

Experience and Knowledge in Lyme Disease:
A Scoping Review of Patient-Provider Communication

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Abstract

Purpose: Limited research exists on the patient-provider communication dynamic with respect to Lyme disease (LD). There is evidence that being informed, on the part of both patient and provider, enhances communication, resulting in better patient satisfaction and higher quality health outcomes. The purpose of this review was to summarize and disseminate current research findings on both patient and provider knowledge and experiences in clinical settings with respect to LD. This included assessing where providers obtain information, where patients obtain information, and if that information is clearly understood and translated between the two groups.

Methods: I conducted a scoping literature review by searching electronic databases PubMed, CINAHL, Scopus, and PsycINFO for articles published between January 2000 and September 2018. **Results:** From a total of 1,960 unique studies, 23 met inclusion criteria and were reviewed. From these 23 articles, I found pertinent concepts, themes, and gaps within five key topic areas related to patient-provider communication: provider knowledge and beliefs, patient knowledge and beliefs, provider experience, patient experience, and patient-provider relationship or interaction. No study specifically addressed the patient-provider communication dynamic with respect to LD. **Conclusion:** I found critical research gaps regarding where patients and providers obtain information on LD and how that information is being translated between these two groups. Future research should assess practice patterns of nurse practitioners and physicians assistants; educational tools providers can use in dialogue with patients; point of care interventions; and shared decision making strategies providers can utilize in communication with LD patients.

Introduction

Lyme disease (LD), a multisystem inflammatory disease, is the most common tickborne disease in the northern hemisphere.¹ It was first recognized in the mid-1970's as the result of a cluster of cases in the eponymous town Old Lyme, Connecticut.² The spirochete *Borrelia burgdorferi sensu stricto* was first identified as the disease-causing bacterium in 1982 by Wilhelm Burgdorfer.³ Today, other bacteria in the genus *Borrelia* have been described that may cause Lyme-like symptoms in humans.⁴⁻⁶

The spirochete is transferred to humans from infected nymphal or adult *Ixodes* ticks.⁷ The bacteria can be transmitted in as little as 24 hours after tick bite attachment, however, transmission risk increases with attachment time.⁸ Ticks infected with *B. burgdorferi* are primarily found in northeastern and upper-midwestern regions of the US, although the range of infected ticks has increased in recent years.⁷ The Centers for Disease Control and Prevention (CDC) reports that approximately 30,000 cases of LD are reported in the US each year.⁹ However, recent estimates made using methodology alternative to standard national surveillance, such as utilizing medical claims databases and commercial laboratory data, report that the incidence of LD in the US may be closer to 300,000 cases per year.^{10,11}

LD is typically described in three stages: early localized, early disseminated, and late-disseminated, although, these stages are theoretical and may not be consistent with clinical findings.^{7,12} Presentation of early LD typically involves fever, chills, headache, fatigue, muscle and joint aches and erythema migrans (EM) rash.¹³ An estimated 70-80% of patients with early LD present with EM rash.^{13,14} Late disseminated LD can occur months to years after the initial infection and may include nervous system, joint, and cardiac manifestations.⁷

The Infectious Disease Society of America (IDSA) practice guidelines state that clinical findings are sufficient for diagnosis of EM rash and Lyme disease infection. However, for a patient without EM rash, a provider must use their clinical judgement to discern if serologic testing is appropriate.¹⁵ Before ordering serologic testing, providers must deem the patient to have high pretest probability of infection, and consider some of the common ‘pitfalls’ of testing: the early period of infection where the antibodies are still developing, thus yielding a negative result, background seropositivity, reinfection, and exposure.¹⁶ When deemed appropriate to test, providers should follow the CDC recommended two-tier laboratory testing procedure including an ELISA screening followed by an IgM or IgG Western Blot (WB) for confirmation.¹⁷ The order in which these tests are performed is also crucial for appropriate interpretation, such that the ELISA must be ordered as a screen, followed by the IgM or IgG WB for confirmation. If two-tiered testing is used according to recommended guidelines, proper interpretation and ordering of serologic testing, like many aspects of LD diagnosis, involves clinical judgement.^{15,16}

LD presents with varying signs and symptoms and can exhibit diversity in its disease course. As a result, it is sometimes difficult for physicians to recognize and diagnose Lyme infections.¹⁸ In addition, the two-tiered serodiagnosis recommended by the CDC is subject to low specificity when used inappropriately, and while not all patients develop the EM rash, those that do can be diagnosed on the basis of clinical presentation.¹⁹

The recommended treatment for early LD includes oral antibiotics (doxycycline, amoxicillin, or cefuroxime axetil) for 10-21 days, though alternative intravenous antibiotic treatment may be necessary for some neurological or cardiac manifestations.^{7,20} When treated with oral antibiotics for the recommended time, many patients recover fully.²¹ However, some patients exhibit non-specific symptoms after the treatment for LD, sometimes referred to as Post-

Treatment Lyme Disease Syndrome (PTLDS).²² Causes of these symptoms are unknown, and these patients rarely show signs of active infection.²² Studies have shown little to no benefit of extended or long-term antibiotic therapy in such cases.²² Further, the diagnosis of Chronic Lyme disease (CLD) has been given to patients both with and without prior LD infection and because of this confusion regarding a clinical definition, the use of CLD as a diagnosis is not supported by IDSA, CDC, NIH and many experts in the field.^{23,24} The International Lyme and Associated Diseases Society (ILADS) controversially maintains support for CLD as a diagnosis and prolonged use of antibiotics as subsequent treatment.²⁵ They do so despite the lack of endorsement for the diagnosis and long term treatment by the CDC and IDSA.

The most recent LD guidelines from the IDSA were published over a decade ago in 2006.¹⁵ The outdated guidelines, coupled with heightened social and conventional media attention on the disease, can yield misleading and conflicting information for both physicians and patients on the diagnosis and treatment of LD.²⁶⁻³¹ Mainstream media and news stories, often with the intention of spreading LD awareness, sensationalize individual accounts.³² This tactic of reporting often considers emotional arguments to carry equal, or more, weight as grounded scientific evidence.³¹ Websites focused on LD often include individual anecdotal evidence or are non-evidence based.³³ Both types of sources, typically focused on the CLD controversy, alternative treatments or testing, are easily accessible to the public and hold the potential to disseminate inaccurate, or confusing information.³¹⁻³³ Much of the scientific literature on LD addresses the clinical presentation of the disease, seeks to understand its biological mechanisms, or assesses the effectiveness of treatment strategies and serological testing. Further, there is a subset of literature focused on the controversial topics of CLD, putative persistence of bacterial

infection after treatment, and the effectiveness of long-term antibiotic use. Little of the published literature focuses on patient-provider communication and interaction with respect to LD.

There is strong evidence that being informed, on the part of both patient and provider, enhances communication.³⁴ Effective patient-physician communication may result in higher-quality health outcomes, better patient satisfaction with care, and lower costs of care.^{35,36} Such evidence dates back to the 1980's where Kaplan et al. demonstrated that diabetes patients who were more participatory in visits subsequently had lower blood pressure and better metabolic control compared to more passive patients.³⁷ Since, studies including a variety of study populations from cancer, to diabetes, to lupus patients have demonstrated that improved communication through the means of intervening variables (patient understanding, patient-provider agreement), improve a variety of health outcomes such a pain, organ damage, emotional well-being, and improved metabolic indicators to name a few.³⁶ Given the lack of updated guidelines, confusion surrounding the clinical management of the disease, and minimum insight on the current status of patient-provider communication, it is important to synthesize what is known about provider and patient experiences and understanding of LD.

I addressed this critical knowledge gap by performing a scoping review of the literature. My goal was to summarize and disseminate the current research findings on both patient and provider knowledge and experiences in clinical settings with respect to LD. This included where providers obtain information, where patients obtain information, and if that information is clearly understood and translated between the two groups.

Methods

I conducted a scoping review of the literature following the Arksey & O'Malley five-stage methodological framework. This included (i) identifying a research question, (ii)

identifying relevant studies, (iii) performing study selection, (iv) charting and collating, and (v) summarizing and reporting results.³⁸ The aim of a scoping review is to map rapidly the key concepts underpinning a research area and the main sources and evidence available.³⁸

Literature Search

I conducted a comprehensive search of the electronic databases PubMed, CINAHL, Scopus, and PsycINFO for articles published between January 2000 and September 2018. Searches were conducted using the general categories: Lyme disease (LD), patient, provider, knowledge and experience, clinical, and combinations of these categories utilizing Boolean operators. The complete search terms and PubMed strategy are outlined in Table 1. Reference lists of articles identified through the database search were reviewed for additional relevant articles. I did not include review articles in the scoping review, but relevant primary sources identified from the reference lists of reviews were included.

Selection Criteria

Articles were included if they: (i) were conducted in the United States; (ii) were an empirical study; (iii) were explicitly conducted with respect to or within a healthcare setting; (iv) examined LD, CLD, PTLDS, or any synonym; and (v) explicitly included an assessment of one or any combination of the following: experience of patient and/or provider, knowledge or understanding of patient and/or provider, perspective of patient and/or provider, or patient-provider communication. Articles were also limited to data collected from at least the year 2000 (after the release of the initial Infectious Disease Society of America (IDSA) guidelines). Studies

that did not meet any one of the above listed inclusion criteria were excluded from the scoping review.

Review Process

The review process was conducted using Covidence online software (Covidence, Melbourne Victoria). After removing duplicates, each article was screened for inclusion by title and abstract by a single reviewer (either AN or EM); the remaining articles underwent a full text review. Each article was screened by two reviewers independently (AN and EM). Conflicts about article inclusion or exclusion, as well as the exclusion criteria applied, were resolved and finalized by the two reviewers.

