The Public Health Impact of Lyme Disease in Maryland

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The purpose of this study was to estimate the health burden imposed by Lyme disease (LD) in Maryland during 1992 and 1993. A cross-sectional 1-in-15 survey of physicians (total, 1200) in Maryland was conducted to estimate the incidence of diagnosed LD, presumptive cases of LD, patients with tick bites, and diagnostic tests ordered for LD. Results show that LD is underreported by 10- to 12-fold in Maryland, that 80% of cases are managed by primary care physicians, and that there is discordance between the actual clinical treatment of patients and the recommended approach. In addition, the much greater numbers of patients treated for presumptive LD, seen and given prophylaxis for tick bites, and having diagnostic tests indicate that real and perceived LD is a far greater public health problem and uses more medical resources than official surveillance data suggest.

More than 65,000 cases of Lyme disease (LD) have been reported to the Centers for Disease Control and Prevention (CDC) since the disease became nationally reportable in 1982 [1]. From 1982 to 1989, reported cases increased 20-fold nationwide and doubled each year. However, this increase leveled off from 1990 to 1994, when 13,083 cases were reported. A similar trend is occurring in Maryland (figure 1) [2, 3]. A preliminary survey of physicians in the state in 1991 indicated LD was underreported by ~6-fold, but due to the small sample and biased sampling methods, the actual amount could not be definitively determined [4]. Other studies have also suggested underreporting of LD may be at least partly responsible for the plateau in cases [5–7]; however, no studies, with the exception of our preliminary survey, have investigated the amount of underreporting [4].

The primary objective of this study was to estimate the public health impact on the state of Maryland during 1992 and 1993 from real and perceived cases of LD, including the clinical care of diagnosed and presumptive cases and of patients with tick bites, as well as the impact of diagnostic tests. Secondary objectives were to detect which physician specialties were diagnosing and treating patients with LD and to ascertain whether their clinical management followed that generally recommended in the literature [8–10].

Methods

In July 1993, a questionnaire was designed to collect data on the number, clinical characteristics, and antibiotic treatment regimens of LD cases diagnosed in Maryland in 1992 and the first 6 months of 1993. Because we were interested in assessing physicians' treatment of both real and perceived LD, we chose to define LD as a clinical diagnosis made by the responding physician. Also on the questionnaire were questions regarding characteristics of the reporting physicians and their patients, the number of patients they treated for LD even though the diagnosis was uncertain, the number of patients they saw for tick bites and the proportion given prophylactic antibiotics, and the number of LD diagnostic tests they ordered.

A computer-generated sample of 10% of the 21,821 physicians with a license to practice medicine in Maryland was constructed. Among the 2182 physicians in the sample, 383 not living in Maryland or in a contiguous state were excluded, leaving 1799. Two-thirds of these were selected by systematically eliminating every third name on the computer list, resulting in a final sample of 1200 physicians. The sample size was selected to achieve a 90% power to detect a 2-fold difference between the number of LD cases officially reported by the Maryland Department of Health and Mental Hygiene (SDH) and cases diagnosed by the surveyed physicians, if there was indeed such a difference.

Questionnaires and letters explaining the study were sent to each physician in July 1993. After 3 weeks, a follow-up questionnaire was sent to those not responding to the initial mailing. After 3 additional weeks, attempts were begun to contact all nonrespondents by telephone. Physician telephone numbers were obtained from local telephone directories, the membership directory of the Medical and Chirurgical Faculty of Maryland, a nationwide directory of physicians registered in the United States, and by calling telephone operators for those not covered in the above.
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Results

LD diagnoses. SDH received 187 and 210 LD case reports meeting the CDC surveillance case definition in 1992 and 1993, respectively (figure 1). Results of the physician survey, however, revealed a much greater number of LD diagnoses. Of the 1200 physicians in the survey, 59 (4.9%) reported diagnosing 127 cases of LD in 1992, and 61 (5.1%) said they diagnosed 101 cases from January to June 1993. For 1992 and 1993, respectively, 65.4% and 54.5% of these clinically diagnosed cases met the CDC surveillance case definition. Projecting from our 1-in-15 survey sample, we estimated that Maryland physicians diagnosed 1905 cases of LD in 1992 and 2447 cases in 1993.

When the names of the 59 surveyed physicians who diagnosed LD in 1992 were compared with those reporting LD to SDH during the same year, only 6 (10.2%) matched. In 1993, only 5 (8.2%) of the 61 physicians reported their LD cases to SDH. Therefore, LD was underreported by 10-fold during 1992 and by 12-fold in 1993, as estimated by two independent methods of calculation.

Primary care physicians (i.e., general internists, pediatricians, family or general practitioners, and emergency room physicians) diagnosed 78.6% of the LD cases. Although neurologists diagnosed almost 5% of cases, other specialists that would be expected to see patients with LD made few primary diagnoses (i.e., infectious disease physicians [2.2%], rheumatologists [0.4%], and dermatologists [1.5%]). Most cases reported by surgeons (4.8%) were among patients having aspirations of knee effusions by orthopedic surgeons.

Treatment of patients with presumptive LD. Sixty-six (5.5%) physicians said they treated an additional 275 patients for LD in 1992, although they were uncertain if this was the correct diagnosis. We estimated that 4125 patients in 1992 and 4022 in 1993 were treated for presumptive LD. Thus, antibiotic therapy was given to almost twice as many patients with presumptive diagnoses as to those who were believed to have LD.

