

Qualitative Description of the Exertional Symptoms of Participants with Persistent Symptoms of Lyme Disease during a Low Intensity Resistance Training Intervention

Original Research

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Abstract

Introduction: Greater emphasis needs to be placed on approaches to improve the health-related quality of life of patients with persistent symptoms of Lyme disease (PSLD), but little information exists to inform an exercise professional's expectations of their supervision of resistance training (RT) programs with PSLD patients. In order to build this knowledge base, a secondary qualitative analysis was performed to explore the RT exertional symptoms of PSLD patients that participated in a 4-week study investigating the feasibility of an RT intervention.

Methods: Comments regarding exertional symptoms that were recorded in a daily exercise log were the main source of data for this secondary analysis. A manifest content analysis was performed in order to identify recurrent themes of exertional symptoms experienced by this sample of PSLD patients during RT.

Results: The reported findings revealed that strain, discomfort, crepitus, tightness, shaking, and control loss were the major themes of exertional symptoms recorded during the RT intervention.

Conclusions: These results provide insights intended to inform the expectations of supervisors of exercise (personal trainers, physical therapists, exercise researchers, etc.) when directing RT programming with patients with PSLD.

Key Words: Exercise log, RPE, *Borrelia burgdorferi*, resistance exercise.

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Introduction

Lyme disease (LD) is the most common tick-borne illness in the United States ¹. The identification and isolation of the etiologic agent of LD, *Borrelia burgdorferi*, was first reported in 1982 ². *B. burgdorferi* is one of several species of spirochetal (spiral shaped) bacteria typically transmitted to humans through a bite from an *Ixodes scapularis* tick, also known as a black legged tick or deer tick ^{3,4}. Originally, LD was thought to be a form of inflammatory arthritis, with the majority of the earliest identified cases found in young people in Wisconsin and Connecticut ⁵. Since then, the incidence of LD in the United States has rapidly increased. Recent estimates project more than 300,000 new cases of

LD per year ⁶. As of 2018, cases of LD have been reported in all fifty states ⁷. The geographic expansion of LD is causally multifactorial with climate change, increased travel and trade, and greater participation in outdoor recreation considered significant contributors ^{8,9}.

An LD infection has long been regarded as easily treatable following diagnosis ^{10,11} despite a number of patients who fail to respond to the traditional antibiotic therapy or experience only a temporary improvement in symptoms ¹². LD is often identified by a characteristic skin rash, known as Erythema migrans (EM) (also known as a bullseye rash) which may appear in association with fever, headache, malaise, and musculoskeletal pain ¹³. EM can be difficult to observe on darker skin tones, under hair, or when it does not resemble a bullseye in appearance ¹⁴. It is estimated that 60,000 new cases of LD do not exhibit a rash ¹ or the commonly associated summertime flu-like symptoms. This may delay a person from seeking timely medical attention and receiving effective pharmacological intervention ¹⁵. Without early treatment, many patients experience neurological and rheumatic conditions that may manifest long after the first exposure to the pathogen ^{16,17}. It has been demonstrated that an LD infection can persist despite antibiotic therapy, as evidenced by detection of the pathogen in fluids and tissue cultures ¹⁸.

Patients with LD who delayed in receiving treatment or were under-treated often experience a variety of persistent symptoms including fever, rash, fatigue, muscle, and joint pain, and neurological disturbances ^{1, 19-21}. The National Institutes of Health (NIH) have designated this persistent constellation of symptoms, post-treatment Lyme disease syndrome (PTLDS) ²². PTLDS is typically systemic and can range from mild to severe. PTLDS has been reported in both prospective and population-based studies in endemic LD regions. The CDC has estimated that approximately 10% to 20% of individuals with LD experience PTLDS ¹⁶. However, PTLDS patients represent only a small contingent of those beleaguered by persistent symptoms of Lyme disease (PSLD) ²³. PSLD is likely more widespread and of greater importance as a public health issue than PTLDS. Patients with PSLD represent a much larger group that accounts for all symptomatic LD patients, including both treated and previously untreated patients ²³. Some authors suggest the prevalence of PSLD is on the order of one million cases ²⁴.