Data Extraction

Characteristics of the included literature were tagged using ATLAS.ti 8 (ATLAS.ti Scientific Software Development GmbH, Berlin). Document tags were used to categorize type of publication, study type, methods, and study population. A coding outline was developed based on a preliminary review of the full texts, and used to extract quotations from the full text that contributed to the understanding of five general areas of interest: provider knowledge and beliefs, patient knowledge and beliefs, provider experience, patient experience, and patient-provider relationship or interaction. Experience, for the purpose of inclusion in this review, is defined as something personally encountered, undergone, or lived through, or the act or process of directly perceiving events or reality. The distinction was made between provider knowledge and beliefs and provider experience in instances such as testing accuracy based on the evaluation of knowledge and comprehension in didactic form, compared to evaluation of practice patterns.

In this review, experience relates to how knowledge informs provider practice patterns. Although providers may demonstrate appropriate knowledge in a survey or interview setting, their actions and practice patterns may not reflect this background during patient encounters; the distinction between the experience and the knowledge categories was based on this difference.

Results

Summary of Included Articles

As shown in the PRISMA diagram, (Figure 1), a total of 4500 references were imported for screening. After duplicates were removed, 1960 unique studies remained for title and abstract screening. Of these, 148 studies were screened for inclusion via full-text review. A total of 23 articles met the criteria for inclusion in this review.

Of the 23 included documents, two were doctoral dissertations and the remaining 21 were articles published in peer-reviewed journals. These studies include 16 cross-sectional analyses, six qualitative studies, and one prospective cohort study. The studies primarily assessed either the patient perspective (14) or that of the health care provider (9) via their study populations. Of those that assessed the patient perspective, the study populations included: patients with a diagnosis of LD (2), patients with CLD (3), patients with a diagnosis of LD with chronic symptoms (2), US immigrants (2), and the general public (5).

Tables 2-6 summarize the 23 included studies in one of the five key areas of interest. Tables include the relevant articles to the area of interest, study population and number of subjects, methods and study type, main relevant findings, and topic areas. Topic areas include themes that emerged and were coded within the texts of the articles during the coding process.

Provider Knowledge and Beliefs

Of the included articles, eight evaluated clinicians' knowledge and beliefs regarding LD (Table 2). General findings from the articles indicated that health care providers had an overall high understanding of the etiology of LD.³⁹⁻⁴² Many of the studies evaluated provider knowledge through the use of surveys, which often asked the same or similar questions across studies. However, knowledge level varied regarding the signs, symptoms and stages of LD, with percentages of correct answers for these assessments ranging from a low of 50.8% of health care providers⁴⁰ to a high of 70% among West Virginia physicians.^{39,40,42}

Several studies assessed knowledge of appropriate testing recommended by the Centers for Disease Control and Prevention (CDC) through the use of clinical scenarios. These scenarios assessed health care providers' decision making regarding false negatives, patients with non-specific symptoms, and erythema migrans (EM) rash.^{39,40,42,43} Findings from studies that assessed provider knowledge of EM rash indicated that, overall, low percentages of physicians are aware that EM rash itself is diagnostic. Specifically, 49% of Connecticut physicians,⁴⁴ 34.1% of health care providers,⁴⁰ 56% of West Virginia physicians,³⁹ and 25.4% of Arkansas physicians⁴² surveyed were aware that EM rash is itself diagnostic. The articles also assessed provider knowledge of treatment approaches for different clinical scenarios. Across these studies, physicians struggled with clinical scenarios that assessed treatment of long-standing non-specific symptoms, and those that assessed treatment for known recent tick bites with no symptoms.^{39,40,45}

Information on where providers acquire information on LD is very limited. Only two of the eight relevant studies included some information on where providers acquire information on LD. Butler et. al report that providers prefer accessing online manuals.⁴¹ Bakken reported that physicians learn about diagnosis of LD through experience; specifically, through atypical

counter-cases, such as non-disease or disease-like cases, as opposed to typical ‘textbook’ cases.⁴⁶ Although these two studies include information about how providers may theoretically learn to diagnose LD, or would theoretically prefer to access information, no study provided data on where and how providers are acquiring information on LD in practice.

Patient Knowledge and Beliefs

Information on patient knowledge and beliefs regarding Lyme disease (LD) was contained in ten of the included articles (Table 3). Findings from these articles indicated that, generally, the public is aware of the etiology of LD, including that blacklegged ticks (*Ixodes scapularis*) carry the pathogen for LD. However, immigrant populations studied in three articles struggled with this knowledge.⁴⁷⁻⁵⁰ This trend was consistent in patient knowledge of signs and symptoms of LD, with the general populations surveyed being aware of early and late LD symptoms, and immigrant populations struggling to identify signs and symptoms.⁴⁷⁻⁵¹ One study also included information regarding patients’ beliefs of the psychological and mood manifestations of LD. Patients in this study tended to see these not as physical manifestations of disease or an emotional response to their physical limitations, but rather as an ‘interrelated aspect of the illness experience’ with an unknown origin.⁵²

Articles focusing on patient beliefs regarding disease course and chronicity reported that patients believe they (or others) may never fully recover from LD^{50,53} and that the Lyme bacteria can still persist in the body after antibiotic treatment.⁵⁰ When asked about perceived likelihood to recover using the scale 0 ‘will never recover’ to 100 ‘will completely recover,’ the mean among patients with CLD was 31.⁵³ Study populations in articles that addressed patient understanding and beliefs regarding treatment for LD generally understood that antibiotics were the appropriate

treatment for LD; however, these subjects also demonstrated doubt about the ability of antibiotics to cure LD. Many believed that long-term antibiotics are useful for LD treatment.^{47,48,50}

Six of the ten articles included information on where patients and the public gather information on LD. Mostly, patients reported learning from experience (e.g., from having LD or knowing someone who had it).^{47,50} Many patients reported feeling responsible to educate others^{50,52,54} and themselves.^{54,55} One article assessed the 100 most viewed YouTube videos on LD, noting that while many LD videos exist on YouTube, academic and government sources represented only 1.8% of the available content.⁵⁶

Provider Experience

In the seven articles assessing provider experience with respect to LD, providers expressed uncertainty regarding either testing^{43,57} or the diagnosis and presentation (Table 4).⁴⁶ Treatment practices of physicians regarding tick bite prophylaxis (antibiotic treatment for prevention of LD after a recognized tick bite) and treatment for EM rash were also assessed.^{44,45} Surprisingly, Hill and Holmes found that 39.6% of physicians in Arkansas reported initiating treatment when they did not believe LD was present.⁴²

Of the articles that assessed provider experience with diagnosis, inappropriate testing practices were commonly reported, with 49% of physicians surveyed in Connecticut reporting that they had ordered serology for patients with EM rash.⁴⁴ Ramsey and others found that 53% of tests ordered by physicians were discretionary, and 27% were inappropriate.⁵⁷ The role of experience in diagnosis was addressed in these studies, finding that increased experience with LD increased the likelihood of a physician to test for LD.^{42,44} Further, Bakken found that

physicians learn to diagnose problems through a learning loop in which increased experience (specifically with aforementioned counter-cases) contributes to the physicians' diagnostic learning process.⁴⁶ However, as opposed to the other four articles, Singh and colleagues found that knowledge of West Virginia clinicians was not associated with experience (patients seen per week or years in practice).³⁹

Patient Experience

Patients' experience with LD was a theme relevant to ten of the included articles (Table 5). Most of these articles addressed the provider(s) seen throughout the experience of gaining a LD diagnosis. This included seeing a large number of providers and types of specialists.^{52,54,55,58,59} Often patients reported feeling frustrated with their primary care provider and seeking out new providers or treatment from a Lyme specialist.^{53,54} In respect to testing, patients reported getting multiple tests,⁵⁴ as well as unconventional testing.^{55,58} Patients typically reported the decision to consult a health care provider was due to finding a tick or a rash.^{59,60} Reasons for delay in consulting a medical professional included financial reasons and appraisal delay, defined as a gap between first symptoms and recognition that they were ill.⁵⁹ Patients often experienced multiple misdiagnoses before arriving at a diagnosis of LD.^{55,59} Four of the studies covered the emotional nature of LD diagnosis. Patients expressed that the road to diagnosis is long and frustrating.^{52,54,55} Many patients felt relief to have a diagnosis and the diagnosis left them with a feeling of validation.⁵³⁻⁵⁵

Articles assessing patient experience with treatment included experience with antibiotic treatment, such as length of treatment, prolonged treatment, and retreatment.^{53,60,61} Patients with chronic symptoms often reported use of unconventional therapies due to negative experiences in

mainstream healthcare^{53,55} or the belief that unconventional therapies were key to healing from CLD.⁵⁵ Patients reported having to travel long distances for treatment.^{54,58} Further, patients had trouble receiving insurance coverage and what they felt was appropriate care.^{53,54,58}

A common theme relating to disease experience, course, and outcomes was that patients expressed having uncertainties regarding their LD. They doubted the severity of their illness or symptoms, and were unsure of themselves and their medical decisions.^{50,52,59} Further, patients expressed uncertainty about the present and future, including doubts about if they will recover, the normalcy of their illness experience, and if their LD was actually gone.^{50,52,53} Common emotions felt by patients throughout their disease experience included frustration, hurt, and anger.⁵² Patients often experienced polarizing feelings of hope or optimism and despondence throughout the disease experience.⁵²⁻⁵⁵

Social and financial burden of disease was a common component of the disease experience. Patients frequently felt social isolation and lack of support due to their illness.^{52,53,55} Four articles noted that the social burden of disease included the effect of CLD on their ability to work.^{53,59} and that CLD resulted in a seriously altered quality of life.^{52,53,55} Financial burden of disease included difficulty getting insurance coverage.^{54,58} Further, the cost of care was expensive and patients reported experiencing financial worry.⁵³⁻⁵⁵ Patients expressed that the combination of missing work due to LD and the high cost of care led them to apply for disability coverage.^{53,54,58}

Patient-Provider Interaction & Relationships

None of the included articles specifically addressed patient-provider interaction and relationships as the main objective. However, in nine of the included articles, themes regarding

patient-provider interaction and relationships were prevalent. These themes included contrasting relationships with providers, patient self-advocacy, and provider experiences of pressure from patients.