Tick bites and prophylaxis. In 1992, 1615 patients saw 172 (14.3%) of the surveyed physicians for tick bites without signs or symptoms of LD, and 371 (23.0%) of these patients were treated with prophylactic antibiotics. Oral doxycycline, tetracycline, or amoxicillin was the prophylaxis used for 82.5% of these cases. We calculated that 24,225 patients in 1992 and 23,625 in 1993 were seen for tick bites. Of these, 5565 in 1992 and 5888 in 1993 were treated with prophylactic antibiotics. Therefore, 11 times more patients were seen for tick bites than were treated for diagnosed LD in the state during the 2 years, and >2.5 times more patients were given prophylactic antibiotics for tick bite than were treated for LD.

Laboratory tests. Two hundred one physicians (16.8%) reported ordering 2035 serologic tests for LD in 1992, and they considered 128 (6.3%) of these tests positive; 84 of these (65.6%) were believed to be associated with a confirmed diagnosis of LD. We estimated that 30,525 and 36,951 diagnostic tests for LD were done in Maryland in 1992 and 1993, respectively, >90% being screening tests. Of these, 14.3% of the surveyed physicians for tick bites without signs or symptoms of LD, and 371 (23.0%) of these patients were treated with prophylactic antibiotics. Oral doxycycline, tetracycline, or amoxicillin was the prophylaxis used for 82.5% of these cases. We calculated that 24,225 patients in 1992 and 23,625 in 1993 were seen for tick bites. Of these, 5565 in 1992 and 5888 in 1993 were treated with prophylactic antibiotics.

Discussion

The data from this study indicate LD is diagnosed and treated 10–12 times more frequently in Maryland than official SDH reports suggest. The true incidence of LD appears to be increasing in the state, and we estimate that 1900–2400 cases are being diagnosed each year, a dramatically greater number than the 180–340 cases reported by SDH to CDC annually.
In support of our conclusion that LD is markedly underreported in Maryland is the projection of the 1993 half-year data, which confirm the 1992 entire-year results. In fact, despite the conservative method of calculation used, there were more cases of LD in 1993 than in 1992. In addition, when the names of physicians reporting cases of LD to the SDH’s LD registry were checked against those surveyed, the calculated degree of underreporting was 10-fold for 1992 and 12-fold for 1993, results identical to those obtained by our calculations, derived from multiplying the number of cases that our sampled physicians said they saw by 15.

The public health impact of LD is even more striking when clinical management decisions for patients with presumptive diagnoses and tick bites are considered. Our survey is compatible with results reported by Steere et al. [9], who concluded that, because of overdiagnosis, more patients not having the condition were being diagnosed and treated for LD than were patients who met their criteria for LD. Results from our survey show that 4.5 times as many patients who had presumptive LD diagnoses or who only had tick bites were given antibiotics as were patients actually diagnosed as having LD. Antibiotic prophylaxis for tick bites has not been recommended, even in areas with high numbers of endemic ticks [11, 12], based upon the incidence of LD calculated from official reports to CDC. However, this policy remains controversial, and some areas of the state, for example, the Eastern Shore, may actually have incidence rates at levels that make administration of antibiotic chemoprophylaxis for well-documented black-legged tick bites cost effective [13]. Some physicians may be choosing to treat tick bites in response to patient requests, convenience, or fear that the patient will not return if symptoms develop. A cause of concern is that almost 1 in 6 patients receiving prophylaxis for tick bites were treated with drugs more costly and potentially more toxic than the recommended drugs (oral doxycycline, tetracycline, and amoxicillin).

Our data also suggest that Maryland physicians are ordering a large number of laboratory tests for LD: >30,000 diagnostic tests were ordered in 1992, and we estimate that 37,000 were ordered for patients in 1993. Another study in a prepaid health plan in California concluded that only 1 in 5 serologic tests for LD were done because the physician suspected a diagnosis of LD [14]. In Maryland, most treatment decisions have been made on the basis of ELISA results, without benefit of the recommended Western blot confirmation. Because of the relatively low prevalence of LD, even if the ELISA had 90% sensitivity and 95% specificity, there would be many false-positive results. Thus, physicians need to be counselled about the limitations of serologic tests for LD in order to make more appropriate testing decisions and to confirm positive screening tests before treating patients with atypical clinical presentations [9, 10, 14]. It is obvious that many physicians understand this principle, since ~60% of the positive tests were considered associated with a diagnosis of LD.

In a recent publication, primary care physicians reported ~80% of cases to the Connecticut Department of Health Services [7], a proportion consistent with our own. In the Connecticut survey and in our survey, dermatologists diagnosed only 1% of cases, even though the most characteristic sign of LD is a large, expanding, annular dermatitis. Infectious disease specialists and rheumatologists diagnosed very few cases in our study.

Our physician survey confirmed our impression that LD is a much greater public health problem in Maryland than indicated by official reports. Our conclusions are supported by the fact that the 12.2% refusal rate to respond to our survey is lower than the rate for almost all physician surveys, the same results were obtained by using two separate methods of calculation and data sources, and the results for the second year confirmed those of the first. In addition, we adjusted our data analysis due to the incomplete sample and because we assumed the surveyed physicians were overreporting during the second year. Both of these conservative adjustments would err on the side of reducing our estimate of the number of LD cases seen by the physicians. The results indicate that real and perceived LD is a greater public health problem and consumes far more medical resources in Maryland than official surveillance data suggest, and they indicate that there is discordance between published recommendations for diagnosis and treatment of LD [8-10] and the actual clinical treatment of many patients with LD and tick bite exposures.

References