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The Many Faces of Lyme Disease

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THE MANY FACES OF LYME DISEASE

by

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Bachelor of Science, Hartwick College, 2006

An Independent Study

Submitted to the Graduate Faculty

of the

University of North Dakota

in partial fulfillment of the requirements

for the degree of

Master of Science

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Permission

Title The Many Faces of Lyme Disease

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Degree Master of Science

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Abstract

Lyme disease is the most common vector-borne disease in the United States today, and cases continue to grow every year. Lyme disease can be challenging to diagnose due to the many presenting symptoms. This independent study is meant to describe symptoms of Lyme less traditionally discussed in medical and nursing literature when considering how and when to diagnose Lyme disease. It is also meant to examine common diagnostic problems in pediatric, maternal, and elderly populations. This was accomplished with the use of a literature review, resulting in the development of a white paper and educational brochure for dissemination to health care providers and the general public. Lyme disease presents without the well-known "bull's eye" rash more often than providers may suspect. In some endemic areas, the most common reason for a presenting complaint of meningitis, arthritis or facial palsies in children is the Lyme bacteria. Elderly patients may present with neurological symptoms of Lyme disease that are mistaken for other neurological diagnoses. Treating these complaints with common antibiotics and other treatments may not correctly treat Lyme disease. Therefore, health care providers and patients need to be aware of these different symptoms to avoid delayed diagnosis and unnecessary or costly treatments. The literature review was limited by the limited amount of studies that focus on this particular topic. Pieces that were included focused on symptoms of Lyme other than *erythema migrans*.

Introduction

In 1982, epidemiologists tracking what was thought to be a bizarre outbreak of juvenile arthritis cases around Lyme, Connecticut at last isolated the bacterial culprit (*borrelia burgdoferi*) responsible for the outbreak of symptoms. Named after the town where the cases were first discovered, Lyme disease has since spread throughout the Northeast and the upper Midwest. The disease, though not unknown to other tick species in the United States, is in the United States primarily spread through the bite of the infected deer tick (*ixodes scapularis*) (Knisley & Johnson, 2004). Although isolated Lyme cases have been found in other areas of the United States, in 2011 ninety-six percent of cases in the U.S. were reported in only thirteen different states. Unsurprisingly, these thirteen states are also the states where deer ticks are the most common. In 2011 Lyme disease was the most commonly reported vector born disease in the United States and the sixth most common nationally notifiable disease (Centers for Disease Control and Prevention [CDC], 2012a).

Lyme disease cases in the United States have continued to rise steadily in the past decade. For example, from 2006 to 2011, confirmed and probable cases of Lyme in Vermont alone rose from 105 to 623 (Vermont Department of Health, 2011). In 2001, there were 17,021 confirmed cases of Lyme disease nationwide, concentrated heavily in southern New England and the Mid-Atlantic Seaboard, with a smattering of cases in the upper Midwest. After a high of 29,959 cases in 2009, there were 24,364 confirmed cases in 2011, with cases now spreading steadily outward from the original outbreak in Connecticut into northern New England and across the upper Midwest (CDC, 2012b). Following a mild winter in 2012, confirmed cases are expected to rise for that year when information is completely reported. The highest incidence rates in 2011 were reported in Delaware (84.6 per 100,000 people), Vermont (76.0 per 100,000), New Hampshire

(67.3 per 100,000), and Maine (60.3 per 100,000) often reflecting the smaller population of these States. In one of the few success stories, Connecticut has been able to lower its Lyme incidence rate from 133.5 per 100,000 people in 2002 to 56.0 per 100,000 people in 2011, while other States, late to initiate prevention measures, continue to struggle to control the disease outbreak (CDC, 2012c).

In the State of Massachusetts, Lyme disease has been labeled a public health crisis as it reaches near-epidemic proportions (Commonwealth of Massachusetts, 2013). Despite this, the state still finds that their approach to dealing with the epidemic has been haphazard at best, with legislators noting that virtually everyone in the State either has had Lyme or knows someone who has (Linsky & Swan, 2011). A vaccine approved for Lyme disease in humans in the late 1990s was removed from the market in 2002 due to low sales, complaints of adverse affects, and litigation threats against the company that produced the vaccine. A Lyme vaccine is in use for dogs and horses, but the human vaccine has never been reintroduced, and no other company has moved to fill this gap, despite the growing call for a new Lyme vaccine (Hu, Cotton, Taichman, & Williams, 2012).

As a result of misdiagnosis and unreported cases, the true economic cost of Lyme has never been studied in depth. In 2006, one study estimated that the cost of Lyme for that year in the United States was roughly 200 million US dollars (Zhang et al., 2006). As the numbers of Lyme cases are projected to rise as the disease spreads slowly across the United States, prevention and early detection remain crucial to keeping the cost, physical and economic, under control.

With tens of thousands of people affected each year by Lyme disease and health care costs in the United States steadily rising, Lyme is of great interest to many researchers and the

population at large in affected areas. However, it remains less well known to the majority of Americans, despite the fact that Lyme has been diagnosed in forty-nine of fifty states in the U.S. in our increasingly mobile society, which is largely due to travel to endemic areas by those living outside affected areas (CDC, 2012c). Health care practitioners practicing in non-endemic areas may not be on the alert for the early symptoms of Lyme disease, and many specialty practitioners are finding that referrals for arthritis and other symptoms are in fact caused by Lyme disease, delaying diagnosis (Saulsbury, 2005) and increasing the burden of Lyme disease borne by the public at large and the health care community. Lyme disease is also becoming a growing health concern in Europe, where it has recently become the most common tick-borne infection on the continent and is carried by multiple tick species (Stanek et al., 2011). Europeans have long been affected by the widespread Tickborne Encephalitis Virus (TEV), endemic in many areas of the continent, and the discovery of a new tick-carried virus has troubling connotations (CDC, 2011a). Interestingly enough, it is now thought that Lyme disease has been present in Europe for over a century, and that the North American and European varieties differ in some characteristics and presenting factors, which may have made isolating the Lyme spirochete less of a priority for European researchers (Abele & Anders, 1990).

It is important to continue to study Lyme disease due to the fact that the spread of Lyme disease in the United States, and worldwide, has not been particularly slowed by prevention measures taken by individuals, health care providers, or States alone. When diagnosis is delayed, it increases the economic burden of lost days at work, and increases the arguments over the very existence of "chronic Lyme disease", a controversial subject made louder with the growing number of Lyme-positive subjects in the United States. Certain populations not thought of as traditionally at risk for Lyme disease will continue to see their risk for Lyme increase as the

disease continues to spread and cases increase. With this in mind, it is important for all health care practitioners as well as the public at large to be interested in continuing developments in the prevention of Lyme disease.

