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Healthcare access and burden of care for patients with Lyme disease: A large United States survey

Lorraine Johnson [a], Alexandra Aylward [b], Raphael B. Stricker [a,*]

[a] *California Lyme Disease Association, Marysville, CA, United States*
[b] *Department of Psychiatry and Behavioral Sciences, Stanford University School of Medicine, Palo Alto, CA, United States*

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ABSTRACT

Objective: To evaluate the challenges faced by Lyme disease patients in obtaining adequate healthcare.
Methods: A web-based survey conducted over nine months was analyzed for the study. The survey focused on medical status, access to healthcare, and burden of illness. For inclusion in the study, survey respondents had to reside in the United States, be more than 10 years old, and have clinically diagnosed Lyme disease with chronic symptoms and positive laboratory testing.
Results: Responses from 2424 patients were included in the study. Half of the respondents reported seeing at least seven physicians before the diagnosis of Lyme disease was made. Nearly half had Lyme disease for more than 10 years and traveled over 50 miles to obtain treatment. Most respondents experienced symptoms lasting six months or more despite receiving at least 21 days of antibiotic treatment. A quarter of respondents had been on public support or received disability benefits due to Lyme disease symptoms, and over half had visited an emergency room at least once as a result of these symptoms.
Conclusions: Lyme disease patients frequently endure extensive delays in obtaining an initial diagnosis, have poor access to healthcare and suffer a severe burden of illness.

1. Introduction

Lyme disease is the most common vector-bone disease in the United States today [1,2]. The disease is caused by the spirochete *Borrelia burgdorferi*, and infection with this organism has reached epidemic proportions across the country [1–6]. In 2008, the number of new Lyme disease cases reported by the Centers for Disease Control and Prevention (CDC) was 35,198 [7]. This represents a 40% increase over the number of cases reported in 2006 [7]. The CDC acknowledges that the true number of Lyme disease cases is probably 6–12 times higher than the number of reported cases, so roughly 200,000–400,000 people contract Lyme disease each year in the United States [8].

Lyme disease is also a highly controversial illness. Over the past decade, two opposing viewpoints have emerged in the scientific debate over this tick-borne illness. One viewpoint is represented by the Infectious Diseases Society of America (IDSA), which maintains that Lyme disease is a rare illness localized to well-defined areas of the world [9–13]. According to IDSA, the disease is ‘hard to catch and easy to cure’ because the infection is rarely encountered, easily diagnosed in its early stage by distinctive clinical features and in more advanced stages by accurate commercial laboratory tests, and effectively treated with a short course of antibiotics over 2–4 weeks [9–13]. In IDSA's view, chronic infection with the Lyme spirochete is rare or non-existent [13].

The opposing viewpoint is represented by the International Lyme and Associated Diseases Society (ILADS), which

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[*] Corresponding author at: 450 Sutter Street, Suite 1504, San Francisco, CA 94108, United States. Tel.: +1 415 399 1035; fax: +1 415 3991057.
E-mail address: rstricker@usmamed.com (R.B. Stricker).

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argues that Lyme disease is not rare and, because its spread is facilitated by rodents, deer and birds, it can be found in an unpredictable distribution around the world, accompanied by other tick-borne coinfections that may complicate the clinical picture. According to ILADS, tick bites often go unnoticed, and commercial laboratory testing for Lyme disease often yields inaccurate results [1–6]. Consequently the disease is often not recognized and may persist in a large number of patients, requiring prolonged antibiotic therapy to eradicate persistent infection with the evasive Lyme spirochete [1,6].

