Differential Diagnosis & Intervention in Clinical Neurology April 13, 2016

The Impact of Physical Therapy on

Individuals Diagnosed with Lyme Disease

Overview and Pathology

Lyme Disease (LD) is caused by the bacteria *Borrelia burgdoferi* and is most commonly transmitted to humans through a bite of an infected tick. It was first recognized in the 1970s in a group of pediatric cases in Lyme, Connecticut (Nichols & Windemuth, 2013, p. 362). Since 1991, lyme has become a national notifiable condition in the United States. However, while this disease may occur nationwide, the majority of cases occur in the Northeast regions of the U.S - with 96% of cases occurring in 14 states ("Data and Statistics! Lyme Disease | CDC", 2016).

Typically, the incidence of LD occurs between May and November - prime outdoor activity period - with a peak during the months of June and July (Nichols & Windemuth, 2013, p. 362). This also coincides with tick development and maturity. By spring, larva ticks have matured to nymphs (about 2 mm in length), which make them difficult to spot on the body. Between the spring and summer months, nymphs feed on mammals in order to sustain development. During this time is when humans are most likely to get infected. Couple this with the nymph's tiny proportions and numerous outdoor activities, and you can account for the high incidence during this time. It is worth mentioning that of those patients diagnosed with LD, only 25% to 30% are able to recall a tick bite (Nichols & Windemuth, 2013, p. 362).

Adult ticks can also transmit LD through their bite. However, they are usually easier to spot on the body. If a person does find a tick on their person, the Center of Disease Control (CDC) recommends removing the tick with a pair of tweezers, grasping the tick as close to the skin as possible, making sure you pull the tick perpendicular from the skin without crushing the

tick. After tick removal, the area and your hands should be wiped clean with alcohol followed by immediate disposal of the tick, tightly bound or bagged so as not to escape. Post removal, if you develop early symptoms of an infection, the CDC recommends visiting your doctor immediately and reporting the tick incident. However, the best way to prevent LD is to prevent tick adhesion in the first place.

When it comes to preventing tick bites, the CDC offers useful information for a wide variety of situations. They provide strategies for preventing tick bites on pets, landscaping techniques to create an uninviting atmosphere for ticks, and even natural remedies, such as essential oils and garlic (with research references) in order to decrease the chances of being bitten. Of course, no method is guaranteed, therefore it is important to recognize ticks on the body and how to deal with them appropriately.

When enjoying the outdoors during prime tick season, the CDC recommends certain precautions that may prevent tick attachment and bites. They recommend wearing clothing that covers most of your skin and spraying clothing with permethrin or using bug repellant with at least 20% deet. In addition, particularly during hikes, they recommend following the designated path and avoid dense wooded and grassy areas. After an outdoor activity, a shower is recommended followed by a thorough inspection of the body, checking for areas such as belly buttons, underarms, in and around the ear, back of knees, and particularly in the hair. It is also important to check pets and any gear that was used in your activity as that is a way for ticks to enter the home. Finally, laundering all clothes immediately after an outdoor activity will reduce the chances of getting a tick bite.

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Clinical Manifestations & Differential Diagnosis

Lyme Disease is transmitted to humans when a tick, infected with the bacteria *Borrelia burgdoferi*, bites an individual. Once a person is bitten, an erythema migrans may develop around the bite. The rash may be of typical appearance with a circular red rash and a central clearing that slowly expands (most classic presentation) or it may take other forms. The CDC states the rash may reach 12 in. or more in diameter and may feel warm but rarely itchy or painful. However, only 70% to 80% of infected persons will develop a rash ("Signs and Symptoms | Lyme Disease | CDC", 2016). Therefore, there are other symptoms to look out for.

According to the CDC, symptoms of LD can be separated into two timelines. Between 3 to 30 days post infection, early signs include: fever, chills, headache, fatigue, muscle and joint aches, and swollen lymph nodes ("Signs and Symptoms | Lyme Disease | CDC", 2016). After 30 days, new, more serious symptoms may occur including: severe headaches and neck stiffness, arthritis with joint swelling particularly in knees, Bell's palsy, heart palpitations, episodes of dizziness, SOB, nerve pain, numbness or tingling in hands or feet, memory deficits, and intermittent pain in tendons, muscles, and bones. However, these are not hard and fast rules. One of the more common early symptoms according to Rizvi and Diamond (2008), is painful radiculoneuropathy which can, unfortunately, be misdiagnosed as a nerve impingement. If any of these symptoms occur, the CDC recommends seeking medical attention and informing them of your recent travels and activities, especially any that might have exposed you to lyme infected ticks.