Purpose

The purpose of this independent study project is to research the latest studies on Lyme disease in order to create educational materials that highlight the risks of Lyme, particularly towards populations that are not traditionally thought of as high risk, and of Lyme symptoms that are often missed by general health providers. Early symptoms are similar to the flu with joint pain, fever, headaches and stiff neck. The classic red rash is not present in all cases of Lyme, and patients may not remember being bitten or even having a tick on them. Health care providers in areas where Lyme is endemic are becoming more proficient in treating Lyme and screening for the disease, but in areas where the disease is newly present these providers may not think of Lyme first when investigating joint pain, fevers, and other non rash signs of Lyme. Health care practitioners may not investigate the possibility of Lyme disease in children or pregnant women until the signs and symptoms are severe and multiple other problems have been ruled out, often taking weeks or months.

The use of this literature review will be to examine infrequently discussed symptoms of Lyme for the purpose of creating new educational materials for the use by the general public and health care workers. This will take the form of a white paper and an informational brochure. The information provided in these materials will focus not only on the classic signs of Lyme but also symptoms that are less commonly considered when diagnosing problems. It will also be targeted towards populations, such as children and pregnant women, who are at risk for Lyme but are not necessarily thought of by health providers when searching for the cause of common symptoms.

The questions that are being addressed in this paper are “What symptoms of Lyme disease are most often missed by health care providers, particularly in non-traditional populations?” and “What information would be helpful for health care practitioners to differentiate symptoms of Lyme from separate diagnoses across all populations, including nontraditional ones such as children and pregnant women?”

Significance

In summary, Lyme disease is endemic in multiple parts of the United States and is considered a national problem as the most common vector borne disease in the country. Despite the publicity surrounding Lyme in these common areas, it is still considered underreported. Populations that continue to see rises in Lyme cases include children and younger males as well as older adults (CDC, 2008).

Lyme disease is most often associated by the public and by health care practitioners with the classic “bull’s eye” rash. However, *erythema migrans* (EM) is often missed, misdiagnosed, or not present at all. In one study, 23% of patients presenting with EM were misdiagnosed without noting the rash at all, and 65% of those whose rash was noted were misdiagnosed with other skin conditions (Aucott et al., 2009). Lyme is known to imitate or present with other health conditions later in the disease course, including cellulitis, spider bite, septic arthritis, Bell’s Palsy, meningitis, carditis, and other neurological complaints that mimic Parkinson’s and Alzheimer’s. Recognizing Lyme disease, and gaining experience with the different presentations of this disease, will be extremely valuable to individuals and the public as a whole. Lyme disease is continuing a slow spread outwards through the U.S., and most practitioners will encounter a case where this knowledge will be valuable at some point in their careers, even if they rule Lyme out instead of ruling it in.

This work is meant to be helpful to all health care practitioners, including those working in office and public health settings. It will be helpful for health care workers looking for information on Lyme disease to have an easy way to access data on the myriad of different symptoms that appear in this disease. From a nursing perspective, much of what has been written in the nursing literature for general distribution has related to brief summaries in nursing magazines or case studies relating the danger of Lyme disease for the public. Therefore, this study will add to available literature by its discussion of the ongoing problem and the as a means for health care practitioners to access evidenced based information on this topic more easily.

Theoretical Framework

Nurses are involved and interested in every area of health care that affect health, including the environment, epidemiology and allied health fields. Due to the ability of nursing to touch so many fields, a public health model was used to frame this study.

Social-ecological model has been used heavily for public health research in the past century. Some of the most well-known research relates to Bronfenbrenner's Human Development Models and his work on child abuse (Swick & Williams, 2006), but the model has been used for prevention of everything from domestic violence to mental illness to cancer prevention. The CDC uses this model in many of their prevention programs. Social ecological model is a systems model that represents the individual and the influences felt on health or another problem being studied. There are five tiers in this model, as the individual is surrounded by interpersonal, organizational, community and policy influences in a rainbow model, one rising above and beyond the others with the policy level at the top. Programs such as those used by the CDC target prevention measures at all five levels (CDC, 2013). The policy level has also

been called the society level, and through these levels we see the individual affected by their individual, physical and social environments (Queensland Health, 2007).



Centers for Disease Control and Prevention. (2013). Social ecological model. Retrieved from <http://www.cdc.gov/cancer/nbccedp/sem.htm>

To increase Lyme prevention by using this model, an individual public health intervention would, for example, target prevention tactics towards things that one person would be able to do alone, such as using insect repellent while outside or clearing brush on one's own property. Personal beliefs targeted by using this model could include attitudes towards screening programs or attitudes towards health care workers and antibiotics. On the interpersonal level, family, friends, health care workers, and community members would work together to educate and recommend materials and prevention activities towards individual and each other, working only in the immediate physical and social environment that the individual lives within. Organizational activities, such as workplaces, social institutions, and clubs have rules that can encourage further prevention and screening activities. These organizations may have direct influence over their members and their environment, allowing them to expand their influence

beyond mere individual or interpersonal levels. Prevention for Lyme at the organizational level could include trail clubs requiring the use of long pants for hiking activities, or workplaces requiring a vaccine in Lyme-endemic areas. Workplaces are also able to add Lyme prevention and treatment options to their employee-benefit programs (Queensland Health, 2007).

Larger coalitions and health departments operate at the community level, affecting change in the community at large but not necessarily in society at large. Policy or society level involves changing laws, affecting policy, and directly changing and controlling decisions made by the individual or their community (CDC, 2013). For health care workers, a policy or society level change might involve mandating that all pregnant women were tested for Lyme disease, or that insurers were required to pay for screening and treatment.

Definitions

For the purpose of this paper, Lyme disease is defined within the 2011 CDC definition of the disease. Lyme disease is a systemic, tick borne infection that is considered as a confirmed diagnosis when *erythema migrans* is present, or when there is laboratory confirmation of the disease (CDC, 2012d). A nontraditional symptom of Lyme can be considered to be anything outside the CDC definition of the disease.

Process

There is a large body of Lyme disease research available at this time. However, much of the research focuses on the biological and specific vulnerabilities of the Lyme bacteria itself. Much of the literature that describes and discusses different aspects of Lyme disease is dated, written in the 1990's or even earlier. This mirrors when Lyme was first being discussed by the medical community and was beginning to spread out of Connecticut and Long Island and into greater New England and the Mid-Atlantic. A large body of research was also available from the

late 90's to early 2000's. This information is still useful today, as there is not much new research being produced on the symptomatic Lyme aspect this paper is focused on. What is being produced is largely being written by European researchers, who are seeing an increase in Lyme disease in Europe.

