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Exploring an alternative approach to Lyme disease surveillance in Maryland

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Summary

In Maryland, Lyme disease (LD) is a reportable disease and all laboratories and healthcare providers are required to report to the local health department. Given the volume of LD reports and effort required for investigation, surveillance for LD is burdensome and subject to underreporting. We explored the utility of International Classification of Diseases, 9th Revision, Clinical Modification (administrative) codes for use with LD surveillance. We aimed to collect the administrative codes for a 10% sample of 2009 LD reports (n = 474) from 292 facilities stratified by case classification (confirmed, probable, suspected and not a case). Sixty-three per cent (n = 184) of facilities responded to the survey, and 341 different administrative codes were obtained for 91% (n = 430) of sampled reports. The administrative code for Lyme disease (088.81) was the most commonly reported code (133/430 patients) among sampled reports; while it was used for 62 of 151 (41%) confirmed cases, it was also used for 48 of 192 (25%) not a case reports (sensitivity 41% and specificity 73%). A combination of nine codes was developed with sensitivity of 74% and specificity of 37% when compared to not a case reports. We conclude that the administrative code for LD alone has low ability to identify LD cases in Maryland. Grouping certain codes improved sensitivity, but our results indicate that administrative codes alone are not a viable surveillance alternative for a disease with complex manifestations such as LD.

Keywords

administrative codes; Lyme disease; surveillance

1 | INTRODUCTION

Lyme disease (LD) is a nationally notifiable disease and the most commonly reported vector-borne disease in the United States. Nationwide, 38,069 confirmed and probable LD cases were reported in 2015, with 95% of these cases occurring in just 14 states, including

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CONFLICT OF INTEREST

The authors have no conflict of interests to declare.

Maryland (CDC, 2016). In 2015, the Maryland Department of Health (MDH) reported 1,727 confirmed and probable LD cases, for an incidence rate of 28.8 cases/100,000 persons (Maryland Department of Health, 2016).

Public health surveillance for LD allows for an understanding of the burden of the disease in the population, characterization of who is affected and assessment of its geographic spread. Maryland statutes and regulations (COMAR, 2015) require healthcare providers to report all LD cases and laboratories to report all positive LD test results to the local health department (LHD). The vast majority of LD reports in Maryland are submitted to LHDs by laboratories. LD cases diagnosed by healthcare providers without laboratory confirmation are rarely reported, despite the fact that early LD may be diagnosed by providers solely on clinical criteria (i.e. erythema migrans).

Local health department staff investigate LD reports by requesting additional information from the provider or laboratory, such as onset and diagnosis dates, signs and symptoms and any additional test results. All data are entered into the Maryland National Electronic Disease Surveillance System (NEDSS) Base System, and LHD staff use these data to classify the report as confirmed, probable, suspected or not a case according to the national surveillance case definition for LD (CDC, 2008). Confirmed and probable cases require clinical data and supporting laboratory evidence (although laboratory evidence is not currently required in LD endemic areas for cases with erythema migrans rashes). Suspected cases have positive laboratory reports indicating infection but lack clinical data. LD reports not classified as confirmed, probable or suspected cases are deemed not a case. If additional clinical and test information were available, some suspected and not a case reports would likely be otherwise classified.

The investigative process is resource-intensive for surveillance staff (Rutz, Wee, & Feldman, 2016, this issue) and can divert efforts from other situations that require immediate public health action (e.g. foodborne disease outbreaks or other local infectious disease issues). While acknowledging both the utility of LD surveillance and the limitations of the current surveillance system in Maryland, we aimed to explore other options to detect LD cases.