In order to properly diagnose lyme disease, it is important to have a detailed history, an accurate list of symptoms and appropriate blood tests. In order to confirm lyme disease using laboratory evidence, the accepted standard as advised by the CDC, is a 2-tier testing procedure.

The first test is an enzyme immunoassay (EIA), or an indirect immunofluorescence assay (IFA), although this second test is done rarely. If these first tests are negative, then no further testing is recommended. However, if the first test is positive or equivocal, then the second test, the Western blot is performed. It should be noted, a confirmed positive of LD only occurs if both tiers are positive.

In the event LD is not properly diagnosed or appropriately addressed moving beyond the 1 month period, more serious issues may occur. Left untreated, skin, heart, joint, or neurological issues are common. When speaking about neurological issues, in the central nervous system (CNS), the most well-defined syndrome according to Rizvi and Diamond (2008), is lyme encephalopathy and lymphocytic meningitis. With Lyme encephalopathy, patients may experience difficulty concentrating, lability, memory and attention difficulties, and sleep disturbances. These researchers also state the more common symptoms of later LD to be photophobia, headache, and neck stiffness. However, these are variable. In addition, syndromes although rare, include intracranial hypertension syndrome, encephalomyelitis, and myelopathy. When LD affects the peripheral nervous system (PNS), the sensory and motor pathways affected may include paresthesias, decreased sensation, and weakness.

When LD affects the joints, it is termed lyme arthritis. The most affected joint is the knees, where it manifests as an intermittent or constant inflammation ("Lyme disease Symptoms - Mayo Clinic", 2016). Finally, LD can also affect the heart - Lyme carditis. According to Ljøstad and Mygland (2012), infection to the heart has a variety of presentations including atrioventricular conductions blocks, myocarditis, pericarditis, and in a few rare cases documented only in Europe, cardiomyopathy.

The appropriate early intervention that is supported and recognized in medical management is a course of antibiotics which will be explained in the following section. However, if symptoms continue to persist despite treatment and patients continue to report symptoms, patients are then diagnosed with post lyme disease syndrome (PLDS), which is not to be confused with chronic lyme disease.

There exists controversy regarding the appropriate classification of individuals who continue to suffer from lyme symptoms, long after treatment and diagnosis. From the research, chronic lyme diagnosis was used when there were varying presentations of the disease - even at times when there was no previous history of lyme disease. This confusion led to the Infection Disease Society of America (IDSA) defining the condition these individuals experienced as Post Lyme Disease Syndrome (PLDS). The definition, according to Nichols and Windemuth (2013), "requires that patients have documentation of appropriately treated prior LD and persistent subjective symptoms without other medical explanations." Despite this, there seems to be skepticism about this disease because the cause of PLDS is unknown. Ljøstad and Mygland (2012), states there is a belief among medical professionals that continued symptoms are a caused by an unresolved, lingering infection. Still others are dubious given the lack of clinical and laboratory evidence. Regardless of the cause, more research is required in this area to further understand the cause and nature of this syndrome in order to provide better patient care.

General Medical Management

Standard intervention for early detection of lyme disease is a course of antibiotics such as doxycycline, amoxicillin, and cefuroxime axetil. They may be given either orally or intravenously, and length of treatment depends on the time since diagnosis and severity of symptoms. However, prolonged or multiple courses of antibiotics is not recommended due to potential harm to an individual, the growing issue of antibiotic resistance, and its unproven efficacy (Nichols & Windemuth, 2013). During this literature search, the only medical management discussed is antibiotic therapy which is unfortunate considering many of the symptoms have a physical component.

Physical Therapy Implications

When it comes to LD and how physical therapy may aid people suffering from this disease, the research is scare. A literature review reveals very few articles that directly investigate physical therapy as an intervention and how it affects the symptoms of people diagnosed with LD. Along with this discovery, it is not surprising when D'Adamo, McMillin, Chen, Lucas, and Berman (2015) state that exercise is currently not part of the clinical practice guidelines offered by the CDC, Infectious Disease Society of America, nor in the International Lyme and Associated Diseases Society - especially when many of the symptoms may involve a physical aspect of the individual's life. After an extensive literature review, one article by D'Adamo et al. (2015) attempted to address this concern by aiming to directly address the feasibility and efficacy of resistance exercise and persistent symptoms of Lyme disease.

