National Survey of State Epidemiologists to Determine the Status of Lyme Disease Surveillance

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Synopsis

In 1990, the Council of State and Territorial Epidemiologists and the Centers for Disease Control made Lyme disease (LD) nationally notifiable and developed a national case definition. State epidemiologists were surveyed about their State LD surveillance system. Responses were received from all States and the District of Columbia.

As of November 1991, LD was notifiable in 45 States. A total of 44 of these 45 States use the 1990 national case definition for case confirmation. Twenty-five State health departments offer diagnostic testing for LD, and 38 States have conducted surveys for infected ticks.

This study has shown that there has been greater standardization of LD reporting with the adoption of a new national case definition for LD. However, many States confirm cases using data that are not a part of the criteria used for the national case definition.

In 1975, STEERE AND COLLEAGUES described a cluster of cases of arthritis in children and adults in Connecticut (*1*). This disease, which was later called Lyme disease (LD), was shown to be caused by a bacterium, *Borrelia burgdorferi* that is transmitted to human beings by the bite of *Ixodes* ticks (*2*). Patients with LD may first have a characteristic rash called erythema migrans (EM) and later develop rheumatologic, neurologic, or cardiac manifestations (*3*). The diagnosis and surveillance of LD is complicated, however, by the lack of a reliable diagnostic test for the disease (*4*).

National surveillance for LD was begun by the Centers for Disease Control (CDC) in 1982, and the disease was made nationally notifiable by the Council of State and Territorial Epidemiologists (CSTE) and CDC in 1990. CSTE is an organization of State epidemiologists that recommends additions and deletions to the list of nationally notifiable diseases.

The national case definition for LD includes the following criteria: (*a*) physician-diagnosed EM (>5 cm in diameter) or (*b*) specific rheumatologic, neurologic, or cardiac signs with a positive diagnostic test result for LD (*5,6*). States collect reports of possible LD from health care practitioners and, in some cases, laboratories within their jurisdictions.

Methods

State epidemiologists who are located in State health departments are responsible for notifiable diseases in their respective States. A questionnaire was sent to all State epidemiologists and the District epidemiologist in the District of Columbia on September 10, 1991, to determine whether LD was notifiable and to ascertain the characteristics of LD surveillance within their jurisdictions. States were phoned to request the return of missing questionnaires and to obtain responses to questionnaires with missing information. Statistical analyses were conducted using Epi-Info (version 5.01) software (*7*).

Results

Responses were received from all States and the District of Columbia. A total of 45 States reported that LD is currently notifiable; the District of Columbia was planning to add the disease to the

list of notifiable diseases. The respondents for Alaska, Florida, Idaho, Nebraska, and Oregon reported that LD was not notifiable in their State as of November 1991.

Of the 45 States in which LD is notifiable, all but one use the current national case definition for LD. All 45 States that require reports of LD specify that physicians report. In addition, 24 States (53.3 percent) require nurses to report, 28 (62.2 percent) require infection control practitioners to report, and 25 (55.6 percent) require hospital administrators to report. Twenty-five State health departments, including DC, (51.0 percent) offer diagnostic testing for LD.

Fully 46 respondents (90.2 percent) stated that laboratory tests for some communicable diseases were notifiable in their State; however, only 26 States and the District of Columbia (51.0 percent) reported that positive serologic tests for LD were notifiable. A total of 32 States (62.7 percent) responded that they followup positive LD serology reports by calling physicians' offices to determine if patients may have a diagnosis of LD. Followup of positive laboratory tests may identify patients who may meet their State case definition.

To determine if States use information beyond that required by the national case definition, the State epidemiologists were asked, "What information do you use to help you confirm reports of erythema migrans?" The possible responses and the number of States collecting this information are listed in the table.

All States that use a case definition determine whether reports meet their case definition criteria in order to confirm cases of LD. All but two States in which LD is notifiable responded that they send LD reports to CDC only after they have been reviewed and found to meet their case definition.

In the 25 States and the District of Columbia that offer diagnostic testing for LD, the following tests are offered in health department laboratories: enzyme-linked immunosorbent assay in 19 State laboratories, indirect immunofluorescent antibody in 11, and the Western blot in 4 States. Four State laboratories offer to culture for *B. burgdorferi*.

Among the 51 respondents to the mail survey, 38 (74.5 percent) have conducted active surveillance for infected ticks. Surveys were conducted by State agencies in 22 States (57.9 percent) and by another institution or agency in 30 States (78.9 percent). Eighteen States (47.4 percent) that have conducted surveys have attempted to determine if there is a correlation between infected ticks and reported cases.