Articles included in this paper are largely from the past ten years (2003-2013), with some studies and case studies from earlier years that were considered exceptionally useful for the purpose of the paper. The first stage of this search involved using the search engines Academic Search Premier, CINAHL, Medline, Cochrane Review and Google Scholar to identify promising studies for this review. Once helpful studies or writings were identified, the ancestry approach was used to identify other helpful, earlier studies, followed by the decendancy approach in order to find other studies that had cited these studies in their own work. Searching the sites of specific publishers was also helpful, particularly with journals Pediatrics and the Journal of the American Medical Association. This literature search took place in January, February, and March of 2013.

Search terms used included "Lyme", "Lyme Disease", "symptoms", "prevention", "diagnosis", "beliefs", "pediatrics", "elderly", "geriatrics", "children", "maternal" and "pregnancy", with the later terms always in combination with "Lyme" or "Lyme Disease". Due to the large body of current Lyme research, the search was narrowed further to include articles or primary and secondary research that dealt with non-traditional Lyme symptoms, commentaries, and case studies. It was also narrowed to look specifically at populations less likely to be discussed by federal or large national bodies, such as maternal child health and pediatrics. However, the more the search guidelines were narrowed to find studies on these populations, the less useful the research that appeared in the search results. No useful meta-analysis studies on this topic were found. Included in this literature review are twenty papers, encompassing large

cases studies and experimental design, that that are able to paint a picture of the difficulty of diagnosing Lyme disease in nontraditional populations. The experimental studies are largely retrospective in design. Most of the research done in this area has focused on pediatrics. Only a few studies noting aspects of maternal Lyme and its presence in elderly populations were found. Fifteen studies that are considered the core of this literature review are contained within Appendix A. The graph in Appendix A compares these studies by design, sample, setting, objectives, findings, and the aspect of Lyme disease that was studied.

This literature review is structured by type of study or case study, by symptoms, and by population studied. The review will first discuss useful secondary writings before moving to case studies and primary research. The final product from this literature review and paper includes a white paper and a brochure. The white paper will be made available to local medical offices and hospitals. The brochure will be made available to the general public at community gathering places, trail clubs, schools, and possibly medical offices as well for the benefit of patients. The white paper and brochure will be made available to the local Health Departments and the hospital in which this writer is employed. This paper was structured with guidance from advisor Lucy Heinz, MS, RN, COHN-S, CCM, CDMS, and the epidemiology nurse at the Springfield Vermont Health Department.

Review of the Literature

Classic signs and symptoms of Lyme disease include the well-known "bull's eye" (*erythema migrans*) rash around the original site of the tick bite, fatigue, fever, and joint aches. Later signs have included facial palsy, severe headaches and neck aches, worsening joint pain, and heart palpitations. It is in these later symptoms that confusion often arises during diagnosis, as the early signs of Lyme may not be present, and patients may not recall a tick bite. When left

untreated for years, patients may complain of neurological problems with memory loss and shooting pain in the extremities, and may experience heart block and severe arthritis. In the later stages of Lyme, patients may continue to experience these unchecked symptoms even after completing prescribed treatment. However, Lyme diagnosis with and without presenting tick bite or rash varies wildly depending on study and provider. Flu or viral-like symptoms can be easily missed or dismissed by health care providers, or by the patients themselves (Aucott, Seifter, & Rebman, 2012).

Lyme disease is most prevalent in the northeast and upper Midwest, but the numbers affected are growing, and the CDC states that it does not know the true number of people affected, which may be ten times the amount actually reported (Savely, 2010). The bacteria accounts for as many as 90% of vector-borne illnesses in the United States, far beyond any other cause of these illnesses (Shelby Smith & Rechlin, 2010). The spirochete responsible for the disease resides in the gut of affected ticks, most often the *Ixodes scapularis* or deer tick. These ticks go through a larval, nymph, and adult stage and require blood meals for survival at each stage. The nymph and adult ticks can both transmit Lyme disease, but the nymphs are so miniscule-less than 2mm wide, the size of pencil dot-they are difficult to spot even if the affected person is actively searching for them. This is important, because it takes at least 24 hours of feeding for the tick to transmit the spirochete to the human or animal host (Shelby Smith & Rechlin, 2010). Not every deer tick in the United States carries Lyme, but as the number of ticks grows, the greater the risk of coming into contact with a tick that is positive.

Stage one of Lyme disease is considered to last from a few days to a month. This stage is classically marked with the red bull's eye rash, *erythema migrans*, considered characteristic of Lyme disease, though the rash is not present in all cases. Stage two of Lyme may present with

fever, fatigue, headache, stiff neck, sore throat, and other symptoms of localized infection. Joint pain and cardiovascular block may be found in patients in this stage. The disease has been popularly referred to as the new "great imitator" (a moniker popularly given to syphilis infections, a disease closely related to Lyme) as the infection can affect every system in the body as it travels throughout the host. Neurologic symptoms may begin to appear at this stage, including those mimicking meningitis, photosensitivity, confusion, and facial paralysis (often mistaken for Bell's Palsy). These symptoms may resolve for a time, but if left untreated they will eventually return, often after life stress depletes the body's immune response (Savely, 2010). Stage three Lyme disease is a persistent infection, difficult to treat, that has spread to the nervous system or musculoskeletal system with persistent arthritis (affecting 60% of cases) and severe neurological complaints (Shelby Smith & Rechlin, 2010).

In early stage two Lyme, with its mercurial symptoms, the disease may be ruled out by unwary providers who either do not realize that Lyme is endemic to their area or because the patient does not remember a tick bite or rash. Early symptoms may resemble a minor virus, and may disappear with time. Later symptoms have been mistaken for other diagnosis affecting every system in the body, including fibromyalgia, chronic fatigue syndrome, irritable bowel syndrome, restless legs syndrome, multiple sclerosis, Lupus, Lou Gehrig's disease, Parkinson's disease, Alzheimer's, autism, and severe arthritis. Determining how patients respond to treatment, and how well, has been the subject of a number of controversies, but research groups in this country usually conclude that current Lyme treatment is effective (Seltzer, Gerber, Cartter, Freudigman, & Shapiro, 2000). Patients complaining of later symptoms or seeking initial diagnosis may be written off as "doctor shopping" for a true reason behind their symptoms, or as suffering from emotional or psychological distress (Savely, 2010). Current testing controversies

can delay diagnosis further, as the Infectious Disease Society of America currently recommends a positive titer for Lyme disease before beginning treatment (Maloney, 2009). These guidelines do not mention that the titer is not considered completely accurate.