Four articles addressed the topic that patients typically experience contrasting relationships with providers during their journey with LD (Table 6). These included mention of positive compared to negative interactions. Bakken found that from the provider perspective, knowing a patient's history and background is a significant factor in framing a diagnostic problem and contributes to a positive interaction and likelihood of accurate diagnosis.⁴⁶ From articles that presented the patient perspective, positive interactions included providers who patients felt were supportive, attentive, good listeners, and validated the patients' experience, symptoms, and, or, feelings.^{53,55} Often times, patients found this in alternative or mental health providers rather than mainstream primary or specialty care healthcare providers.^{53,55} Patients often expressed having had negative interactions with health care providers.^{52,53,55} The studies which reported patients' negative interaction commonly found that these experiences included physicians who patients felt were dismissive, condescending, patronizing, and left patients feeling invalidated.^{52,53,55}

Patient self-advocacy was a theme that emerged in four of the studies. This included patients themselves suggesting LD as a diagnosis to their physician.^{46,54} Further, these studies reported that patients felt they were required to be their own advocates and make important medical decisions themselves.^{52,54,55} Rebman and colleagues found that patients with chronic symptoms reported that this sense of responsibility and self-advocacy or reliance was promoted by the pervasive uncertainty surrounding a diagnosis of CLD/PTLDS in the medical community.⁵²

Comparatively, five articles reported that providers frequently, or at some point, felt pressure or received suggestions from patients regarding LD diagnosis, testing, or treatment. This included patients either requesting LD serologic testing (LDST),⁵⁷ non-standard serology,⁴³ tick bite prophylaxis or other treatment for LD,^{42,45} or patients introducing the idea of a LD diagnosis.⁴² Ramsey et al. found that such patient-initiated LDST testing was more likely to be inappropriate than that initiated by clinicians.⁵⁷ A Vermont provider reported that often patients who requested nonstandard serology would eventually see a ‘Lyme Literate MD.’⁴³

Discussion

Of the articles included from the review, five main themes relating to knowledge, beliefs, and experiences of both patients and providers emerged. These five themes together with document characteristics attempt to answer the three outlined review questions: where do providers obtain information, where do patients obtain information, and how is that information translated between the two groups. Five key gaps in the literature were found related to these three questions and are summarized in Table 7, along with recommendations to address these gaps.

Where Do Providers Obtain Information?

With respect provider knowledge and perspective on LD, the studies demonstrated fairly consistent and concerning knowledge patterns among providers. Areas that providers commonly struggle with include recognition and diagnosis of erythema migrans (EM) rash and how to proceed with patients who have non-specific and long-standing symptoms.^{39,40,42,43} Despite Bakken’s qualitative study showing that providers learn to diagnose LD from experience and their peers, there was no published study which assessed where providers are acquiring their

knowledge on LD.⁴⁶ Additional information in this area would provide insight on the cause of the apparent wide range and clear gaps in LD knowledge among health care providers.

Not only do we not understand where physicians are gaining their LD information, but we also do not understand how and if they are able to incorporate knowledge gained into practice. As reported in four articles, providers often felt pressure from patients to test or treat for LD despite not believing that testing or treatment was the clinically appropriate protocol.^{42,43,45,57} Further, a high percentage of Arkansas physicians reported initiating treatment against their own clinical judgement.⁴² This dynamic of uncertainty and inconsistent practice patterns related to LD testing and treatment mirrors physician experiences in other areas of clinical uncertainty, such as identifying and treating low vitamin D status.⁶² Further research should assess what continuing education and point of care resources providers are using, and how they incorporate these into their practice. Gaining more information in this area would not only help to understand the misalignment between knowledge and practice patterns, but also would carry implications for how providers educate and engage in dialogue with future patients.

Of further importance is a clear gap in study populations among providers studied: we do not understand the knowledge and practice patterns of Nurse Practitioner (NP), or Physician Assistant (PA) providers, who may often see LD patients. In respect to the provider knowledge category, four out of eight studies exclusively assessed physicians. Of those that included NPs or PAs in the assessment, this group represented only a small percentage, with ranges from 16% to 34% of total providers studied.^{41,45} A dissertation by Greseth was the only included study which exclusively assessed nurses, NPs, or PAs; the results of this study contained the lowest knowledge scores of all healthcare provider knowledge assessments represented.⁴⁰ This demonstrates a clear gap in the literature regarding a specific and important study population.

Prompt treatment in the acute phase can prevent spread of *B. burgdorferi* infection to joints, the heart, and nervous system, and thus potential longstanding and multi-system symptoms.⁶³ NPs assess, diagnose, treat, and manage acute episodic and chronic illness.⁶⁴ PAs take medical histories, perform physical exams, order and interpret laboratory tests, diagnose illness, and manage treatment plans for patients.⁶⁵ Acute LD presentation is well within the scope of practice for NPs and PAs. Understanding their knowledge and practice patterns is important for developing targeted educational interventions, preventing misdiagnosis, and avoiding preventable longstanding symptoms.

Where Do Patients Obtain Information?

Patients and the public report gaining the majority of their information from peers or family members who have had LD.^{47,50} However, high percentages reported inaccurate beliefs regarding LD treatment, disease progression, and chronicity.^{47,48,50,53} It is clear that patients, particularly those identifying with CLD, have a highly conceptualized and personal understanding of their disease and disease experience, meaning that they gather their information about the disease from their own personal, familial, or peer experiences.^{47,50} Further, they feel responsible to educate and share their LD experience, knowledge, and beliefs with others.^{50,52,54} Few survey respondents or patients with LD reported gathering information from their providers, pamphlets, or other messaging created specifically by healthcare providers.^{47,50,52,54-56} In the study by Basch et al. which studied the 100 most viewed YouTube videos related to LD, none of the top 100 were created by healthcare providers.⁵⁶ Of the 100 most viewed, they found criteria, such as celebrity presence, was correlated with increased number of views.⁵⁶ Evaluating why information from the medical community is viewed as less trustworthy, or at least not as salient,

as that gathered by word of mouth, and identifying the information gathering patterns of patients could be used to enhance health messaging and, thus, improve the accuracy of information and beliefs within the LD patient and surrounding communities.

How is this Information Translated between the Two Groups?

Conspicuously lacking from the published literature was a study that specifically addressed the patient-provider communication dynamic with respect to LD. However, experiences reported by patients and providers allude to an interesting dynamic between CLD or LD patients with chronic symptoms and providers. Patients report negative and polarizing experiences in mainstream healthcare settings.^{52,53,55} Providers feel pressure to accommodate patient wishes when counter to their professional opinion.^{42,43,45,57} Further, feelings of frustration or invalidation from providers perceived as paternalistic often result in patients opting to leave mainstream medicine for alternative, or ‘Lyme literate’, providers.^{52–55} Alternatively, providers lacking an effective way to discuss treatment or testing that goes against medical advice may acquiesce to the patients’ wishes.

It is clear from these qualitative studies that additional evidence is needed on tools that can support productive dialogues between patients and providers. The negative experiences reported by patients, which led to the departure from mainstream healthcare treatment and providers, is concerning. Lantos and others found that, of the 30 alternative therapies recommended for LD on the internet, none are backed by evidence meeting the standards by which the scientific community accepts or rejects new treatments, and some are potentially harmful.²⁹ This highlights the importance of exploring the patient-provider communication dynamic and evaluating shared decision-making tools, or point of care interventions, to support

constructive communication between patients and doctors. Shared decision making, for example, is a patient-centered approach that has potential as an effective option with clinical benefits for cancer screening, diabetes, and other serious illness.⁶⁶⁻⁶⁸ Due to the patient engagement and voicing of patient concern incorporated in shared decision making, this could be a worthwhile future avenue to explore with LD patients with chronic symptoms or identifying with a diagnosis of CLD.

It is important to also consider that the majority of the qualitative studies that addressed patient experience included patients with CLD or chronic symptoms. Only one of these qualitative studies represented a population of patients with acute LD. We do not, therefore, understand the experiences of the general patient population that come into contact with LD but are not CLD/chronic symptoms patients. The majority of patients who present with acute LD, and are diagnosed and treated appropriately, do not progress to chronic or prolonged symptoms.^{7,24,61} Future studies focusing on non-CLD patients will help us more fully understand the patient-provider communication dynamics with respect to LD.

Conclusion:

The objective of this scoping review was to summarize and disseminate current research on patient and provider experiences in the clinical setting with respect to Lyme disease (LD). This includes where providers obtain information, where patients obtain information, and if and how that information is understood and translated between the two groups. Despite the fact that understanding these dynamics is critical to improving LD patient care, I found major research gaps in all three of these areas.

In general, the literature is disproportionately focused on patient experience and knowledge compared to that of providers. Only nine articles with providers as the study

population we identified, as compared to 14 patient focused articles. There should be a greater focus on provider knowledge and experience with respect to LD. Future studies should focus on where physicians gain information and how they translate it into their practice. In addition, understanding the knowledge and practice patterns of NPs and PAs would allow for directed interventions for those providers often seeing acute presentations of LD. What tools and resources providers use to educate patients, and the content of clinical encounter discussions on LD, should be explored. Further, understanding why patients often seek information from sources outside of the medical community may aid in developing and enhancing health messaging related to LD. Lastly, negative and polarizing patient experiences juxtaposed with uncertainty in provider experiences may produce poor health outcomes for patients with chronic symptoms.

Ultimately, we lack research that seeks to understand the dynamic of a patient with LD communicating with their provider. Future research should explore this area to identify where this communication dynamic can be strengthened or improved. Other areas of study have shown that improving patient-provider communication can lead to better health outcomes and patient satisfaction.^{35,69} It is, therefore, important to understand and improve this dynamic related to LD.