The uncontrolled pilot study by D'Adamo et al. (2015) occurred over a 4 week period in which subjects would undergo a supervised resistance exercise program three times per week. Inclusion criteria for the study required previous clinical diagnosis of LD, medical clearance to participate in a resistance exercise program, and not currently on a training program. The exercise program was supervised by a certified exercise trainer for all eight qualifying subjects and consisted of leg presses, seated rows, standing heel raises, vertical chest presses, and supine abdominal crunches. The outcome measures included three validated questionnaires and an

exertion scale. This scale, the Purvis Effort Continuum Scale (PECS), was one of the limiting factors of this study lacking formal validity testing due to its novelty. However, investigators reasoned that the current validated exertion scales, such as the Borg or the OMNI, were only useful for high intensity exercises. This study, because of the unknown nature of exercise in this population, focused on low level intensity exercises, for which the investigators stated a scale for it did not exist and current scales did not capture.

Each training session was supervised by the same trainer and adjusted according to the PECS - ensuring that the subject was performing a low level intensity training program but still increasing in resistance and repetitions. For all exercises except heel raises, the difference in volume of exercise between baseline and at 4 weeks was statistically significant with exercise volume measured as the number of repetitions multiplied by the amount of resistance. For the questionnaire outcome measures, the only statistical significant difference was the number of days that participants felt healthy and full of energy. In addition, there were no reports by the subjects of adverse events during the training period that would be of concern when recommending this type of training for individuals without professional assistance.

Despite its lack of functional outcome measures, this study demonstrated that people experiencing persistent LD symptoms are able to exercise safely and improve their ability to tolerate a resistive exercise protocol for 4 weeks. According to D'Adamo et al. (2015) this finding is the first step in addressing the lack of exercise guidelines and clinical practice recommendations, despite its accepted benefits, from major medical organizations, which on the forefront of research for this disease. Furthermore, this research opens the door for physical therapy to address the functional needs of patients with persistent LD symptoms. This article demonstrates that these patients can safely exercise and can make significant improvements while having a multi-systemic disease affecting nerves and muscles.

D'Adamo et al. (2015) was the only article that looked into exercise as a treatment intervention and its affect on patients with LD. In an effort to provide additional corroboration and solutions for this topic, the literature review was expanded to include exercise training and its effects on general polyneuropathies. Regardless of the disease, the symptoms and effects of the physiological responses are similar. (Smith & Mulligan, 2014; Tofthagen, Visovsky & Berry, 2012). Therefore, looking at general polyneuropathy research that focuses on strength, balance, and gait may support recommendations for exercise training in patients with LD.

There are several diseases or ways to be affected with a neuropathy. Diabetes, the most common, along with Guillain-Barré syndrome (GBS), Charcot-Marie-Tooth disease, HIV, cancer, infections, toxins and LD are just some of the causes that can lead to an individual suffering from a neuropathy. The demyelination or axonal degeneration that occurs in the peripheral neuropathy affects the sensory and/or motor system. According to Smith and Mulligan (2014), if it is a motor involvement, there may be decreased strength, paralysis, paresis, diminished or absent reflexes, loss of range of motion, and fatigue. Sensory involvement would impair or alter sensations such as proprioception, touch, pressure, and pain. Loss in either or both will lead to functional impairments and increase the risk of falls. Unfortunately, Smith and Mulligan (2014), state that out of the many diseases that cause peripheral neuropathies, many are not treatable. Additionally, Tofthagen, Visovsky, and Berry (2012) state medications are useful in helping to treat the pain associated with neuropathy; however, research has not shown that medications improve strength, gait or balance. Therefore, the impact physical therapy can have on these individuals may be significant.