International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) codes (also referred to as administrative codes in this paper) are typically used for administrative purposes such as billing. Others have previously explored the use of these codes to support or supplant traditional public health surveillance and to address some of the surveillance issues highlighted above (Elkin & Brown, 2013; Mahajan, Moorman, Liu, Rupp, & Klevens, 2013; Pyrgos, Seitz, Steiner, Prevots, & Williamson, 2013; Sickbert-Bennett, Weber, Poole, MacDonald, & Maillard, 2010). Results are mixed and depend on the disease in question. Only one study, conducted in a low-incidence area for LD, has explored the use of administrative codes in identifying LD cases (Jones, Coulter, & Conner, 2013). To determine whether the use of administrative codes could serve as an alternative approach to identifying cases of LD, the Emerging Infections Program at MDH collected administrative codes and reviewed medical records for a sample of 2009 LD reports submitted to MDH via the traditional public health surveillance processes.

2 | METHODS

In 2009, there were a total of 4,768 LD reports in Maryland NEDSS. Balancing our aim for a robust sample size with the resources available for this effort, we took a 10% stratified random sample of the 2,546 confirmed, probable and suspected LD reports. Of the 2,222 LD reports in NEDSS classified as not a case, we included in our analysis 10% of the reports most likely to be reclassified given additional laboratory or clinical information.

The sampled reports were reviewed to identify patients' providers and dates of LD testing so that we could request administrative codes for the patient visit associated with the LD test. We requested codes for the date of LD diagnosis, or if there was no clear diagnosis date, for the date of the office visit most closely associated with the date LD testing was ordered. In addition, we asked details about the type of practice. We made up to six attempts to contact providers for this information.

We reviewed medical records of suspected and not a case reports to obtain missing information to be used for potential reclassification. We attempted to review records for 100% of sampled suspected cases, 50% of sampled not a case reports with Western blot (WB)-positive tests and 25% of sampled not a case reports submitted by physicians. With the newly acquired data, reports were reclassified to confirmed or probable, as indicated, according to the national case definition for LD.

Using the final classification for reports following medical record review, we analysed the administrative codes associated with each report classification to determine the best predictors of a LD case. First, we calculated the frequency of codes assigned to confirmed cases. In some instances, we combined codes which indicated different anatomic sites of the same condition (e.g. the codes for insect bite, regardless of anatomic location of the bite, see Table 2 footnote). Sensitivity, specificity and positive predictive value (PPV) were calculated for each code (or multiple anatomic site codes) comparing confirmed cases to not a case LD reports.

To explore whether including multiple codes for different manifestations or conditions might improve our ability to predict confirmed and probable cases, we reviewed the list of codes which occurred in at least three (2%) confirmed cases, were biologically plausible indicators of LD and had a PPV for identifying a confirmed case of LD greater than 50%. These codes were used to build a set of codes that might predict confirmed and probable cases. To generate the codes in this set, each code (or multiple site codes) was added sequentially in the order of highest PPV by an "or" statement to the Lyme disease code (088.81); we calculated sensitivity and specificity of the resultant set of codes for confirmed and probable LD cases.

To assess whether this set of codes could potentially identify confirmed or probable cases that had been originally classified as suspected cases, we reviewed the suspected cases for any code in our code set. Cases identified as having one or more codes were then compared to the sampled suspected cases (potentially reclassified) following medical record review to determine agreement.

We used Microsoft Office Excel 2007 to characterize administrative codes and used Epi Info 7 for data entry and analysis of medical record review data. SAS version 9.3 was used to analyse the administrative code data.

3 | RESULTS

Our initial 10% stratified random sample from NEDSS consisted of 147 confirmed, 56 probable, 52 suspected cases and 219 not a case reports, resulting in a total of 474 reports (Figure 1). From these, a total of 292 healthcare practices were identified for administrative code and medical records requests. We obtained responses from 184 (63%) healthcare facilities, of which 15 (8%) were hospitals, 42 (23%) were single-provider practices and 127 (69%) were multiprovider practices.

We collected administrative codes for 430 (91%) of our 474 sampled reports. We were unable to collect codes for 44 patients for the following reasons: the office had closed or the provider had retired ($n = 15$); the provider did not respond to our request ($n = 12$); records were not available ($n = 9$); there was no record of the patient in the provider's files ($n = 7$); and one patient classified as not a case had a final diagnosis other than LD.