Figures and Tables

Figure 1: PRISMA Flow diagram

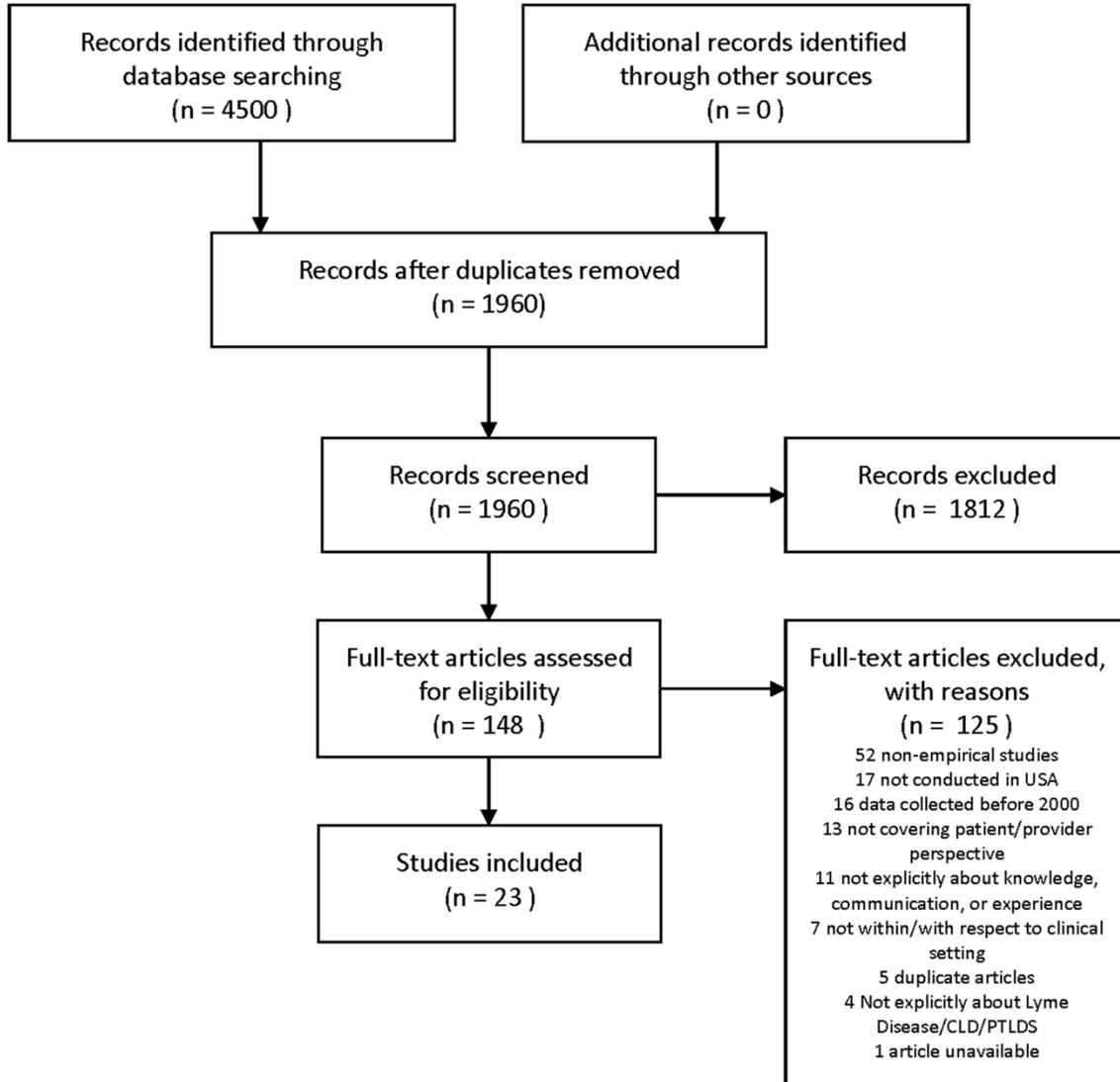


Figure 1 The PRISMA flow diagram for the systematic review details articles retrieved from databases, abstracts screened, full texts retrieved and reviewed, and articles included. Articles excluded based on abstract screen met at least one exclusion factor.

Table 1: PubMed Search Strategy

1	((Lyme[mesh]) OR (lyme[tiab]) OR (chronic lyme disease[tiab]) OR (post treatment lyme disease syndrome[tiab]))
2	((communication[mesh]) OR (communication[tiab]) OR (knowledge[tiab]) OR (experience*[tiab]) OR (belief*[tiab]) OR (attitude*[tiab]) OR (perspective*[tiab]) OR (understanding[tiab]) OR (practice*[tiab]) OR (education[tiab]) OR (perception[tiab]) OR (encounter*[tiab]) OR (learn*[tiab]) OR (aware*[tiab]))
3	((patient*[mesh]) OR (patient*[tiab]) OR (public[tiab]) OR (community[tiab]) OR (resident*[tiab]) OR (client[tiab]) OR (individual*[tiab]))
4	((provider[mesh]) OR (provider*[tiab]) OR (physician*[tiab]) OR (doctor[tiab]) OR (clinician[tiab]) OR (practitioner*[tiab]) OR (healthcare provider[tiab]) OR (healthcare professional[tiab]))
5	((clinical[mesh]) OR (clinic*[tiab]) OR (practice*[tiab]) OR (family medicine[tiab]) OR (urgent care[tiab]) OR (primary care[tiab]) OR (healthcare[tiab]) OR (emergency room[tiab]) OR (general practice[tiab]) OR (health center*[tiab]))
6	1 AND 2 AND 3
7	1 AND 2 AND 4
8	1 AND 2 AND 5

Table 1. PubMed Search Strategy. Searches were conducted using the general categories: Lyme disease (LD), patient, provider, knowledge and experience, clinical, and combinations of these categories utilizing Boolean operators. Terms [mesh] and [tiab] are terms which direct the database to include search terms if they are included as a mesh term or are included in the title/abstract respectively.

Table 2: Provider Knowledge and Beliefs

Provider Knowledge & Beliefs					
Author (year)	Study Population	Sample Size	Study Design; Methods	Relevant Main Findings	Topic Areas
Conant et al. (2018) ⁴³	VT Clinicians	144	Cross-Sectional; mixed methods (survey & observation of calls to testing center)	<ul style="list-style-type: none"> • Most physicians demonstrated basic knowledge of diagnostic protocols • Many misinterpreted WB results: 42.4% incorrectly interpreted positive IgM results as overall positive in a patient with longstanding symptoms • 10.5%, 46.1%, and 57.9% of participants correctly identified engorged adult female blacklegged tick, dog tick, and lone star tick respectively at baseline 	<ul style="list-style-type: none"> • Testing • EM rash
Butler et al. (2017) ⁴¹	Primary Care Providers from endemic states	76	Cross-sectional; Identification of ticks with and without manual & knowledge questionnaire	<ul style="list-style-type: none"> • Use of the manual significantly improved identification of ticks; participants reported they would use the manual in practice if made available 	<ul style="list-style-type: none"> • Etiology • Where acquiring information
Gresseth (2017) ⁴⁰	Health care providers (HCPs)	305	Cross-Sectional; Questionnaire	<ul style="list-style-type: none"> • Health care providers (HCPs) were knowledgeable about etiology of disease and testing protocols • HCPs had lesser knowledge of signs and symptoms; only 34.1% of HCPs knew EM is diagnostic for LD • HCPs struggled identifying correct prophylactic and acute LD treatments, and understanding clinical scenarios where appropriate to treat with antibiotics (51% or lower for each scenario) • Overall, physicians answered 70% of etiology and signs and symptoms knowledge questions correctly • 27.8-47.5% (depending on specialty) answered correctly that CDC recommends ELISA and WB 2-tiered testing • 42-50% of WV physicians correctly interpreted a clinical scenario about a patient with long-standing non-specific symptoms and negative test results • 56% of physicians knew that EM is diagnostic for LD 	<ul style="list-style-type: none"> • Etiology • Disease Course • Signs and Symptoms • Testing • EM rash • Treatment
Singh et al. (2016) ³⁹	WV physicians (varying specialty)	91	Cross-Sectional; Survey	<ul style="list-style-type: none"> • HCPs from high incident states more likely to prescribe one dose doxycycline for prophylaxis than those from low incidence states • 48% of physicians said they would not prescribe antibiotics for tick bite prophylaxis and would tell patient to stay alert for fever and rash 	<ul style="list-style-type: none"> • Etiology • Signs and Symptoms • Testing • EM rash • Treatment
Perea et al. (2014) ⁴⁵	Primary care providers	1485	Cross-sectional; survey	<ul style="list-style-type: none"> • Respondents had a correct response rate of 59.1% for symptom recognition, 46.2% for knowledge of recommended testing processes, and for 78.9% for knowing LD is a reportable disease 	<ul style="list-style-type: none"> • Treatment • Etiology • Signs and Symptoms • Testing • EM rash
Hill & Holmes (2014) ⁴²	Arkansas Primary Care Physicians	660	Cross-sectional; survey	<ul style="list-style-type: none"> • Serology for patients with EM rash was ordered more frequently by CT physicians who saw 1-3 cases per year than those who saw 4 or more • Learning to diagnose LD occurs via a learning loop Unusual cases are prompt them to look up more information about LD • These cases are used in subsequent patient encounters and when engaging with colleagues 	<ul style="list-style-type: none"> • EM rash
Murray et al. (2001) ⁴⁴	Primary care physicians from CT	267	Cross-sectional; Survey	<ul style="list-style-type: none"> • Serology for patients with EM rash was ordered more frequently by CT physicians who saw 1-3 cases per year than those who saw 4 or more • Learning to diagnose LD occurs via a learning loop Unusual cases are prompt them to look up more information about LD • These cases are used in subsequent patient encounters and when engaging with colleagues 	<ul style="list-style-type: none"> • EM rash
Bakken (2002) ⁴⁶	Physicians (varying specialty)	9	Qualitative; semi-structured interview	<ul style="list-style-type: none"> • Serology for patients with EM rash was ordered more frequently by CT physicians who saw 1-3 cases per year than those who saw 4 or more • Learning to diagnose LD occurs via a learning loop Unusual cases are prompt them to look up more information about LD • These cases are used in subsequent patient encounters and when engaging with colleagues 	<ul style="list-style-type: none"> • Where acquiring information

Table 2. Provider Knowledge and Beliefs: included articles that contain information relevant to provider knowledge and beliefs. With the article is listed important information regarding study population, and methods. Main relevant finding were extracted from full texts of the article. Topic areas indicate themes that emerged and were coded within the full texts during the coding process.