Despite this suggestion, few studies exist investigating treatments to improve a PSLD patient's health-related quality of life (HRQoL) ²⁵. The positive effects of regular exercise on health are well supported ²⁶. Exercise, regardless of the mode, can serve as a complementary treatment method for many chronic diseases with functional limitations ²⁷. Resistance training (RT) has been demonstrated feasible for conditions such as persistent symptoms of Lyme disease (PSLD) ²⁸, peripheral neuropathy ²⁹, Parkinson's disease ³⁰, rheumatoid arthritis ³¹, heart failure ³², fibromyalgia ³³, and dynapenia ³⁴. Although exercise is feasible and supported in a majority of chronic disease contexts ³⁵, exercise tolerance and adherence in these groups can be unpredictable ³⁶.

Only one study, to the authors' knowledge, has demonstrated feasibility of a supervised RT intervention with PSLD patients ²⁸. In that study, D'Adamo et al. ²⁸ also sought to assess the influence of RT participation on symptoms of PSLD. The purpose of this study is to explore the exertional symptoms reported by PSLD patients during the RT intervention in D'Adamo et al.

Scientific Methods

This study is a secondary qualitative description (SQD) of data collected from previous research ²⁸. SQD is an effective way to address a different research question than that which was asked in the primary study ³⁷. SQD is especially suited for this study as it yields straightforward answers to the research question ³⁸. The philosophical orientation of this research is based largely upon naturalistic inquiry ³⁹.

Participants

Both the original study approval and the use of these data for secondary analysis were obtained from the institutional review board of the University of Maryland School of Medicine. This SQD was undertaken by a co-investigator that designed the primary study's RT protocol and who was the exercise trainer for seven of the eight participants in the study. All information for the current study was collected and de-identified.

Study participants were recruited by a board-certified physician in their private medical practice in Baltimore, MD. Informed written consent was obtained from all participants prior to the start of the study. Eight eligible participants between the ages of 18 to 60 with a previous clinical diagnosis of LD and at least three months of persistent symptoms participated in the study. A symptoms questionnaire (SQ) designed to assess persistent symptoms was given to participants prior to the beginning of the RT intervention and at the end of each week by the exercise trainer.

Participants rated the severity and frequency of persistent symptoms such as joint pain in the knees, joint pain in the hips, joint swelling in the knees, joint swelling in the hips, stiffness in the joints or back, back pain, muscle pain, muscle weakness, and fatigue.

Protocol

The exercise intervention was conducted at an exercise facility in Baltimore, MD. Participants performed one set of each of five RT exercises. Selectorized machines (Cybex Int'l, Medway, MA) were used to perform the leg press (LP), the seated row (SR), and the chest press (CP). The supine abdominal crunch (AC) and the standing heel raise (HR) were performed using the participant's bodyweight, with additional external weights added as necessary. The number of repetitions for each set was dependent on the value reported by the participant on a novel momentary-predicted rating of perceived exertion (RPE) scale. The five-point RPE scale was used to assess the level of exercise exertion and to assign the number of repetitions in each set that the participant could perform. The participants were instructed to report their RPE level between repetitions while unloaded. The RPE was based on feelings of effort, strain, discomfort, and or fatigue they predicted for a subsequent repetition based on their experience of the preceding repetition. The exercise trainer terminated the set when the RPE reported by the participant changed from level 2 ('Based on the last repetition, I can continue with another repetition with no strain.') to level 3 ('Based on the last repetition, I can continue with another repetition with some strain.'). The RPE was recorded by the exercise trainer in an exercise log (EL). If the participant noticed a change in perceptual feelings (e.g., discomfort, crepitus, tightness, etc.) elicited during a set, they were informed to report it to the exercise trainer, who then recorded it as a comment on the EL. If the exercise trainer observed motor behavior indicative of an exertional symptom (e.g., shaking, loss of control, etc.) during the participant's performance of the repetition, it was recorded in the same manner.