For our reclassification analysis, medical record reviews were conducted on 44 suspected cases and 92 not a case reports. Of these, 16 (36%) suspected cases and six (6.5%) not a case reports were reclassified to confirmed or probable given the additional data collected.

For our administrative code analysis, we used LD reports for which we were certain of the case classification and for which we had administrative codes. All confirmed and probable cases had sufficient information to assure us of the classification. The reports that had undergone medical record review were included with the final case classifications; the suspected cases and not a case reports that did not undergo medical record review were not included, as we were uncertain of the true classification. This resulted in a total of 325 reports, comprising 151 confirmed cases, 60 probable cases, 25 suspected cases and 89 not a case reports (Table 1).

Of the 325 total reports, there were 108 that contained the ICD-9-CM LD code, 088.81 (Table 1), including 41% of confirmed cases and 27% of not a case reports. When confirmed cases were compared to not a case reports, the sensitivity and specificity of 088.81 were 41% and 73%, respectively. The sensitivity and specificity of 088.81 for confirmed and probable cases together were 37% and 73%, respectively.

There were 141 different administrative codes collected for the 151 confirmed cases, with 111 (79%) of these codes occurring only once. The most frequently used codes (Table 2) for confirmed cases that occurred in ≥2% of records included codes directly related to LD (e.g. 782.1 rash and 351.0 Bell's palsy); non-specific clinical manifestations of LD (e.g. 780.60 fever and 784.0 headache); and signs and symptoms that are not typically associated with LD but that may be common comorbidities (e.g. 272.0 hypercholesterolaemia). There were a total of nine codes (single or multiple site condition) that met our criteria for assessment as predictors of LD.

Using our established criteria, the resultant code set included the following codes or code groups: Lyme disease; other cellulitis and abscess codes; Bell's palsy; rash and other non-specific skin eruption; insect bite, non-venomous, with or without infection; fever, unspecified; headache; effusion of joint, lower leg; or pain in joint. Beginning with the LD code, we added each of the eight remaining codes by an "or" statement to the previous code set, thus increasing sensitivity (74%) and decreasing specificity (37%) compared with using the LD code 088.81 alone (Figure 2).

We tested this set of codes on the 44 sampled suspected cases (before medical record review) from 2009 to see whether the codes could identify cases that should be reclassified as confirmed or probable. This code set identified 31 (70%) suspected cases as potential confirmed and probable cases. We then compared these 31 cases to our 44 cases following medical record review. Of the 31 suspected cases identified by the set of codes, 12 (39%) had been reclassified to confirmed or probable following medical record review. Another 13 (42%) remained as suspected cases following medical record review. The remaining six (19%) of the 31 had been reclassified as not a case following medical record review. The set of nine codes failed to identify four suspected cases that had been reclassified to confirmed or probable following medical record review.

4 | DISCUSSION

We assessed the potential for using administrative codes to complement or replace traditional public health surveillance methods for LD. The LD code alone, 088.81, had low sensitivity and specificity and is therefore unlikely to be useful for LD surveillance. We increased sensitivity by combining additional codes potentially predictive of LD, but at a cost to specificity. This set of nine codes was tested on our sampled suspected cases, but it was insufficient to detect all truly confirmed and probable cases.

In the light of our findings, and recognizing that LD has a complex case definition, a two-tier diagnostic testing algorithm and a variable clinical presentation, we conclude that the use of administrative codes is not a viable alternative to traditional surveillance for LD. There may be some utility in using this set as a screening tool to enhance current LD surveillance, but this would require additional assessment prior to implementation, such as testing on other data sources and taking into consideration the LD prevalence in the geographic provenance of the data.