Table 3: Patient Knowledge and Beliefs

Patient Knowledge & Beliefs					
Author (year)	Study Population	Sample Size	Study Design; Methods	Relevant Main Findings	Topic Areas
Rebman et al. (2017) ⁵²	Patients with LD and chronic symptoms	29	Qualitative; interview	<ul style="list-style-type: none"> Cognitive and mood changes in patients with chronic symptoms are seen as an interrelated aspects of the 'illness experience' with an unknown origin Patients were aware of the contested nature of their diagnosis 	<ul style="list-style-type: none"> Signs and Symptoms Disease course and chronicity Acquiring info
Basch et al. (2017) ⁵⁶	YouTube Videos	100	Cross sectional; manual coding of 100 most viewed videos	<ul style="list-style-type: none"> The majority of the 100 most popular YouTube videos were not created by health professionals Together, the 100 most viewed YouTube videos about LD were viewed 10,380,848 times 	<ul style="list-style-type: none"> Acquiring info
Butler et al. (2016) ⁴⁷	CT general public	275	Cross-sectional; survey	<ul style="list-style-type: none"> Overall knowledge of tickborne disease was poor; the average knowledge score was 57% Average proportion of correct knowledge questions is significantly higher for those who had been treated for tickborne illness (64.7%) vs. never been treated (55.0%) p = 0.001 	<ul style="list-style-type: none"> Etiology Signs and Symptoms Treatment Acquiring Info Etiology Signs and Symptoms Treatment
Valente et al. (2015) ⁴⁸	Martha's Vineyard MA General Public	946	Cross-sectional; survey	<ul style="list-style-type: none"> Overall knowledge of tickborne illness was poor 37% of respondents reported not knowing the late symptoms of untreated LD or early treatment options (49%) 	<ul style="list-style-type: none"> Signs and Symptoms Treatment
Green (2015) ⁵⁵	Patients with CLD	6	Qualitative; Interview	<ul style="list-style-type: none"> Participants explained that learning about CLD was critical to healing from it Self educating about CLD came from various sources: books by experts, conferences about CLD, documentaries, and the internet 	<ul style="list-style-type: none"> Acquiring info
Ali et al. (2014) ⁵³	Patients with CLD	12	Qualitative; Interview	<ul style="list-style-type: none"> Patients were asked about their perceived likelihood to recover using the scale: 0 = will never recover, 100 = will recover completely. The mean score was 31; this perceived likelihood of recover was related to their beliefs surrounding the pathogenesis of CLD Patients expressed the belief that you never recover completely 	<ul style="list-style-type: none"> Disease course and chronicity Etiology Signs and symptoms
Macauda et al. (2011) ⁵⁰	general public (endemic area)	421	Cross-sectional; mixed-methods (interview & survey)	<ul style="list-style-type: none"> Most participants believe that both symptoms and the bacteria can persist after antibiotic therapy Personal experience with LD was cited as the main source of information for LD knowledge & beliefs 	<ul style="list-style-type: none"> Disease course and chronicity Treatment Acquiring info
Heller et al. (2010) ⁵¹	US Immigrants	103	Cross-sectional; Survey	<ul style="list-style-type: none"> 62% of participants were not certain they could recognize the signs/symptoms of LD 	<ul style="list-style-type: none"> Signs and Symptoms
Drew & Hewitt (2006) ⁵⁴	Patients with CLD	10	Qualitative; interview	<ul style="list-style-type: none"> Patients expressed the need to be your own advocate and educate yourself and others 	<ul style="list-style-type: none"> Acquiring info
Jenks & Trapasso (2005) ⁴⁹	US immigrants	80	Cross-sectional; survey	<ul style="list-style-type: none"> 27.5% of respondents were aware that ticks from the region could carry infection None of the new participants surveyed were aware of LD 	<ul style="list-style-type: none"> Etiology Signs and Symptoms

Table 3. Patient Knowledge and Beliefs: included articles that contain information relevant to patient knowledge and beliefs. With the article is listed important information regarding study population, and methods. Main relevant findings were extracted from full texts of the article. Topic areas indicate themes that emerged and were coded within the full text during the coding process.

Table 4: Provider Experience

Provider Experience					
Author (year)	Study Population	Sample Size	Study Design; Methods	Relevant Main Findings	Topic Areas
Conant et al. (2018) ⁴³	VT clinicians (varying specialty)	144	Cross-Sectional; mixed methods (survey & observation of calls to testing center)	<ul style="list-style-type: none"> Physicians expressed confusion interpreting testing for positive IgM WB in patient with longstanding symptoms (44.4%) and confusion in individually positive WB bands in context of overall negative test results (46.5%) Free standing answers by VT physicians expressed uncertainty or lack of knowledge about LD testing 	<ul style="list-style-type: none"> Feelings of uncertainty
Singh et al. (2016) ³⁹	WV physicians (varying specialty)	91	Cross-Sectional; Survey	<ul style="list-style-type: none"> Clinician’s knowledge of LD was not associated with factors such as medical specialty, number of patients seen per week, or number of years in practice 	<ul style="list-style-type: none"> Diagnosis: Learning from Experience
Perea et al. (2014) ⁴⁵	Primary care providers	1485	Cross-sectional; survey	<ul style="list-style-type: none"> Most common reported reasons for tick bite prophylaxis was to prevent LD (76.9%) and because patients request (40.4%) 56.4% reported prescribing tick bite prophylaxis in past year, but overall their practices do not align well with current recommendations 	<ul style="list-style-type: none"> Treatment practices
Hill & Holmes (2014) ⁴²	Arkansas Primary Care Physicians	660	Cross-sectional; survey	<ul style="list-style-type: none"> 39.6% reported that they initiated treatment for LD when they did not believe LD was present and 52.3% reported that patients often brought up possibility of LD as a diagnosis Years in practice is a confounding variable for assessment of performing additional testing if initial was negative (OR of 0.875) 	<ul style="list-style-type: none"> Treatment practices Diagnosis: Learning from experience
Ramsey et al. (2004) ⁵⁷	physicians (varying specialty)	356	Cross-Sectional; mixed methods (questionnaire & assessment of serologic testing sent to lab)	<ul style="list-style-type: none"> Of serology ordered by physicians, 20% was found to be appropriate, 27% inappropriate, and 53% discretionary Specialty (emergency room/urgent care) and known or suspected preceding tick bite strongly associated with inappropriate testing Repetitive, similar, and counter experiences, combined with cognitive knowledge, contribute to the framework for how a physician frames a problem and influence how the problem is framed along a continuum of familiarity. Experiences serve as information that influences diagnostic decisions and physicians’ behaviors 	<ul style="list-style-type: none"> Feelings of uncertainty Diagnosis: Testing practices Feelings of uncertainty Diagnosis: Learning from Experience
Bakken (2002) ⁴⁶	Physicians (varying specialty)	9	Qualitative; semi-structured interview	<ul style="list-style-type: none"> Most physicians followed guidelines for treating patients with EM, however, many physicians do serologic testing for patients with tick-bites or EM (Serology ordered for 49% of patients with EM) Most physicians do not use prophylaxis for patients with blacklegged tick bites 26% of the surveyed physicians prescribed antibiotic prophylaxis for patients with tick bites. <i>B burgdorferi</i> serology was ordered by 31% of physicians for patients with tick bites 	<ul style="list-style-type: none"> Treatment practices Diagnosis: Testing Practices Diagnosis: Learning from Experience
Murray et al. (2001) ⁴⁴	Primary care physicians from CT	267	Cross-sectional; Survey	<ul style="list-style-type: none"> Most physicians followed guidelines for treating patients with EM, however, many physicians do serologic testing for patients with tick-bites or EM (Serology ordered for 49% of patients with EM) Most physicians do not use prophylaxis for patients with blacklegged tick bites 26% of the surveyed physicians prescribed antibiotic prophylaxis for patients with tick bites. <i>B burgdorferi</i> serology was ordered by 31% of physicians for patients with tick bites 	<ul style="list-style-type: none"> Treatment practices Diagnosis: Testing Practices Diagnosis: Learning from Experience

Table 4. Provider Experience: included articles that contain information relevant to provider experience. With the article is listed important information regarding study population, and methods. Main relevant finding were extracted from full texts of the article. Topic areas indicate themes that emerged and were coded within the full text during the coding process.