States have determined LD endemicity through a variety of techniques. Sixteen States established regional endemicity using the criterion of having two or more confirmed human cases in a specific geographic area. The presence or absence of infected ticks in a specific geographic area was mentioned by 10 States. The mere presence of the tick vector was mentioned by only six States, and establishing an endemic transmission cycle in known vector ticks was not mentioned by any State that has LD notifiable. Twenty-four States with LD notifiable (53.3 percent) have at least one county designated as LD endemic. There was no correlation between States that have conducted surveys for infected ticks and the designation of LD endemic counties within those States.

The responses to the mail survey were stratified to see if there were differences in survey responses between higher and lower incidence LD States in which LD is notifiable. A higher incidence LD State was defined as having an LD case rate that exceeded 4.5 reported cases per 100,000 in the 1990 reports to CDC. Eight States met this criterion: Connecticut, Delaware, Maryland, New Jersey, New York, Pennsylvania, Rhode Island, and Wisconsin. Seven of the 8 higher incidence States offer LD serology testing compared with 16 of 37 States with lower rates (RR = 2.02, 95 percent C.I. = 1.29, 3.18). There were no other differences in responses in the survey noted between higher and lower LD incidence States.

Information used to help confirm reports of Lyme disease in 44 States, November 1991

Information	States	
	Number	Percent
Physician's report of cases	38	86.4
Size of erythema migrans (EM)[1]	30	68.2
Onset of EM from 3 to 30 days after bite	21	47.7
Positive serologic test result for those exposed in an endemic or nonendemic area	18	40.9
Location of probable exposure	18	40.9
Determination of appropriate interval between dates of onset and blood test	13	29.5
Location of patient's residence	13	29.5
Physician's treatment of case	10	22.7
Positive serologic test for those only exposed in a nonendemic area	1	2.3

[1] Case definition requires EM > 5 cm.

Discussion

The results of this survey indicate that most States now require notification of LD cases. Many

State health departments offer LD diagnostic testing, and many State agencies have attempted to determine whether infected ticks are located in their State. The development of the 1990 CSTE-CDC case definition was intended to help standardize reporting of LD. Previously, States used a variety of case definitions that created problems with State and national LD reporting. The adoption of the national case definition by most States is a step towards standardizing LD reporting in this country.

It was apparent, however, by the responses to the survey that some States use information other than that required by the case definition in confirming cases of LD. For cases of EM, some States reported that they use the interval between the tick bite and the onset of EM, positive serologic tests, the physician's treatment of a case, location of probable exposure, and a patient's residence—to name a few additional criteria that are not a part of the national case definition. Other States apparently do not use these criteria.

Although these additional criteria may appear to assist epidemiologists in determining whether reports are actual cases of LD, the fact that different criteria may be applied by different States will probably result in different interpretations of "confirmed" cases of LD. Differences in confirmatory criteria from State to State probably decrease the comparability of their LD surveillance data. This difference in approach may be expected for surveillance of an infectious disease that still lacks accurate diagnostic tests.

It was beyond the scope of this survey to determine the possibility of over- or undercounting actual cases of LD. There are no data sets that can easily be used to evaluate the accuracy of LD surveillance systems. As mentioned previously, there are problems with the accuracy of diagnostic tests for LD that create problems in determining the accuracy of patients' diagnoses. Patients may be given a diagnosis of LD when they have other diseases, or LD may be missed altogether.

In establishing the 1990-91 CSTE-CDC case definition for LD, it was decided by State and Federal epidemiologists to try to design a case definition that would have a high predictive value for LD. This choice would help to ensure that reported cases would be likely cases of LD. Unfortunately, there are subclinical or minimally clinical cases of LD that are unrecognized by physicians and not reported to epidemiologists. Using the more restrictive case definition probably leads to underreporting of cases of LD. The alternative of using less restrictive LD case definition criteria would introduce many other clinical syndromes into the LD surveillance data set. LD surveillance data would then also reflect information gathered on non-LD cases, which would clearly be a problem.

Evaluations of surveillance systems have consistently shown that health care providers underreport other notifiable diseases (*8–10*). Since reporting of LD is through the same national notifiable disease surveillance system, we should also expect that LD is underreported because of a failure to report cases.

Surveillance for LD will improve as diagnostic tests for LD are improved and as a case definition is adopted that uses more accurate test results than are currently available. In the interim, it has been suggested that State epidemiologists and epidemiologists from the Centers for Disease Control convene a forum to discuss the experience with the 1990 CSTE-CDC case definition. This forum could address issues surrounding the State-to-State comparability of surveillance data as well as other LD surveillance issues.

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