Several research efforts have found administrative codes to have good utility for communicable disease surveillance when diseases are common and have simple case definitions and clinical diagnoses (Sickbert-Bennett et al., 2010). Investigations into using these codes for cryptococcal meningitis and hepatitis B virus infection determined that they were accurate and useful for surveillance of those diseases (Mahajan et al., 2013; Pyrgos et al., 2013). However, other researchers have concluded that the use of administrative codes is not a viable alternative to public health surveillance, as the codes had low sensitivity and positive predictive value, were not useful for rare diseases or those with complex case definitions and diagnoses, and were resource-intensive for surveillance purposes (Fiske, Griffin, Mitchel, Sterling, & Grijalva, 2012; Mullen et al., 2013). For example, Elkin and

Brown (2013) showed that administrative codes had low predictive value for influenza, and Marder, Garman, Jones, Dunn, and Jones (2014) found that the codes provided minimal benefit to surveillance for *Salmonella* infections. Specifically related to LD, Jones et al. (2013) concluded that the use of administrative codes for LD from a managed care organization could be used to supplement the current passive reporting system, although their study was conducted in a low-incidence state.

The study may have been limited in that we requested administrative codes for only one healthcare provider visit, although more than one visit may have occurred to diagnose LD. Furthermore, the codes were not requested in ranked order so we did not know the primary diagnosis. Additionally, collecting administrative codes was very time-consuming, and even with up to six attempts to collect them, 12 facilities did not respond to our request. We also used reports classified as not a case as our comparison group for our analysis; yet the not a case reports are not an ideal representation of persons without disease, as clinicians at the very least suspected the patient of having LD and ordered a LD test. However, for the not a case reports that were reviewed, only a very small proportion changed classification to confirmed or probable cases, indicating that the not a case reports likely do represent patients who do not have LD. The International Classification of Diseases 10th Revision, Clinical Modification (ICD-10-CM) has replaced ICD-9-CM codes, and our findings likely do not reflect the potential utility of ICD-10-CM codes for public health surveillance uses. Finally, we did not test our proposed group of codes on other years' or other states' surveillance data.

In conclusion, we did not identify a viable alternative approach to the current LD surveillance process, and we demonstrated that the LD ICD-9-CM code is neither sensitive nor specific enough to identify LD cases in administrative data sets without further methods of screening the records or subsequent investigation.

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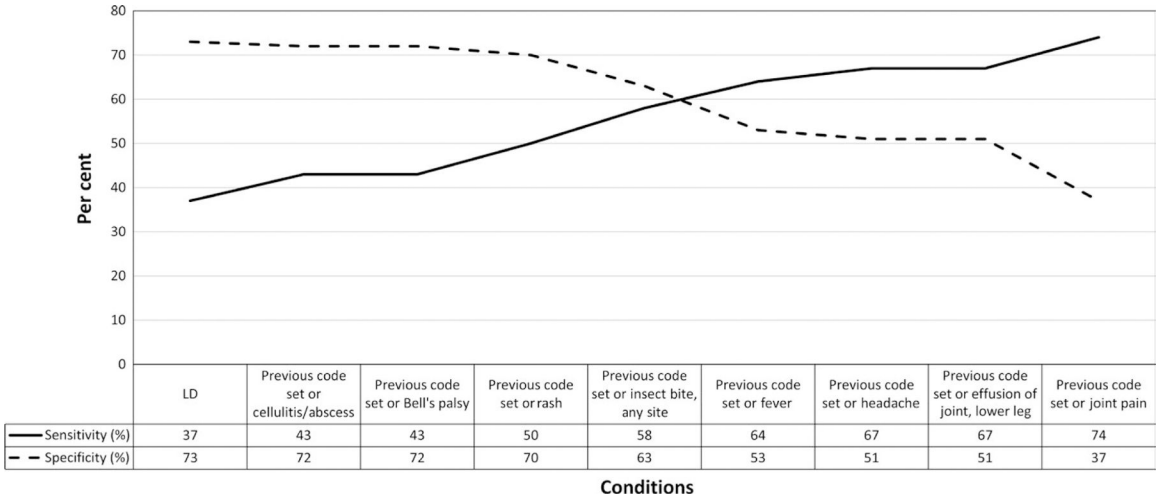
Impacts

- The ICD-9-CM code for Lyme disease, when used for billing purposes, had 37% sensitivity for confirmed Lyme disease cases reported to the Maryland Department of Health.
- Adding other common administrative codes to the Lyme disease code improved the sensitivity but reduced specificity over the Lyme disease code alone when trying to identify Lyme disease cases from administrative data sets.
- It will be challenging to use administrative codes, alone or in combination, to identify cases of Lyme disease for public health surveillance from administrative data sets.