Data Analysis

Based on the sample of participants ($n = 8$), one qualitative data set was analyzed by manifest content analysis³⁸ in order to answer the research question. The unit of analysis was the text written in a field on the EL by the exercise trainer, which represented the contemporaneous commentary describing the exertional symptoms reported by the participant and or observed by the exercise trainer. For this SQD, the comments were converted to digital text from their native handwritten form and grouped both by exercise and by participant using a writing application called Ulysses for Mac (Ulysses GmbH & Co.). This format allowed the comments to be read easily to identify coding units related to participant and exercise. Two qualitative data displays were created within which the coded data was placed in order to best identify the presence of themes visually³⁹. The first data display was framed in an exercise-centric format and the second data display was framed in a participant-centric format. A symptoms questionnaire (SQ) designed to assess persistent symptoms was given to participants prior to the beginning of the RT intervention and at the end of each week by the exercise trainer. Participants rated the severity and frequency of persistent symptoms such as joint pain in the knees, joint pain in the hips, joint swelling in the knees, joint swelling in the hips, stiffness in the joints or back, back pain, muscle pain, muscle weakness, and fatigue. These data were used to provide insight as to an association, if any, with the exertional symptoms experienced during RT.

Results

The analysis revealed that recurrent themes regarding exertional symptoms with PSLD patients could be viewed from either the context of each exercise or each participant. Theme categories were created based on the recurrence of seemingly synonymous descriptors of an exertional symptom found in the comments as they were written. For instance, the category of control loss describes symptoms such as 'slight loss of control', 'slightly unstable on level 3 repetition', and 'unsteadiness on the eccentric phase of the repetition'.

Leg Press

The LP exercise was performed bilaterally on a Cybex VR3 Leg Press at a repetition tempo of 11 s (5 s concentric, 1 s isometric, 5 s eccentric). The RPE and exertional symptoms were reported during a 1 to 2 s unloaded phase between each repetition and recorded in the EL by the exercise trainer. Prior to performing each exercise on each day, the exercise trainer assessed each participant's exercise specific active range of motion⁴⁰. This assessment allowed for the machine settings to be adjusted to ensure that the resistance was never applied beyond the active range of motion (ROM) limits of the moving joints involved in the exercise. The exertional symptoms identified in the comments recorded during the performance of the LP were categorized into seven major themes: strain, discomfort, crepitus, tightness, shaking, control loss, and other. The perceptive experiences described by the participant fell into the categories of strain, discomfort, crepitus, and other. The categories of shaking and control loss described motor behaviors observed by the exercise trainer.

The majority of the strain symptoms were associated with the muscular system and localized to the quadriceps muscles (e.g., ‘slight strain in both quads’). The discomfort symptoms related to the articular system and were localized to the patellofemoral joint (e.g., ‘pain under knee cap’), knee joint (e.g., ‘pain in back of left knee’), and the hip joint (e.g., ‘twinge in left hip’). Crepitus symptoms were described as being felt at the patellofemoral joint (e.g., ‘knee cap popping’) or knee joint (e.g., ‘knee clicking’). Tightness symptoms were described as localized to the muscular system (e.g., ‘tight in quads’) or the articular system (e.g., ‘right knee tightening’). Shaking and control loss symptoms were observed in the lower body and typically described as relating to the phase of the repetition (e.g., ‘shakiness on concentric’ and ‘unsteadiness on eccentric’). Other symptoms included: ‘wooziness,’ ‘fatigue,’ ‘odd feeling on back of left knee,’ ‘burning,’ and ‘spasm.’

Seated Row

The SR exercise was performed bilaterally on the Cybex VR3 Row following the same procedures as the LP. Exertional symptoms were categorized into six major themes: strain, tightness, shakiness, control loss, discomfort, and other. Similar to the LP, the categories of strain, tightness, discomfort, and other described the perceptual experiences reported by the participant. The categories of shaking and control loss described motor behaviors observed by the exercise trainer. The majority of the strain and tightness symptoms were described by body region (e.g., ‘back of shoulder strain’ and ‘tightness in both shoulders,’ respectively). Shaking symptoms were described as related to the body region (e.g., ‘quivering in arms’) or relating to a phase of the repetition (e.g., ‘shakiness on concentric’). Control loss symptoms were described without further nuance (e.g., ‘slight loss of control’). Discomfort symptoms were related to a joint (e.g., ‘left elbow pain’). Other symptoms included: ‘slight muscle burn in back of left upper arm,’ ‘fatigue on level 3,’ and ‘loss in the range of motion.’