The professional membership of IDSA differs significantly from the professional membership of ILADS. The majority of IDSA members are infectious disease researchers, academicians, or government employees [14]. ILADS members, on the other hand, are primarily community health care providers who are attempting to address significant and sometimes incapacitating illness in their patients [1]. Of equal importance, the controversy between IDSA and ILADS over the diagnosis and treatment of Lyme disease has been uneven in terms of power and resources. IDSA is the largest infectious disease specialty society in the world, publishes the two largest medical journals in the field, dominates related peer review, often functions as a gatekeeper for hospital staff privileges, and provides expert testimony to enforce its views through medical board disciplinary action [15–17]. As a result, IDSA has been able to assert tremendous influence over the treatment of Lyme disease in the United States and has been the subject of an antitrust investigation by the Connecticut Attorney General [15–17]. However, the consequences of IDSA's influence from the patient perspective have not been studied on a national level in the United States.

Two significant aspects of the health policies that influence medical status related to Lyme disease are access to healthcare and burden of illness. According to the Institute of Medicine (IOM), access to healthcare can reduce the incidence of preventable diseases, provide early detection and diagnosis of treatable diseases, and reduce mortality and morbidity of chronic diseases [18]. Barriers to care may be related to geographic, financial, or organizational factors that result in failure to provide needed services [19]. Key factors include insurance coverage, healthcare costs, travel time and distance to obtain care, and availability of care [19,20]. Furthermore, the IOM defines "access to healthcare" as the timely use of medical care to obtain the best possible outcome, framing the issue as follows:*The most important consideration is whether people have the opportunity for a good outcome—especially in those instances in which medical care can make a difference. When those opportunities are systematically denied to groups in society, there is an access problem that needs to be addressed* [18].

This study describes the results of an on-line survey of persons living with Lyme disease who were asked about their medical status, access to healthcare and burden of illness related to the tickborne infection.

2. Materials and methods

2.1. Data sources

This study analyzes the responses of adults and adolescents who completed a web-based survey developed by the California Lyme Disease Association (CALDA), a non-profit organization that supports the interests of Lyme disease patients. The survey entitled "Stand Up and Be Counted Now" was designed by first reviewing the Lyme disease literature on diagnosis, access to health care, and burden of illness, drawing heavily from a previous survey by Vanderhoof and Vanderhoof-Forschner [21]. In addition, items were drawn from previous surveys, including a small online survey that pilot-tested and refined the questionnaire used for this study. CALDA administered the current survey between June 2009 and March 2010. An analysis of the survey's findings for variables not addressed in this study was the subject of a previous published report [22]. The current study focused on the assessment of three domains associated with Lyme disease: medical status, access to healthcare, and burden of illness.

To promote participation in the survey, various recruitment strategies were utilized: CALDA posted a blog entry with a link to the survey on its website and distributed an announcement about the survey to its email list. The blog post and announcement were subsequently redistributed throughout the internet on different websites and message boards. Participation in the survey was voluntary, and all respondent identities remained strictly confidential. The survey analysis was approved by the Stanford University Institutional Review Board (IRB), which determined that the study could be implemented without further IRB submission because none of the data contained identifiable personal information.

2.2. Study participants

A total of 4196 people responded to the survey, including persons from countries outside the United States. To form a clearly defined cohort for this analysis, the study sample was narrowed to include 2424 of these respondents who met the following six criteria: (1) answered the survey on behalf of themselves or their minor children; (2) resided in the United States; (3) reported their birth year as 1999 or earlier; (4) reported that they have clinically diagnosed Lyme disease; (5) responded to an item asking whether they had experienced chronic subjective symptoms of Lyme disease for six months or more; and (6) reported positive testing for Lyme disease by CDC criteria or other laboratory methods. By applying these inclusion criteria, 1772 cases were excluded from the sample for the following reasons: (1) did not answer on behalf of themselves or their minor children ($n = 624$); (2) resided in countries other than the United States ($n = 175$); (3) had missing birth year or reported being born in 2000 or later ($n = 346$); (4) selected "no" or "I don't know" for having Lyme disease ($n = 211$); (5) had missing data for the item concerning chronic symptoms ($n = 10$); (6) did not report positive testing for Lyme disease by CDC criteria or other laboratory methods ($n = 386$); or (7) were duplicate