The CDC (2011b) recommends a two-tier testing tree to test for Lyme. The tree starts with the Enzyme Immunoassay or Immunofluorescence Assay. If the test is negative, the provider should move on to an alternate diagnosis, possibly treating and following up with another test if the patient has been complaining of symptoms for less than thirty days. If the patient is positive and has had symptoms for less than thirty days, an IgM western blot test can be performed. If the patient has had symptoms for more than thirty days, an IgG Western Blot can be performed (CDC, 2011b). This testing is complicated by the window of time when the Lyme bacteria will appear in certain tests. Serologic reactions occur only 50% of the time in patients with early Lyme, and the IgM and IgG tests are most successful at finding Lyme from 2-6 weeks after infection. After that window, the antibodies will drop off, and false positives and negatives abound. Specificity and sensitivity in these tests vary widely depending on the stage of Lyme that patient is experiencing (Shelby Smith & Rechlin, 2010). In 2006 the Infectious Disease Society of America (IDSA) recommended that health practitioners require lab confirmation before beginning treatment (Wormser et al., 2006), followed by an uproar in the Lyme community (Mahoney, 2009) and prompting a lawsuit from the State of Connecticut. However, despite these recommendations from IDSA, clinical judgment is still recommended over laboratory testing in the diagnosis of Lyme by many health providers (Maloney, 2009).

Pediatric patients are likely to exhibit all the classic symptoms of Lyme disease, including *erythema migrans*, fever, malaise and headaches. Male children five to nine years of age have the highest rates of Lyme disease as a population group in the United States, followed

only by adults from thirty- five to fifty- five years of age (CDC, 2012e). Although most clinical cases are similar in nature to adult complaints, identifying Lyme disease in children can be more complicated than adults due to the similarity of symptoms to other pediatric ailments, and as diagnostic approaches are not standardized (Esposito et al., 2013)(Qureshi, New, Zulqarni, & Nachman, 2002). Early signs of Lyme, including *erythema migrans*, fever and fatigue, follow the same clinical path as adults.

Arthritis is the most common later manifestation of Lyme disease in children (Kest & Pineda, 2008), differentiated from septic arthritis by their higher rate of knee involvement, lower fever, and ability to bear weight on the affected joint. In a retrospective study on pediatric patients presenting to a pediatric rheumatologist, patients with Lyme disease were more likely to be male, with markedly swollen lower joints such as knees that were not particularly painful to the affected patient. Lyme arthritis is generally characterized as brief and recurrent as opposed to persistent arthritis which characterizes rheumatoid arthritis and which these patients had originally been referred for. The authors suggested adherence to the diagnostic guidelines for differentiating rheumatoid arthritis from Lyme disease, and of always being open to the prospect of Lyme in endemic and neighboring endemic areas (Saulsbury, 2005). In another retrospective study on pediatric joint aspirations in a Lyme-endemic area, researchers found that up to thirty-one percent of patients who received joint aspirations with a prospective diagnosis of septic arthritis instead were positive for Lyme disease (Milewski et al., 2011). In these cases, adherence to diagnostic guidelines can help bring about the correct diagnosis.

Lyme disease has become a frequent cause of pediatric facial palsy in endemic areas, with up to one third of cases caused by the bacteria. Factors predicting Lyme disease, rather than other causes of facial palsy (such as otitis media, mastoiditis, or Bell's Palsy) include the

presence of headache, fever, bilateral facial palsy, and onset of symptoms during the peak Lyme months of June through October. Meningitis and facial palsy occurring together were highly indicative of Lyme in this study's cohort (Nigrovic, Thompson, Fine, & Kimia, 2008). The researchers defined Lyme disease as either the presence of *erythema migrans* or the presence of serological markers, but noted that only ten percent were positive for a rash and only fifty seven were serologically positive for Lyme, thus confusing diagnosis. Just as in other cases differentiating Lyme from separate diagnosis, the treatment for Lyme versus idiopathic facial palsies is very different (antibiotics vs. steroids), and determining the correct diagnosis rapidly is crucial in order to timely diagnosis Lyme disease. Otitis media was once the main cause of facial palsy in children, but over the past twenty years this has changed with the spread of Lyme (Esposito et al., 2013).

A case study describing Lyme disease misdiagnosed in adults as Bell Palsy and meningitis (Shelby Smith & Rechlin, 2010) highlighted the long diagnostic and treatment route a missed neuroborreliosis case can cover before reaching correct diagnosis, opening the patient to other sources of infection and invasive diagnostic procedures, difficult enough for adults to endure. Another case study (Moses, Riseberg, & Mansbach, 2003) describes Lyme manifesting as chronic headaches in children and complains of the difficulty in differentiating Lyme meningitis from other viral meningitis. However, a larger study described below clearly identifies factors separating the two diagnoses for the aware provider.

A study completed in Scandinavia reported meningitis and facial palsy as the most common signs of neuroborreliosis in children (Oymar & Tveitnes, 2009), with these symptoms found to be much higher in children with neuroborreliosis than adults. Lyme was found to be the major cause of childhood meningitis in another European retrospective study (Tveitnes, Natas,

Skadberg, & Oymar, 2012) with 67% of 211 patients presenting with symptoms of meningitis diagnosed with Lyme meningitis, and only 11% diagnosed with bacterial. Those with bacterial meningitis were more likely to present with fever, loss of appetite and vomiting than those with Lyme meningitis or non-Lyme aseptic meningitis. Headache and neck stiffness were the only symptoms present in 20% of children diagnosed with Lyme disease, with a higher rate of cranial nerve involvement than bacterial or non-specific meningitis. White blood cell counts were lower, and those presenting with facial palsy as well as meningitis symptoms were considered to have a positive predictive value of 97% for Lyme disease. Children with non-Lyme viral meningitis were more likely to have symptoms such as vomiting, fever and signs of systemic inflammation. Bacterial meningitis is now rare in developed countries, and Lyme disease should be considered in endemic areas with patients presenting with stiff neck and headaches, as it. Overall, the authors concluded that the difference between Lyme meningitis and bacterial meningitis as well as between viral and Lyme meningitis should be easy to differentiate. Pediatric patients positive for Lyme neuroborreliosis usually make full or nearly full recovery with appropriate treatment (Skogman et al., 2012) but subjective complaints such as headaches, fatigue and weakness may remain.