Smith and Mulligan (2014), reviewed articles that focused on peripheral neuropathy (PN) and exercise, rehabilitation, and physical therapy; limiting articles to those that were peerreviewed and published after 2009. In one 4-year study with an aerobic/cardiovascular exercise intervention, the investigators found that the onset of diabetic polyneuropathy (DPN) was delayed in subjects who had diabetes. The subjects walked briskly at 50% to 85% of their heart rate reserve as compared to controls who did not exercise aerobically. In another study, subjects with GBS and continued fatigue were placed on a 12 week cycling program to asses fatigue, muscle strength, quality of life, and activities of daily living. Researchers of this study reported an improvement that was statistically significant in all areas. When Smith and Mulligan (2014) looked at resistance training, the researchers found that strength did improve in a statistical significant manner. However, it is important to note from this study, the improvement of overall strength did lead to a positive effects in ADL, sit to stand, supine to sit, and stair climbing - all functional tasks. Similarly, in an article by Allet et al. 2009, the researchers reported improved strength and balance, walking speed, and decreased fear of falling after subjects participated in a 60 min, twice a week, for 12 weeks intervention that included strength, balance, and functional training. The training program was deemed feasible and safe, and results were sustained 6 months post intervention.

Smith and Mulligan (2014), also reviewed articles that focused on balance as an intervention and how that changed in individuals with PN. One article focused on balance exercises and limiting visual feedback - something these individuals relied on heavily to aid in balance. The results of this study showed significant improvement on outcome measures such as Berg Balance Scale (BBS), Functional Reach, Timed Up and Go, and gait speed. Two other interesting articles used Tai Chi as an intervention to address balance issues in individuals with

PN. Both articles demonstrated that Tai Chi improved balance scores and one article showed improvement in stride length and single limb stance. Additionally, studies by Hartmann, Murer, and Bruin (2009), Miller, Magel, and Hayes (2010), and Iwamoto et al. show that interventions that target strength, balance, and range of motion have been effective in improving gait and reducing falls.

When it comes to movement disorders, no matter what the cause, physical therapist have the knowledge and background to assist in improving functional mobility. In the cases of individuals with LD, our role, is to use a combination of education, exercises, and modalities to maximize function despite the nature of these progressive diseases. D'Adamo et al. (2015), while not focusing on functional outcome measures, did show LD patients can exercise safely and make gains under low intensity loads. Combining their research with the research on general PN and the improvements made in gait, balance, strength, and range of motion, there exists treatment protocols that can be implemented and further researched in particular to individuals with LD. Ultimately, our knowledge about movement and functionality can help treat these patient's functional limitations with the goal of improving it and their quality of life.

Case Scenario (5.3 pages)

Past Surgical History: None

<u>Past Medical History</u>: Patient A is a 36 year old female diagnosed with LD when she was 31 years old with symptoms first noticed at 19 years old after a trip to Upstate New York. Following this trip, patient developed chronic bronchitis, fatigue, and a rash - not classic bulls-eye associated with LD. Immune system was compromised for a few years post trip. Patient continued to experience infections which were all treated effectively with antibiotics. For the

next few years, patient maintained a healthy lifestyle which reduced overall fatigue and number of infections.

Symptoms, however, continued to progress. At 25 years old, patient experienced increased infections and memory deficits. At 26 years old, after a trip to Vermont, patient returned from trip with a rash on chest. After a couple of weeks, patient's symptoms expanded to severe headaches, neck stiffness, fever, weakness, fatigue, hair loss, and IBS. Doctor ordered LD test with equivocal results. Other exams included Lupas, and HIV. By 30 years old, patient's symptoms include: fatigue, tremor on 3rd finger, shooting left lower extremity sensation, poor concentration and memory, loss of sensation on bilateral feet, left sided Bell's Palsy, and muscle twitches. Patient was tested for MS and ALS and were ruled out.

At 31 years old, patient self diagnosed LD and confirmed diagnosis with specialist. Patient was placed on antibiotics which improved cognitive and physical functions. After 28 months of several different antibiotic treatments, doctor discontinued antibiotics. Six weeks later, patient's symptoms returned and new ones emerged including vertigo, burning soles of feet, cold sensation of upper and lower extremities. Patient resumed antibiotics until symptoms subsided and then taken off with no change in health status for nine months.

At 36 years old after a trip to Dominican Republic, patient developed pudendal neuralgia. Patient once again resumed antibiotic treatment for another 18 months before deciding to discontinue treatment against medical advice. Patient was concerned of potential kidney issues due to urine discoloration, foaminess, and discomfort.

<u>History of Present Illness</u>: Patient is a 37 year old female diagnosed with LD in 2010. Patient presents to clinic on Jan. 18, 2016 with bilateral cold upper extremities, pins and needles on

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bilateral hands, bilateral burning on soles of feet, Bell's Palsy grade 2, headache, neck stiffness, memory issues, fatigue, and poor endurance.

