported that the following diseases occur

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