Lyme carditis in children covers a broad spectrum of presentation, covering everything from benign first degree block to advanced heart block requiring transcutaneous pacing. Most of the pediatric patients presenting with carditis in one study done in an endemic area were also positive for other aspects of Lyme, mirroring findings of carditis in Lyme-positive adults since the early years of Lyme research (Costello et al., 2009). This study suggested that Lyme carditis is more likely to progress to high-grade heart block than was previously thought, and that children with long PR intervals in first degree block were more likely to develop high-grade

heart block than other children presenting with the same symptoms. Older pediatric patients and those who presented with carditis symptoms were also more likely to present with Lyme carditis in the study's endemic area. Timing, treatment, and resolution of carditis were found to mimic adult cases of Lyme carditis. Symptoms of carditis were thought to be more easily missed in younger children, as they were found to be less likely to complain of joint pain, and thus less likely to be considered for Lyme at all.

In the case of maternal Lyme borreliosis, much research remains to be done. No studies were identified focusing specifically on maternal presentation of Lyme disease, and much of the literature on maternal Lyme is dated to the 1980's and 1990's. A case study written in 1985 described a case in which the infant of a Lyme-positive mother died soon after birth (Schlesinger et al., 1985). A large, prospective study (Strobino et al., 1993) dismissed the fear that Lyme disease led to more adverse outcomes in pregnancy, but noted that all of its study participants who were found to be positive for Lyme during their pregnancy were immediately treated with appropriate antibiotics. The authors stated that mothers in endemic areas were probably not at risk for Lyme disease, and that there was no cause for alarm in this population. Lyme disease has become much more common in the U.S. since this study was completed. A more recent small study by Lakos and Solymosi (2009) described pregnancy outcomes when the mother was infected with Lyme, which were described as having adverse outcomes in 60% of untreated women, with pregnancy loss being the most common adverse outcome. Mothers who are positive for Lyme are assumed to follow the same clinical course as non-pregnant Lyme carriers. These small studies only offer more questions and highlight the need for more research in this area.

Another area that requires more research is the manifestation of Lyme disease in the elderly. Studies that focus on aspects of Lyme in geriatric patients are also not particularly forthcoming in the literature. Salzman and Studdiford (2007) presented a case study from a geriatrics journal on the uncomplicated diagnosis of Lyme disease in an older patient. More interesting than the description of this basic diagnostic case with presenting tick bite was the reminder that the later neurological aspects of Lyme disease can be seen to mimic Alzheimer's disease. With the prevalence of dementia in today's society, it is frightening for patients to consider being incorrectly diagnosed with Alzheimer's or dementia rather than diagnosed with a largely curable disease such as Lyme. Older studies that first described Lyme, such as Logigian, Kaplan, and Steere (1990), described later neurological symptoms that affected memory, mood and sleep followed by language deficits. Providers should recall this clinical aspect when considering neurological symptoms in Lyme-endemic areas.

In traditional adult populations, the most common presenting symptoms of Lyme disease are generally rash (Hu, Cotton, Taichman, & Williams, 2012) and fatigue with other flu like symptoms (Cottle et al., 2012). Aucott et al. (2009) noted that when the presence of *erythema migrans* is either not present or missed by providers or patients, diagnosis will easily be delayed, and patients may be treated with inappropriate antibiotics for their flu-like symptoms. Rashes were often misdiagnosed as spider bite, cellulitis or shingles. Patients and physicians who noted a rash early in the disease process often did not realize its significance. This may be due to author's note that only 19% of those presenting with *erythema migrans* had the traditional "bull's-eye" rash presentation. Aucott et al. (2009) also noted that the IDSA guidelines do not provide options for patients who present with non-specific viral like symptoms, despite this presentation being present in as many as 16% of patients. These patients are also much more

likely to be exposed to ineffective antibiotics than those presenting with other complaints, prolonging treatment and increasing the cost of care. In addition, inappropriate steroid use was common in adults presenting with facial palsy. Another study done by Aucott, Crowder, Yedlin, and Kortte (2012) found that the general public is not able to easily self-diagnose different *erythema migrans* rashes, leading to the assumption that health care providers are not necessarily skilled in this field either.

These flu-like symptoms of Lyme disease, though confusing for providers and patients, can usually be differentiated from other illnesses (at least in Lyme endemic areas) by the absence of respiratory or gastrointestinal symptoms (Wormser, 2006) Late Lyme disease is often confused with chronic fatigue syndrome and fibromyalgia syndrome (Cottle et al., 2012), again leading to difficulty in diagnosis.

Discussion

This literature review covers a broad range of topics within the greater discussion of Lyme disease that exists within health care literature. Broken into smaller groups or classes of symptoms, it would have lost some of the breadth of the current Lyme discussion. Lyme disease has now been labeled the new "great imitator" that appears as or mimics many different diseases. What this literature review shows are some of the many manifestations of Lyme disease, and the confusion that can result before correctly diagnosing the problem. This review also reminds us of the growing threat of Lyme in States and populations that are not yet endemic for Lyme, for these populations may visit endemic areas in the course of their business and leisure travel. Providers who live outside endemic areas can then left to decipher confusing and nonspecific patient complaints. Lyme is also being recognized in Europe at a much greater rate than has been previously seen, though there remain some differences in disease presentation. Lyme disease will

not disappear without concentrated attention from both the health care community and the general population. Hiking, camping, and outdoor recreational activities are rising in popularity. While recreational use is increasing, suburban and urban sprawl push ever further into wooded and brushy areas where deer and other wildlife live side by side with humans.

An ongoing question in this literature review, separate from symptoms review but related to the question, is how providers learn to diagnose Lyme disease. Health care providers such as physicians, Nurse Practitioners, and RNs are taught early on that if they hear hooves, they should “think horses, not zebras” when diagnosing and considering patient symptoms. When the most common diagnosis is most often the correct one, it is not evidenced based or economically practical to immediately consider exotic diagnosis for every patient who presents with flu-like symptoms. Some would say that it is irresponsible practice at best (Kazandjian, 2002) or fraudulent at worst in this era of health care reform. This advice unfortunately becomes complicated in the case of Lyme disease, as its most well-known symptom-*erythema migrans*-can so easily be mistaken for other diagnoses by unwary providers (Aucott et al., 2009). The high rate of difficulty in diagnosing may no longer be as common in Lyme endemic areas, but as Lyme spreads slowly out of the Northeast and upper Midwest and into areas where the diagnosis was previously unseen, there is a pronounced learning curve in education and diagnosis for both the population and the local health care providers (Bakken, 2002).