Table 5: Patient Experience

Patient Experience					
Author (year)	Study Population	Sample Size	Study Design; Methods	Relevant Main Findings	Topic Areas
Hirsch et al. (2018) ⁵⁹	Patients with diagnosis of LD	26	Qualitative; interview	<ul style="list-style-type: none"> • Patients experienced uncertainty early on about their symptoms. They often misattributed symptoms to minor injuries, or influenza. delaying time to diagnosis • Commonly reported appraisal delay • Delays between first visit with HCP due to LD symptoms and treatment for LD were generally reported to be result of misdiagnosis • Most common reason for gap between recognition of being ill and seeking care was lack of health insurance or financial 	<ul style="list-style-type: none"> • Diagnosis: • Disease experience, course, and outcomes • Social & Financial Burden
Rebman et al. (2017) ⁵²	Patients with LD and chronic symptoms	29	Qualitative; interview	<p>Three predominant themes emerged:</p> <ul style="list-style-type: none"> • Physical and social limitations lead to fundamental shifts in ‘ways of being in the world’ • Symptom and illness invisibility affect social support • Pervasive medical uncertainty regarding PTLDS/CLD promotes an increased sense of personal responsibility for care 	<ul style="list-style-type: none"> • Diagnosis: • Disease experience, course, outcomes: • Social & Financial burden
Bechtold et al. (2017) ⁶¹	Patients with diagnosis of LD	133	Prospective; patients with confirmed early LD symptom and QOL measures over time	<ul style="list-style-type: none"> • 8/107 cases were retreated with antibiotics due to new objective findings, or EM rash did not fade after treatment, or new rash; 2 were PTLDS patients, 6 were non PTLDS • Findings suggest that ideally-treated early LD patients recover well and experience symptom resolution over time, though a small subgroup continue to suffer with symptoms that lead to functional decline • Patients saw many HCPs, were subject to repetitive testing & received many different diagnoses before getting a diagnosis of CLD • Most participants had negative experiences with mainstream healthcare providers; this and ongoing symptoms drove them to seek Lyme literate MDs or alternative care providers • Finding the right healing modality often came through alternative therapies • CLD causes psychological distress; stigma or lack of support make it worse • Common theme emerging was that treatment for CLD was expensive with 4/6 participants reporting that financial cost was major barrier to healing 	<ul style="list-style-type: none"> • Disease experience, course, and outcomes • Treatment
Green (2015) ⁵⁵	Patients with CLD	6	Qualitative; Interview	<ul style="list-style-type: none"> • 10.1% of respondents who had found tick on them or family member during previous year sought medical attention • Reported lengths of antibiotic treatments: 39.0% reported <4 weeks; 20.3% 5-8 weeks; >8 weeks 35.6% <p>Four major themes emerged:</p> <ul style="list-style-type: none"> • Changes in health status and the social impact of chronic LD • Doubts about recovery and the future • Contrasting doctor-patient relationships • The use of unconventional therapies to treat CLD 	<ul style="list-style-type: none"> • Diagnosis • Treatment • Disease experience, course, and outcomes • Social & Financial Burden
Hook et al. (2015) ⁶⁰	General public	12283	Cross-Sectional; survey	<ul style="list-style-type: none"> • 10.1% of respondents who had found tick on them or family member during previous year sought medical attention • Reported lengths of antibiotic treatments: 39.0% reported <4 weeks; 20.3% 5-8 weeks; >8 weeks 35.6% <p>Four major themes emerged:</p> <ul style="list-style-type: none"> • Changes in health status and the social impact of chronic LD • Doubts about recovery and the future • Contrasting doctor-patient relationships • The use of unconventional therapies to treat CLD 	<ul style="list-style-type: none"> • Diagnosis • Treatment • Disease experience, course, and outcomes • Social & Financial Burden
Ali et al. (2014) ⁵³	Patients with CLD	12	Qualitative; Interview	<ul style="list-style-type: none"> • 10.1% of respondents who had found tick on them or family member during previous year sought medical attention • Reported lengths of antibiotic treatments: 39.0% reported <4 weeks; 20.3% 5-8 weeks; >8 weeks 35.6% <p>Four major themes emerged:</p> <ul style="list-style-type: none"> • Changes in health status and the social impact of chronic LD • Doubts about recovery and the future • Contrasting doctor-patient relationships • The use of unconventional therapies to treat CLD 	<ul style="list-style-type: none"> • Diagnosis • Treatment • Disease experience, course, and outcomes • Social & Financial Burden

Johnson et al. (2011) ⁵⁸	Patients with LD and chronic symptoms	2424	Cross-Sectional; survey	<ul style="list-style-type: none"> • Half of the respondents reported seeing at least seven physicians before a diagnosis of LD • Nearly half had LD for more than 10 years and traveled over 50 miles to obtain treatment • Symptoms lasting six months or more despite antibiotic treatment • A quarter of respondents had been on public support or received disability benefits due to LD symptoms 	<ul style="list-style-type: none"> • Diagnosis • Treatment • Social & Financial Burden
Macauda et al. (2011) ⁵⁰	general public (endemic area)	421	cross-sectional; mixed-methods (interview & survey)	<ul style="list-style-type: none"> • As symptoms persist, patients are unsure if symptoms are just of everyday rundown from life, or still lasting symptoms of LD • 48% of Brazilian population surveyed in MV reported being ill and not seeing doctor, reasons included: lack of money or health insurance (41%) lack of time (30%) 	<ul style="list-style-type: none"> • Disease experience, course, and outcomes • Social & Financial Burden • Diagnosis
Heller et al. (2010) ⁵¹	US Immigrants	103	Cross-sectional; Survey	<ul style="list-style-type: none"> • Participants expressed feelings of frustration • Long road to diagnosis. • Multiple diagnostic tests and numerous health care providers. • Financial stress. • Self-advocacy and validation when a diagnosis was made. • Despite the chronicity of their illness, hopefulness for their future. 	<ul style="list-style-type: none"> • Diagnosis • Treatment: • Disease experience, course, and outcomes • Social & Financial Burden
Drew & Hewitt (2006) ⁵⁴	Patients with CLD	10	Qualitative; interview		

Table 5. Patient Experience: included articles that contain information relevant to patient experience. With the article is listed important information regarding study population, and methods. Main relevant finding were extracted from full texts of the article. Topic areas indicate themes that emerged and were coded within the full text during the coding process.

Table 6: Patient-Provider Interaction and Relationships

Patient-Provider Interaction and Relationships						
Author (year)	Study Population	Sample Size	Study Design; Methods	Main Findings	Topic Areas	
Conant et al. (2018) ⁴³	VT Clinicians (varying specialty)	144	Cross-Sectional; mixed methods (survey & observation of calls to testing center)	<ul style="list-style-type: none"> • 38.2% of Physician reported having experienced patient request for unvalidated tests 	<ul style="list-style-type: none"> • Patient suggestion & Pressure • Contrasting Relationships with Providers • Patient Self-Advocacy 	
Rebman et al. (2017) ⁵²	Patients with LD and chronic symptoms	29	Qualitative; interview	<ul style="list-style-type: none"> • Many felt that physicians didn't even believe what they were saying • Patients reported that physicians often 'threw in the towel early' or were unsure of what to do next, leaving the patients with a great amount of personal responsibility about the future of their health 	<ul style="list-style-type: none"> • Contrasting Relationships with Providers • Patient Self-Advocacy 	
Green (2015) ⁵⁵	Patients with CLD	6	Qualitative; Interview	<ul style="list-style-type: none"> • 50% described early interactions with medical community as leaving them overwhelmed with sense of despair, alienated, and invalidated by medical professionals who did not recognize their symptoms or treatment & offered no treatment • Alternative medicine and mental health professionals were most helpful in facilitating healing • Participants described contrasting relationships with providers: • Patients described helpful doctors as: attentive and good listeners, willing to acknowledge patient concerns, open minded, supportive, optimistic, willing to take holistic approach • All participants reported some negative experience with physicians (particularly mainstream HCPs). • Unhelpful doctors are: condescending or patronizing and this sometimes led to seeking a new primary care provider 	<ul style="list-style-type: none"> • Contrasting Relationships with Providers • Patient Self-Advocacy 	
Ali et al. (2014) ⁵³	Patients with CLD	12	Qualitative; Interview	<ul style="list-style-type: none"> • Unhelpful doctors are: condescending or patronizing and this sometimes led to seeking a new primary care provider 	<ul style="list-style-type: none"> • Contrasting Relationships with Providers 	
Perea et al. (2014) ⁴⁵	Primary care providers	1485	Cross-sectional; survey	<ul style="list-style-type: none"> • Most common reported reasons for tick bite prophylaxis was to prevent LD (76.9%) and patients request (40.4%) 	<ul style="list-style-type: none"> • Patient suggestion & Pressure 	
Hill & Holmes (2014) ⁴²	Arkansas Primary Care Physicians	660	Cross-sectional; survey	<ul style="list-style-type: none"> • 39.6% reported that they initiated treatment for LD when they did not believe LD was present and 52.3% reported that patients often brought up possibility of LD as a diagnosis 	<ul style="list-style-type: none"> • Patient suggestion & Pressure 	
Drew & Hewitt (2006) ⁵⁴	Patients with CLD	10	Qualitative; interview	<ul style="list-style-type: none"> • Patients often realized this throughout their medical work up that they were going to need to be their own advocates and make decisions themselves • Patients researched symptoms by use of internet, medical libraries, networking with support group & took back to physicians/HCP to discuss possibility of LD 	<ul style="list-style-type: none"> • Patient Self-Advocacy 	
Ramsey et al. (2004) ⁵⁷	Physicians (varying specialty)	356	Cross-Sectional; mixed methods (questionnaire & assessment of serologic testing sent to lab)	<ul style="list-style-type: none"> • Patients initiated 27% of serologic testing requests; these requests were more likely to be inappropriate than those initiated by a clinicians 	<ul style="list-style-type: none"> • Patient suggestion & Pressure • Contrasting Relationships with Providers • Patient Self-Advocacy 	
Bakken (2002) ⁴⁶	Physicians (varying specialty)	9	Qualitative; semi-structured interview	<ul style="list-style-type: none"> • Patient-provider interaction initiates the learning process by setting the context for physician's framing the problem according to familiarity • Knowing the patient's history and background is a significant factor in framing the diagnostic problem effectively 	<ul style="list-style-type: none"> • Patient Self-Advocacy 	

Table 6. Patient-Provider Interaction and Relationship: included articles that contain information relevant to patient-provider interaction and relationship. With the article is listed important information regarding study population, and methods. Main relevant finding were extracted from full texts of the article. Topic areas indicate themes that emerged and were coded within the full text during the coding process.