Subject reports pain in left UE and cervical area, and posterior left LE. Pain described as pins and needles and 3/10 in all areas.

<u>Social History:</u> Patient lives in a 5th floor apartment building with her husband. There are no elevators. There are 18 steps between floors and 4 steps to enter. Patient reports independent ADL and a community ambulator. Patient is unemployed.

Active ROM: Patient is WNL for bilateral LE.

Manual Muscle Test

- Bilateral LE 5/5 (hip extension, knee flexion/extension, ankle dorsiflexion/plantar flexion) except for hip flexion, 4-/5.
- Bilateral UE 5/5 (shoulder flexion and abduction, elbow flexion/extension, wrist extension/ flexion, grip) except left shoulder flexion, 4-/5.

<u>Neurological:</u> Pt self reports experienced decreased sensation on left LE and UE. Sensation test reveals normal findings. Rapid Alternating Movement: Pronation/Supination was intact. Mild dysmetria on left UE. Right UE intact. Proprioception on bilateral great toe is intact.

Physical Therapy Program

Session 1

Sit < > stand without assistive device and modified independence. Patient demonstrated decreased speed and required upper extremity support. Patient ambulated 25 feet without

assistive device but used furniture for support. Gait characterized by decreased speed, decreased left LE stance time and left lateral trunk lean.

Given ease of fatiguability, decreased strength of hip flexors, and noticeable difficulty in sit to stand the following exercises were given to increase strength in hip:

- Single Leg Raise bilateral, 5 reps/set, 6 sets if tolerated.
- Bridges 5 reps/set, 6 sets if tolerated.
- Side lying single leg raise bilateral, 5 reps/set, 6 sets if tolerated.
- Hamstring Stretches seated. Hold for 30s, 3 sets post exercise.

Additionally, patient was given an intermittent elliptical program to increase endurance. Patient was instructed to monitor running tolerance by keeping track of time before experiencing fatigue and time of recovery. Patient will then begin intermittent program for 3 cycles. Patient was instructed to cease any exercise if intolerable, produced pain, or experienced severe fatigue.

Session 2

Chief Complaints: Pt. is complaining of balance problems and vertigo.

Strength Re-evaluated: Hip flexion 4+/5. Improvement from previous session(4-/5).

Vestibular Testing:

- Dizziness Handicap Inventory (DHI): 82/100 (higher the score signifies greater self perceived handicapping effects imposed by dizziness)
- VOR1 Horizontal/Vertical saccades noted
- Berg Balance Scale: 43/56; difficulty with higher level balance tasks such as placing alternating foot on stool, tandem stance, and standing on one foot.

• Dynamic Gait Index: 16/24; difficulty with horizontal and vertical head turns during ambulation.

<u>Assessment</u>: The patient demonstrated increased strength in LE hip flexion. However, patient complaints of vestibular issues as well as objectively demonstrating decreased balanced as tested on Berg and Dynamic Gait Index. Pt would benefit from a balance program as described in the following section.

Balance Program:

- VOR1 Horizontal with a fixed point at eye level. 30 head turns a day x 3/day
- Gait with horizontal head turns x 3 x 1 min/day (Range and speed set by the patient with instruction on amplitude and velocity to mild inducing symptoms.)
- Tandem Stance (R) and (L) x 3 x 30seconds/day
- Single leg stance (R) and (L) x 5 x 10 seconds/day

Session 3

Vestibular Testing:

- Dizziness Handicap Inventory: 52/100
- VOR1 Horizontal/Vertical smoother pursuit noted.
- Berg Balance Scale: 54/56; difficulty with standing on one foot.
- Dynamic Gait Index: 22/24;

<u>Assessment</u>: The patient demonstrates increased balance during static standing and ambulations as seen through the increased scores of the Berg Balance Scale and the Dynamic Gait Index. Pt self reports improved confidence with balance and dizziness as demonstrated with a decreased score of the DHI. This case study above is based on a real individual who is currently receiving physical therapy as described above. After 3 session from initial evaluation, she has shown definite improvement in all objective measure as stated above. She will be followed for the next six weeks and her progress will be documented. Despite the paucity of research in this area, the few article that have been done have shown that physical therapy can make an improvement in patients with LD and I look forward to the completion of this project.

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