There is a need for more explicit guidelines in differentiating Lyme disease from other competing diagnosis. There are numerous secondary sources that discuss different aspects of Lyme disease. Research covered in this literature review noted the need for practitioners to adhere closely to diagnostic guidelines in order to avoid mistakenly diagnosing a disease such as rheumatoid or septic arthritis with Lyme. Though many of the secondary literature sources cited

in this paper are “how-to’s” for how to differentiate certain Lyme symptoms from others, they rarely contained explicit instructions. Many writers, including Aucott et al. (2009) noted the need for experience in typical and atypical aspects of Lyme disease in order to avoid incorrect diagnosis. Esposito et al. (2013) commented on the lack of diagnostic codes for pediatric patients in particular.

Many of the studies discussed in this literature review are retrospective in design. Retrospective models are common when researchers are describing a problem rather than testing an intervention. Unfortunately, they are not considered as rigorous as other experimental designs, and convenience sampling from one practice or hospital can be dismissed as strong evidence for change. Though useful in finding certain characteristics of the disease, researchers need to branch out into larger studies. It is speculated that Lyme disease is much more prevalent in the general population than is currently reported by the CDC (Savely, 2010), and studies that apply to all populations throughout the US would be more useful and generalizable than those we are seeing today. Writers continue to discuss the same questions that were first posed thirty years ago when Lyme disease was first described in the United States. This suggests that progress in this area has been slower than hoped for.

Another trend in the literature was the complaint by writers of incorrect diagnosis leading to the incorrect prescription of antibiotics. There is little known today about what response the Lyme spirochete has to certain ineffective antibiotics, and whether these prescription mistakes could, for example, lead to resistance in this organism or others to correct antibiotics. Antibiotics correctly prescribed for Lyme were also found to be prescribed for inappropriate amounts of time or at incorrect doses (Cottle et al., 2012) This complaint is separate from the argument today between health practitioners (Maloney, 2009) and the IDSA (Wormser et al., 2006) regarding

correct and incorrect use of long-term antibiotics to treat what is known as “post-Lyme syndrome”. In all of these problems, more research is needed on the long term effects of these antibiotics on Lyme and the nature of the disease itself.

Despite the chatter about Lyme in endemic states, neighboring states may not feel a pressing need to initiate prevention measures until health problems have reached a crises level. In Massachusetts, legislatures complained of a Lyme “public health crisis” yet without funds earmarked for Lyme prevention in the State budget (Linsky & Swan, 2011). A lack of urgency from politicians may in turn affect public health officials, physicians, and the public at large, muddying the public perception of Lyme and leaving them to rely on general media coverage rather than facts and evidence. In this absence of public health leadership, those affected by Lyme continue to struggle to name their symptoms and to reach out for effective treatment.

The principle risk factor for Lyme disease is residence in suburban or rural areas that are endemic for Lyme and are either wooded or brushy, often overrun with vector-carrying ticks (Committee on Infectious Disease, 2000). Public health professionals and researchers have complained that as mosquito control to prevent illnesses such as malaria area carried out by professionals, tick management and control should be financed by the States or the federal government as well (Piesman & Eisen, 2008). This is an example of the higher societal level in the social-ecological model. Homeowners who clear brush from their own land and individuals who wear insect repellent and long pants are working at the individual level, where it is difficult to affect broader change. Health care in the United States continues to be deeply tied to personal responsibility. When malaria and yellow fever were finally brought under control in the United States in the 1930's and 40's, it was only after malaria became tied to the economic development of the Nation. Eliminating the problem then became the center of a major public health and

engineering campaign by the federal government (CDC, 2010). Eliminating Lyme disease will require the same thorough regional or national response.

Dissemination

The outcome of this literature review is the White Paper (Appendix B) and accompanying brochure (Appendix C). The White Paper is a one-page summary of the results of this literature review, and the brochure is a summary that is formatted for easier reading for the sake of the general public. Dissemination will occur at local health offices and public gathering places. The State of Vermont is considered endemic for Lyme, with numbers rising every year. The southern counties, which are the closest to the early outbreak areas of Connecticut and Massachusetts, have the highest rates of Lyme in Vermont.

Outcome effectiveness can only be measured within the greater push for Lyme prevention recently being sponsored by both the State Health Department and different clubs and organizations. Effectiveness of this intervention is measured by a rise in the comfort level of providers who are diagnosing Lyme disease in this area.

Implications for Nursing

This study is full of implications for nursing practice. Nursing is often the first profession to see patients and populations affected by Lyme, whether it is in the field, such as public health inspectors and planners, or in the office and emergency room, where triage nurse must consider symptoms before assigning level of urgency to patient care. Nurses who are able to recognize symptoms in their patients are of value to their diagnosing colleagues and to the population as a whole. This literature review reinforces the need to take thorough histories on patients and to be familiar with the geographical and environmental concerns that are unique to different areas. There is not a "one size fits all" approach to certain problems and certain areas.

Although there is a large body of research on the topic of Lyme disease at this time, there is still research that could be done on the subject on this area in particular. Quantitative studies in particular are in short supply when focusing on Lyme disease and how people live with it. There is a large amount of talk in media forums regarding different aspects of Lyme, and it would be helpful if those voices could be brought together with medical workers and researchers in order to stop the dissemination of unproven and possibly hurtful information in this field. On the topic of maternity and the elderly, there is little information regarding how these populations alone are affected by Lyme disease. Lyme is a problem that unfortunately will not disappear without a concentrated response. Older studies on small samples should not be generalized to larger populations, as Lyme is more prevalent in the U.S. and Europe than it was in the early 1990's. The fact that researchers are still using and quoting these studies means that much work remains to be done in the Lyme field.

Nurses are very involved in the teaching of patients and populations through their presence in these different fields. One of the strengths of the nursing profession is its incredible versatility, and through that versatility, the ability to see all sides and factors that come within an issue. Lyme disease is yet another example of this, as the environment, individual and greater population all need caring for within the larger context of the disease. Greater education is needed for not only nurses but the public and other areas of the health professions, particularly in differentiating different rashes and Lyme arthritis from other common problems.

On a policy level, nurses should continue to advocate for patients and to treat the individual patient, rather than the disease while still advocating on a population level. Lyme disease is an excellent example of a disease in which focusing on the individual problem is not stopping the spread or burden of the disease in the rest of the population. As stated in the

discussion, policy makers need to move the burden of Lyme from the individual to the societal level. Nurses need to consider the case of Lyme and its population implications when lobbying for different health care policies and programs.