Table 7: Gaps and Future Directions

Gaps and Future Directions		
Gap	Future Direction	Importance
Where are providers obtaining information?		
<ul style="list-style-type: none"> • What kinds of continuing education and point of care resources are providers accessing • Do providers use available resources in a productive and effective way? 	<ul style="list-style-type: none"> • Address what continuing education and point of care resources providers are using • How do providers incorporate these into their practice 	<ul style="list-style-type: none"> • Help understand misaligned practice patterns
<ul style="list-style-type: none"> • Population studied in provider knowledge focuses on physicians rather than NPs or PAs (gap in study population) 	<ul style="list-style-type: none"> • Assess knowledge and practice patterns of NPs or PAs • Assess how often NPs and PAs are diagnosing LD cases (as opposed to physicians) 	<ul style="list-style-type: none"> • NPs and PAs diagnose treat and manage acute, episodic, and chronic illnesses, LD is within their scope of practice • Understanding this is important for developing targeting interventions and preventing misdiagnosis or preventable long-standing symptoms
Where are patients obtaining information?		
<ul style="list-style-type: none"> • Why it is that information from the medical community is viewed as less trustworthy, or at least not as salient as that gathered by word of mouth 	<ul style="list-style-type: none"> • Understand popular sources of information outside of the medical community and behavior surrounding these sources <ul style="list-style-type: none"> • Use information gathered about patient use of information and sources, such as YouTube, to enhance health messaging 	<ul style="list-style-type: none"> • Improve accuracy of information and beliefs of LD patients • Patient education is fundamental to successful patient-provider communication dynamics
How is the information being translated between patients and providers?		
<ul style="list-style-type: none"> • Patient-provider communication dynamic 	<ul style="list-style-type: none"> • Explore patient-provider communication dynamic, possible shared decision making tools and point of care interventions 	<ul style="list-style-type: none"> • Support constructive communication dynamics between patients and providers • Effective communication can yield better/more positive health outcomes and experiences
<ul style="list-style-type: none"> • Qualitative studies on patient experience with LD focus on those with chronic symptoms or who identify with a diagnosis of CLD 	<ul style="list-style-type: none"> • Qualitative studies of patient experience focusing on patients with acute LD who do not progress to have chronic symptoms 	<ul style="list-style-type: none"> • The majority of patients who present with acute LD and are treated appropriately do not progress to have chronic or prolonged symptoms

Table 7. Gaps and Future Directions. Summary of the five key gaps identified in the literature and recommendations to address these gaps. Gaps are organized in relation to the three central questions.

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Citations

1. Stanek G, Strle F. Lyme borreliosis: A European perspective on diagnosis and clinical management. *Curr Opin Infect Dis.* 2009;22(5):450-454. doi:10.1097/QCO.0b013e32832ee880.
2. Steere AC, Malawista SE, Hardin JA, Ruddy S, Askenase W, Andiman WA. Erythema chronicum migrans and Lyme arthritis. The enlarging clinical spectrum. *Ann Intern Med.* 1977;86(6):685-698. doi:10.7326/0003-4819-86-6-685.
3. Burgdorfer W, Barbour AG, Hayes SF, Benach JL, Grunwaldt E, Davis JP. Lyme disease—a tick-borne spirochetosis? *Science.* 1982;216(4552):1317-1319. doi:10.1126/SCIENCE.7043737.
4. Krause PJ, Narasimhan S, Wormser GP, et al. *Borrelia miyamotoi sensu lato* seroreactivity and seroprevalence in the northeastern United States. *Emerg Infect Dis.* 2014;20(7):1183-1190. doi:10.3201/eid2007.131587.
5. Kingry LC, Anacker M, Pritt B, et al. Surveillance for and discovery of *Borrelia* species in US patients suspected of tickborne illness. *Clin Infect Dis.* 2018;66(12):1864-1871.

- doi:10.1093/cid/cix1107.
6. Pritt BS, Mead PS, Johnson DKH, et al. Identification of a novel pathogenic *Borrelia* species causing Lyme borreliosis with unusually high spirochaetemia: a descriptive study. *Lancet Infect Dis*. 2016;16(5):556-564. doi:10.1016/S1473-3099(15)00464-8.
 7. Hu LT. Lyme Disease. *Ann Intern Med*. 2016;164(9):ITC65. doi:10.7326/AITC201605030.
 8. Piesman J, Mather TN, Sinsky RJ, Spielman A. Duration of tick attachment and *Borrelia burgdorferi* transmission. *J Clin Microbiol*. 1987;25(3):557-558. <http://www.ncbi.nlm.nih.gov/pubmed/3571459>. Accessed March 8, 2019.
 9. Centers for Disease Control and Prevention. Data and Surveillance | Lyme Disease | CDC. <https://www.cdc.gov/lyme/datasurveillance/index.html>. Published 2019. Accessed March 8, 2019.
 10. Hinckley AF, Connally NP, Meek JI, et al. Lyme disease testing by large commercial laboratories in the United States. *Clin Infect Dis*. 2014;59(5):676-681. doi:10.1093/cid/ciu397.
 11. Nelson CA, Saha S, Kugeler KJ, et al. Incidence of clinician-diagnosed Lyme disease, United States, 2005–2010. *Emerg Infect Dis*. 2015;21(9):1625-1631. doi:10.3201/eid2109.150417.
 12. Stanek G, Wormser GP, Gray J, Strle F. Lyme borreliosis. *Lancet*. 2012;379(9814):461-473. doi:10.1016/S0140-6736(11)60103-7.
 13. Centers for Disease Control and Prevention. Signs and Symptoms of Untreated Lyme Disease | Lyme Disease | CDC. https://www.cdc.gov/lyme/signs_symptoms/index.html. Published 2018. Accessed March 8, 2019.
 14. Petersen LR, Sweeney AH, Checko PJ, et al. Epidemiological and clinical features of 1,149 persons with Lyme disease identified by laboratory-based surveillance in Connecticut. *Yale J Biol Med*. 62(3):253-262. <http://www.ncbi.nlm.nih.gov/pubmed/2683415>. Accessed March 8, 2019.
 15. Wormser GP, Dattwyler RJ, Shapiro ED, et al. The clinical assessment, treatment, and prevention of Lyme disease, human granulocytic anaplasmosis, and babesiosis: clinical practice guidelines by the Infectious Diseases Society of America. *Clin Infect Dis*. 2006;43(9):1089-1134. doi:10.1086/508667.
 16. Moore A, Nelson C, Molins C, Mead P, Schriefer M. Current guidelines, common clinical pitfalls, and future directions for laboratory diagnosis of Lyme disease, United States. *Emerg Infect Dis*. 2016;22(7):1169. doi:10.3201/eid2207.151694.
 17. Centers for Disease Control and Prevention. Two-step Laboratory Testing Process | Lyme Disease | CDC. <https://www.cdc.gov/lyme/diagnostesting/labtest/twostep/index.html>. Published 2018. Accessed March 8, 2019.
 18. Nadelman RB, Wormser GP. Lyme borreliosis. *Lancet*. 1998;352(9127):557-565. doi:10.1016/S0140-6736(98)01146-5.
 19. Marques AR. Laboratory diagnosis of Lyme disease: advances and challenges. *Infect Dis Clin North Am*. 2015;29(2):295-307. doi:10.1016/J.IDC.2015.02.005.
 20. Centers for Disease Control and Prevention. Treatment | Lyme Disease | CDC. <https://www.cdc.gov/lyme/treatment/index.html>. Published 2018. Accessed March 8, 2019.
 21. Kowalski TJ, Tata S, Berth W, Mathiason MA, Agger WA. Antibiotic treatment duration and long-term outcomes of patients with early Lyme disease from a Lyme disease–