2009 Lyme disease reports in Maryland NEDSS					
	Confirmed	Probable	Suspected	Not a case	Total
Original classification	1,472	557	517	2,222	4,768
↓	↓	↓	↓	↓	↓
10% random sample	147	56	52	219	474
↓	↓	↓	↓	↓	↓
Administrative codes obtained	137	52	46	195	430
↓	↓	↓	↓	↓	↓
Medical records reviewed	n/a[a]	n/a[a]	44	92	136
Final classification following medical record review	151	60	25	89	325

[a]Confirmed and probable reports were not reviewed as there was already sufficient information for classification purposes

FIGURE 1.
Sampling scheme for analysis of administrative codes



	LD	Previous code set or cellulitis/abscess	Previous code set or Bell's palsy	Previous code set or rash	Previous code set or insect bite, any site	Previous code set or fever	Previous code set or headache	Previous code set or effusion of joint, lower leg	Previous code set or joint pain
Sensitivity (%)	37	43	43	50	58	64	67	67	74
Specificity (%)	73	72	72	70	63	53	51	51	37

FIGURE 2.

Sensitivity and specificity of administrative code combinations for identifying confirmed and probable cases (%)

TABLE 1

Lyme disease (LD) reports sampled from NEDSS in 2009, by final classifications and inclusion of LD code 088.81

	Reports by final classification	Reports with 088.81 (%)
Confirmed	151	62 (41)
Probable	60	17 (28)
Suspected	25	5 (20)
Not a case	89	24 (27)
Total	325	108 (33)

NEDSS, National Electronic Disease Surveillance System.

TABLE 2

Most frequent administrative codes from sampled confirmed Lyme disease cases, Maryland, 2009 (n = 151)[a,b,c]

	Condition	Code	Frequency	Per cent (%)	PPV (%)[c]
1	Lyme disease	088.81	62	41	72
2	Pain in joint (all anatomic sites)[b]	719.40–719.49	19	13	53
3	Rash and other non-specific skin eruption	782.1	17	11	89
4	Insect bite codes with/without mention of infection (all anatomic sites, except eye)[b]	910.4/5–919.94/5	15	10	71
5	Other malaise and fatigue	780.79	11	7	44
6	Insect bite, non-venomous, without mention of infection	919.4	9	6	69
7	Bell's palsy	351.0	8	5	89
8	Effusion of joint, lower leg	719.06	8	5	57
9	Fever, unspecified	780.60	8	5	72
10	Pain in joint	719.4	7	5	78
11	Other cellulitis and abscess codes (all anatomic sites)[b]	682.0–682.9	6	4	100
12	Insect bite, non-venomous, infected	919.5	6	4	86%
13	Pain in joint, lower leg	719.46	6	4	46
14	Headache	784.0	5	3	63
15	Pain in joint, multiple sites	719.49	4	3	40
16	Pure hypercholesterolaemia	272.0	3	2	n/a
17	Acute upper respiratory infections, unspecified site	465.9	3	2	n/a
18	Other cellulitis and abscess, leg, except foot	682.6	3	2	100
19	Myalgia and myositis, unspecified	729.1	3	2	50
20	Pain in limb	729.5	3	2	n/a

[a] Shaded areas denote codes used in our analysis.

[b] We combined all other cellulitis and abscess codes (682.0 through 682.9) to include all anatomic sites other than fingers and toes. Similarly, we collapsed 18 codes for superficial non-venomous insect bites with and without infection at various anatomic sites (910.4 and 5 through 919.4 and 5, excluding 918 which pertains to eye injuries) into one group. All joint pain codes for any anatomic site (719.40 through 719.49) were also grouped.

[c] PPV is positive predictive value.