Conclusion

This paper examines symptoms of Lyme disease that are less known not only to the majority of the United States population, but unfortunately to many medical providers. These providers, who have been taught to “think horses, not zebras” when assessing commonplace symptoms, need to remember to consider Lyme as a diagnosis, even when living and practicing areas that are considered non-endemic for Lyme. This vector –borne disease will continue to spread across the United States in habitats that will support populations of different black-legged ticks. Prevention measures have been left to individual landowners and small corporations and clubs rather than to larger public health and governmental services, reducing the scope and reach of these prevention efforts. Due to this spread and the lack of a coordinated response by larger groups, in coming years individuals and their providers will need to shoulder the majority of responsibility for their own health care and the education of the public at large. This response can be changed with greater coordinated efforts from individuals, communities and regions affected by Lyme disease today.

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Appendix A

Reference	Lakos and Solymosi, 2009	Aucott, Seifter, and Rebman, 2012	Cottle et al, 2012	Aucott et al, 2009	Saulbury, 2005
Study Design	Retrospective	Retrospective	Retrospective, Descriptive	Retrospective	Retrospective
Sample and Setting	95 pregnant women with Lyme disease in Budapest, Hungary in the past 22 years	13 adult patients in one practice located in a Lyme-endemic area	115 adult patients referred to an infectious disease practice in Liverpool, UK.	165 adult patients presenting to one practice in a Lyme-endemic area	20 pediatric patients aged 4 to 18 at one practice that was not considered to be located in a Lyme-endemic area
Objective	Not specifically stated. To discover whether untreated Lyme disease is associated with adverse outcomes in pregnancy.	Not specifically stated. To present a case series on untreated patients with persistent symptoms of probable Lyme disease.	To describe patterns of referral, investigation, diagnosis and treatment in patients with suspected Lyme disease	To characterize a group of patients presenting with possible early Lyme, determine how many of those met CDC diagnostic criteria, and characterize patterns of care treatment.	To reiterate the clinical presentation of Lyme arthritis in children and to remind physicians to consider the diagnosis in children presenting with acute arthritis
Lyme Aspect Studied	Lyme affecting pregnancy	Range of symptoms in patients presenting without history of <i>erythema migrans</i> but with positive serology	Differentiating Lyme disease from other diagnosis	Accurate diagnosis of Lyme disease	Lyme arthritis in children
Findings	Adverse outcomes in 60% of untreated women, 31.6% of women treated with oral antibiotics, and 12.1% of those treated with IV antibiotics.	Probable late Lyme disease shares features with confirmed late Lyme disease.	A minority of these patients had Lyme disease (23%) with 33% diagnosed instead with chronic fatigue syndrome. Lyme disease is susceptible to misdiagnosis.	61% were diagnosed with Lyme disease, 13% presented without a rash and 54% of these patients were misdiagnosed	80% presented with swollen knees, and diagnostic time was 3 days to 52 weeks. Only 50% recalled a tick bite, and none were diagnosed with <i>erythema migrans</i> .

Reference	Oymar and Tveitnes, 2009	Milewski et al, 2011	Nigrovic, Thompson, Fine and Kimia, 2008	Skogman et al, 2012	Tveitnes, Natas, Skadberg and Oymar, 2012
Study Design	Descriptive	Retrospective	Retrospective	Prospective, with neurological examination and questionnaire five years after confirmed diagnosis	Retrospective chart analysis
Sample and Setting	143 pediatric patients in a Lyme endemic area	506 joint aspirations in pediatrics patients at a hospital in a Lyme endemic area	313 pediatric patients in one ED in an endemic area	84 children with confirmed Lyme disease	232 children complaining of meningitis in a Lyme-endemic area
Objective	To evaluate the clinical characteristics of children with nueroborreliosis in an endemic area	To define the prevalence of Lyme arthritis vs. septic arthritis in pediatric patients and to compare the presentations	To determine clinical predictors of Lyme disease as the etiology of peripheral facial palsy in children presenting to the ED in a Lyme-endemic area	To determine long term clinical outcomes in children with confirmed Lyme disease	To evaluate the epidemiology of infectious meningitis in a Lyme endemic area, and to study different clinical characteristics
Lyme Aspect Studied	Neurological manifestations in pediatric patients	Lyme arthritis in pediatric patients	Neurological manifestations in pediatric patients, facial palsy	Long term-neurological manifestations in pediatric populations	Lyme meningitis in pediatric populations
Findings	The most common presentations were mild meningitis and facial palsy. EM preceded the neurological symptoms in only 27% of the patients	In Lyme endemic areas, the prevalence of Lyme during arthritis is 31% overall and 45% in the presence of knee effusions. Quantitative data for comparison of septic arthritis and Lyme arthritis	Lyme disease is a frequent cause of facial palsy in endemic areas. Quantitative data presented for comparison of Lyme facial palsy vs. other facial palsies.	Long term recovery rate was 73%. Facial palsy was the most common long term affect. None of these long term affects affected daily activities or school performance and were considered to be mild. Nonspecific complaints were common.	Lyme diagnosed in two-thirds of patients presenting with infectious meningitis. Distinct clinical characteristics identified between different types of meningitis.

Reference	Costello et al, 2009	Strobino et al, 1993	Logigian, Kaplan & Steere, 1990	Qureshi, New, Zulqarni and Nachman, 2002	Bakken, 2002
Study design	Retrospective chart analysis	Prospective, Pilot	Descriptive	Retrospective Case series	Qualitative, grounded theory research
Sample and setting	207 children at a Boston hospital, a Lyme-endemic area	Out of 2014 women, 11 were found to be positive at their first prenatal visit	37 patients with neurologic deficits	216 patients in Lyme-endemic area	Nine physicians
Objective	To identify predictive factors for Lyme carditis in children and to characterize the clinical course of these patients	To determine if prenatal exposure to Lyme disease was associated with an increased risk of adverse pregnancy outcome	To define further the chronic neurologic abnormalities of Lyme disease	To determine the incidence of overdiagnosis and overtreatment of Lyme disease in children residing in an endemic area using standardized CDC diagnostic criteria	To develop a theory describing how physicians learn and formulate decisions in the context of diagnosing Lyme disease
Lyme Aspect Studied	Lyme carditis in pediatric populations	Maternal	Long term deficits in Lyme patients	Pediatric	How decisions are made in the process of Lyme diagnosis
Findings	33 patients in the sample presented with carditis. Description of patient characteristics	Maternal Lyme at conception was not associated with adverse outcomes as a whole	Associated with memory loss, mood disorders, language deficits	Overdiagnosis and overtreatment is a concern in areas endemic for Lyme disease	Repetitive experience combined with cognitive knowledge led to familiarity and to confidence in diagnosis