- hyperendemic area. *Clin Infect Dis*. 2010;50(4):512-520. doi:10.1086/649920.
22. National Institute of Allergy and Infectious Diseases. Lyme Disease Antibiotic Treatment Research | NIH: National Institute of Allergy and Infectious Diseases. <https://www.niaid.nih.gov/diseases-conditions/lyme-disease-antibiotic-treatment-research>. Published 2018. Accessed March 8, 2019.
 23. Infectious Disease Society of America. Statement for the House Foreign Affairs Committee Africa, Global Health and Human Rights Subcommittee’s Hearing on Global Challenges in Diagnosing and Managing Lyme Disease-Closing Knowledge Gaps Submitted by the Infectious Diseases Society of America 2012. <https://www.idsociety.org/globalassets/idsa/topics-of-interest/lyme/lyme-disease-testimony-global-health-subcommittee.pdf>. Accessed May 14, 2019.
 24. National Institute of Allergy and Infectious Disease. Chronic Lyme Disease | NIH: National Institute of Allergy and Infectious Diseases. <https://www.niaid.nih.gov/diseases-conditions/chronic-lyme-disease>. Published 2018. Accessed March 8, 2019.
 25. Cameron DJ, Johnson LB, Maloney EL. Evidence assessments and guideline recommendations in Lyme disease: the clinical management of known tick bites, erythema migrans rashes and persistent disease. *Expert Rev Anti Infect Ther*. 2014;12(9):1103-1135. doi:10.1586/14787210.2014.940900.
 26. Halperin JJ, Baker P, Wormser GP. Common misconceptions about Lyme disease. *Am J Med*. 2013;126(3):264.e1-264.e7. doi:10.1016/j.amjmed.2012.10.008.
 27. Maloney EL. Controversies in persistent (Chronic) Lyme disease. *J Infus Nurs*. 2016;39(6):369-375. doi:10.1097/NAN.000000000000195.
 28. Auwaerter PG, Bakken JS, Dattwyler RJ, et al. Scientific evidence and best patient care practices should guide the ethics of Lyme disease activism. *J Med Ethics*. 2011;37(2):68-73. doi:10.1136/jme.2009.032896.
 29. Lantos PM, Shapiro ED, Auwaerter PG, et al. Unorthodox alternative therapies marketed to treat Lyme disease. *Clin Infect Dis*. 2015;60(12):1776-1782. doi:10.1093/cid/civ186.
 30. Halperin JJ, Shapiro ED, Logigian E, et al. Practice parameter: Treatment of nervous system Lyme disease (an evidence-based review): report of the Quality Standards Subcommittee of the American Academy of Neurology. *Neurology*. 2007;69(1):91-102. doi:10.1212/01.wnl.0000265517.66976.28.
 31. Shapiro ED, Baker PJ, Wormser GP. False and misleading information about Lyme disease. *Am J Med*. 2017;130(7):771-772. doi:10.1016/j.amjmed.2017.01.030.
 32. The Media Must Exercise Greater Responsibility in Reporting Information on Lyme Disease. <http://www.nbcnewyork.com/investigations/Lyme-Disease-Insurance-Fight-Investigation->. Accessed May 15, 2019.
 33. Cooper JD, Feder Jr. HM. Inaccurate information about Lyme disease on the internet. *Pediatr Infect Dis J*. 2004;23(12):1105-1108. doi:10.1097/01.inf.0000145411.57449.f3.
 34. Stacey D, Légaré F, Col NF, et al. Decision aids for people facing health treatment or screening decisions (review). *JAMA J Am Med Assoc*. 2009;302(14):1551-1556. doi:10.1002/14651858.CD001431.pub4.www.cochranlibrary.com.
 35. Ha JF, Anat DS, Longnecker N. Doctor patient communication: a review. *J Bangladesh Coll Physicians Surg*. 2015;32(2):84-88. doi:10.3329/jbcps.v32i2.26036.
 36. Street R. How clinician–patient communication contributes to health improvement: modeling pathways from talk to outcome. *Patient Educ Couns*. 2013;92(3):286-291. doi:10.1016/J.PEC.2013.05.004.

37. Kaplan SH, S Greenfield, Ware Jr. JE. Assessing the effects of physician-patient interactions on the outcomes of chronic disease. *Med Care*. 1998;27(3-Suppl):S110-27. doi:10.2307/3765658.
38. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol*. 2005;8(1):19-32. doi:10.1080/1364557032000119616.
39. Singh S, Parker D, Mark-Carew M, White R, Fisher M. Lyme disease in West Virginia: an assessment of distribution and clinicians' knowledge of disease and surveillance. *W V Med J*. 2016;112(4):48-54.
40. Greseth SR, Gross C. Addressing Lyme disease: an educational module for healthcare providers. [dissertation.] Fargo, North Dakota: North Dakota State University of Agriculture and Applied Science; 2017.
41. Butler AD, Carlson ML, Nelson CA. Use of a tick-borne disease manual increases accuracy of tick identification among primary care providers in Lyme disease endemic areas. *Ticks Tick Borne Dis*. 2017;8(2):262-265. doi:10.1016/j.ttbdis.2016.11.010.
42. Hill D, Holmes T. Provider knowledge, attitudes, and practices regarding Lyme disease in Arkansas. *J Community Health*. 2015; 40(2):339-46. doi:10.1007/s10900-014-9940-9.
43. Conant JL, Powers J, Sharp G, Mead PS, Nelson CA. Lyme disease testing in a high-incidence state clinician knowledge and patterns. *Am J Clin Pathol March*. 2018;149:234-240. doi:10.1093/ajcp/aqx153.
44. Murray T, Feder HM. Management of tick bites and early Lyme disease: a survey of Connecticut physicians. *Pediatrics*. 2001;108(6):1367-1370. www.aappublications.org/news.
45. Perea AE, Hinckley AF, Mead PS. Tick bite prophylaxis: results from a 2012 survey of healthcare providers. *Zoonoses Public Health*. 2015;62(5):388-92. doi:10.1111/zph.12159.
46. Bakken LL. Role of experience and context in learning to diagnose Lyme disease. *J Contin Educ Health Prof*. 2002;22(3):131-141. doi:10.1002/chp.1340220302.
47. Butler AD, Sedghi T, Petrini JR, Ahmadi R. Tick-borne disease preventive practices and perceptions in an endemic area. *Ticks Tick Borne Dis*. 2016;7(2):331-337. doi:10.1016/j.ttbdis.2015.12.003.
48. Valente SL, Wemple D, Ramos S, Cashman SB, Savageau JA. Preventive behaviors and knowledge of tick-borne illnesses: results of a survey from an endemic area. *J Public Health Manag Pract*. 2015;21(3):E16-23. doi:10.1097/PHH.000000000000098.
49. Jenks NP, Trapasso J. Lyme risk for immigrants to the United States: the role of an educational tool. *J Travel Med*. 2005;12(3):157-160.
50. Macaуда MM, Erickson P, Miller J, Mann P, Closter L, Krause PJ. Long-term Lyme disease antibiotic therapy beliefs among New England residents. *Vector-Borne Zoonotic Dis*. 2011;11(7):857-62. doi:10.1089/vbz.2010.0116.
51. Heller JE, Benito-Garcia E, Maher NE, Chibnik LB, Maher CP, Shadick NA. Behavioral and attitudes survey about lyme disease among a Brazilian population in the endemic area of Martha's Vineyard, Massachusetts. *J Immigr Minor Heal*. 2010;12(3):377-83. doi:10.1007/s10903-008-9187-6.
52. Rebman AW, Aucott JN, Weinstein ER, Bechtold KT, Smith KC, Leonard L. Living in limbo: contested narratives of patients with chronic symptoms following Lyme disease. *Qual Health Res*. 2017;27(4):534-546. doi:10.1177/1049732315619380.
53. Ali A, Vitulano L, Lee R, Weiss TR, Colson ER. Experiences of patients identifying with Chronic Lyme disease in the healthcare dystem: a qualitative study. 2014;15:79.

- doi:10.1186/1471-2296-15-79.
54. Drew D, Hewitt H. A qualitative approach to understanding patients' diagnosis of Lyme disease. *Public Health Nurs.* 2006;23(1):20-6. doi:10.1111/j.0737-1209.2006.230104.x.
 55. Green F. Common psychosocial and spiritual factors among individuals who have healed from Chronic Lyme disease. [dissertation]. Keene, New Hampshire: Antioch University. 2015. <http://aura.antioch.edu/etds/242>.
 56. Basch CH, Mullican LA, Boone KD, et al. Lyme disease and YouTube TM: a cross-sectional study of video contents. *Osong Public Heal Res Perspect.* 2017;8(4):289-292. doi:10.24171/j.phrp.2017.8.4.10.
 57. Ramsey AH, Belongia EA, Chyou PH, Davis JP. Appropriateness of Lyme disease serologic testing. *Ann Fam Med.* 2004;2(4):341-4. doi:10.1370/afm.117.
 58. Johnson L, Aylward A, Stricker RB. Healthcare access and burden of care for patients with Lyme disease: A large United States survey. *Health Policy New York.* 2011;102(1):64-71. doi:10.1016/j.healthpol.2011.05.007.
 59. Hirsch AG, Herman RJ, Rebman A, et al. Obstacles to diagnosis and treatment of Lyme disease in the USA: A qualitative study. *BMJ Open.* 2018;8:e021367. doi:10.1136/bmjopen-2017-021367.
 60. Hook SA, Nelson CA, Mead PS. U.S. public's experience with ticks and tick-borne diseases: results from national HealthStyles surveys. *Ticks Tick Borne Dis.* 2015;6(4):483-488. doi:10.1016/j.ttbdis.2015.03.017.
 61. Bechtold KT, Rebman AW, Crowder LA, Johnson-Greene D. Standardized symptom measurement of individuals with early Lyme disease over time. *Arch Clin Neuropsychol.* 2017;32:129-141. doi:10.1093/arclin/acw098.
 62. Rockwell M, Kraak V, Hulver M, Epling J. Clinical management of low vitamin D: scoping review of physicians' practices. *Nutrients.* 2018;10(4).pii:E493. doi:10.3390/nu10040493.
 63. Centers for Disease Control and Prevention. What You Need to Know • How It's Spread • Where It's Found • How It's Prevented • How It's Diagnosed • How It's Treated. <https://www.cdc.gov/lyme/resources/brochure/lymediseasebrochure.pdf>. Accessed March 1, 2019.
 64. American Association of Nurse Practitioners. Scope of Practice for Nurse Practitioners. <https://www.aanp.org/advocacy/advocacy-resource/position-statements/scope-of-practice-for-nurse-practitioners>. Published 2015. Accessed March 1, 2019.
 65. American Academy of PAs. *PA Scope of Practice*.; 2017. www.aapa.org. Accessed March 8, 2019.
 66. Schrager SB, Phillips G, Burnside E. A simple approach to shared decision making in cancer screening. *Fam Pract Manag.* 2017;24(3):5-10. <http://www.ncbi.nlm.nih.gov/pubmed/28671358>. Accessed February 28, 2019.
 67. Austin CA, Mohottige D, Sudore RL, Smith AK, Hanson LC. Tools to promote shared decision making in serious illness: a systematic review. *JAMA Intern Med.* 2015;175(7):1213-1221. doi:10.1001/jamainternmed.2015.1679.
 68. Tamhane S, Rodriguez-Gutierrez R, Hargraves I, Montori VM. shared decision-making in diabetes care. *Curr Diab Rep.* 2015;15(12):112. doi:10.1007/s11892-015-0688-0.
 69. Arora N. Interacting with cancer patients: the significance of physicians' communication behavior. *Soc Sci Med.* 2003;57(5):791-806. doi:10.1016/S0277-9536(02)00449-5.