Appendix B

The Many Faces of Lyme Disease:

A White Paper

The incidence of Lyme disease continues to rise steadily in the United States. In 2011, there were 24,364 confirmed cases in the United States, concentrated largely in the Northeast and upper Midwest. These areas of the United States contain the best habitat for Lyme disease's main vector in the US-*Ixodes scapularis*, commonly known as the blacklegged or deer tick. According to the Centers for Disease Control, Lyme disease is the most common vector-borne disease in the United States and the sixth most common nationally notifiable disease. Despite this prevalence, many health care providers continue to find diagnosing Lyme confusing. Lyme has become known for its ability to imitate a vast number of symptoms and diseases. The purpose of this white paper is to present some of the different diagnoses that are most often confused with Lyme by health care providers, and to remind providers to consider Lyme as a possible diagnosis when living in or near endemic areas. As Lyme disease spreads further across the United States every year, all health care providers need to be aware of the danger of a missed diagnosis not only for patient safety but for health care and economic concerns as well.

Common difficulties in adult Lyme diagnosis:

- Easily missed presence of tick
- Missed or nonexistent rash (*erythema migrans*)
- Erythema migrans does not appear in traditional "bull's eye" form-easily mistaken for spider bite, cellulitis, or shingles
- Early flu like symptoms such as headache, fever, fatigue, stiff neck and headache are assumed to be symptoms of the common cold or "flu"
- Later symptoms are mistaken for problems such as arthritis, fibromyalgia, anxiety, Bell's Palsy, viral meningitis, Alzheimer's, or heart block.

Older adults are at risk for having symptoms of Lyme misdiagnosed as early Alzheimer's, Parkinson's or other neurological diseases. Pregnant women are particularly at risk for missed diagnosis. Several studies have shown a higher risk of adverse outcomes in pregnancy in the presence of untreated maternal Lyme. Obstetricians and midwives may be first line diagnosticians in the presence of perinatal Lyme.

Lyme diagnosis in pediatric patients is similar to adults with several separate considerations.

Common difficulties in pediatric Lyme diagnosis:

- Lyme can be difficult to differentiate from other common childhood diseases
- *Erythema migrans* is more likely to be missed
- Arthritis is the most common late manifestation, often mistaken for juvenile rheumatoid or septic arthritis
- Lyme is now the most common reason for facial palsies in children in the United States, and most often presents as unilateral rather than bilateral
- Lyme meningitis has been found to be the most common type of non-bacterial meningitis in children in some endemic areas

In conclusion, practitioners living in or near Lyme endemic areas must integrate Lyme disease diagnostic criteria into their everyday practice. Delayed diagnosis subjects patients to inappropriate medications and treatments and deepens the economic burden of both individuals and societies.



Common signs of Lyme disease

Rash around site of tick bite, best known in its "Bull's eye" shape

- Rash can be mistaken for spider bite, cellulitis or shingles

Signs of the common cold: fever, headache, and joint aches

Later signs can include arthritis, stiff neck and headache, facial paralysis, forgetfulness, confusion, and heart palpitations.

How do I avoid getting Lyme disease?

Check yourself and pets daily for ticks, especially in the summer months

Check yourself daily for any strange rashes

Keep brush and grass cleared around your house

Wear insect repellent when working or playing outside

Tuck pants into socks when walking in grassy, overgrown area



Things to think about in children:

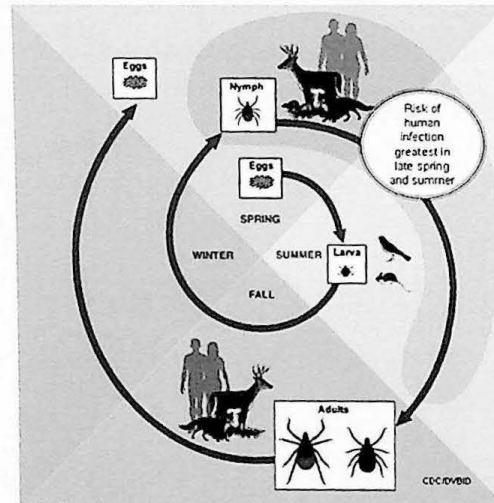
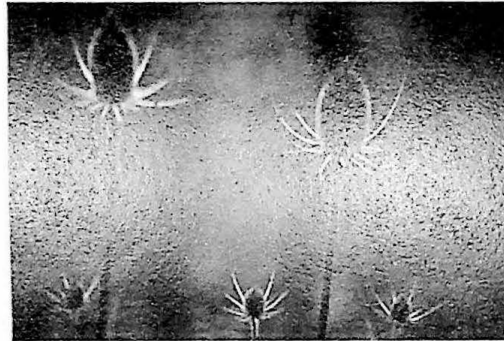
- Rashes are easily missed in children
- Other common Lyme symptoms can be mistaken for childhood illnesses
- Arthritis is the most common late complaint in children!
- In some areas, Lyme disease is now the most common cause of meningitis, facial palsies and arthritis in children

Things to think about in adults:

- Lyme rashes can be mistaken for spider bites, shingles, or other infections
- Other early symptoms can be dismissed as a common cold
- Late Lyme can be mistaken for Alzheimer's and other chronic illnesses
- Pregnant women should take care to check for ticks carefully-Lyme can affect pregnancies

For More Information on Lyme disease, Contact:

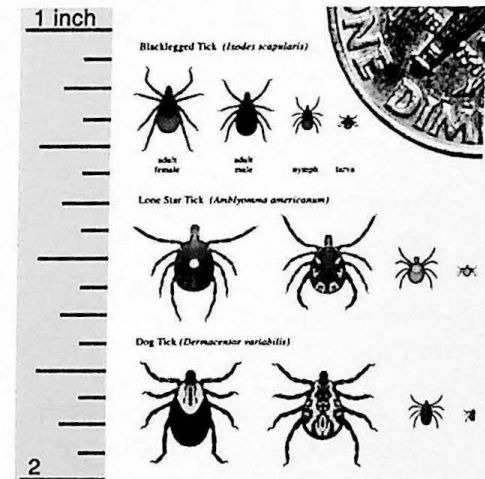
- Your Health Care Provider
- The Centers for Disease Control at www.cdc.gov
- The National Institute of Health at <http://www.nih.gov/>
- The Vermont Department of Health at <http://healthvermont.gov/>
- Your local Vermont Health Department



The Many Faces of Lyme Disease

Blythe Kersula, RN

University of North Dakota



Room: CRSC 103
Location: Thesis/Independent Study
Cabinet

Many Faces of Lyme Disease



CSC11547