Chest Press

The CP exercise was performed bilaterally on the Cybex VR3 Chest Press in the same procedural manner as the LP and SR. Exertional symptoms were categorized into six major themes: discomfort, fatigue, shaking, strain, tightness, and burning. Discomfort symptoms were described both by body region (e.g., ‘right side of neck discomfort’) and affected joint (e.g., ‘wrist pain’). Fatigue symptoms were associated with muscles (e.g., ‘triceps fatigue’). Shaking, strain, and tightness symptoms were described by body region (e.g., ‘left arm shaking,’ ‘slight strain in right shoulder,’ and ‘tightness in the neck,’ respectively). Burning symptoms were associated to the affected muscle (e.g., ‘burn in left triceps’).

Standing Heel Raise

The HR exercise was performed by using bodyweight and the adjustable arms of a Nautilus Freedom Trainer (Nautilus, Independence, VA) machine for balance support. The HR was performed in the same procedural manner as the LP. Exertional symptoms were categorized into six major themes: burning, tightness, discomfort, shaking, control loss, and other. Burning symptoms included descriptions such as ‘burn in calves’ and ‘burning feeling.’ Tightness symptoms were described by body region (e.g., ‘upper calf tension’). Discomfort symptoms were described as relating to both body region (e.g., ‘pain in left calf’) and a joint (e.g., ‘pain on back of knee’). Shaking symptoms were associated with the repetition during which they occurred (e.g., ‘shaking on last repetition’) and the body region where they were observed (e.g., ‘shaking in right leg’). Control loss symptoms were described in terms of the body region where they were observed (e.g., ‘wobbly right foot’). Other symptoms included: ‘joint clicking on last one.’

Supine Abdominal Crunch

The AC exercise was performed on a treatment table using bodyweight in the same procedural manner as the LP. Exertional symptoms were categorized into six major themes: fatigue, strain, shaking, tightness, discomfort, and burning. Fatigue and strain symptoms as described were all localized to the neck (e.g., ‘neck strain’). Shaking symptoms were described simply in terms such as ‘shaking.’ Tightness symptoms were described regionally (e.g., ‘muscle tightness on right side’). Discomfort symptoms were all described as relating to the neck (e.g., ‘neck pain’) and repetition (e.g., ‘neck soreness on last repetition’). Burning symptoms included ‘burning a little bit’.

Participant Themes

Participant 1 was a 25-year-old male. Three major themes emerged from their exertional symptom comments: control loss, shaking, and burning. Participant 1 reported the presence of sore soles of feet, ankle pain, knee pain, hip pain, back pain, stiffness, and muscle pain on the baseline SQ. Participant 2 was a 50-year-old male. Three themes emerged from their exertional symptom comments: discomfort, tightness, and strain. Participant 2 reported the presence of

ankle pain, knee pain, hip pain, back pain, stiffness, and muscle pain on the baseline SQ. Participant 3 was a 32-year-old male. Three themes emerged from their exertional symptom comments: control loss, burning, and shaking. Participant 3 reported the presence of ankle pain, back pain, and muscle pain on the baseline SQ. Participant 4 was a 60-year-old female. Three themes emerged from their exertional symptom comments: crepitus, discomfort and tightness. Participant 4 reported the presence of sore soles of feet, ankle pain, knee pain, hip pain, stiffness, and muscle pain on the baseline SQ. Participant 5 was a 60-year-old female. Five themes emerged from their exertional symptom comments: discomfort, strain, tightness, control loss, and shaking. Participant 5 reported the presence of hip pain and back pain on the baseline SQ. Participant 6 was a 28-year-old female. Three themes emerged from their exertional symptom comments: shaking, strain, and burning. Participant 6 did not report the presence of discomfort symptoms on the baseline SQ. Participant 7 was a 44-year-old female. One theme emerged from their exertional symptom comments: discomfort. Participant 7 reported the presence of ankle pain, knee pain, hip pain, and stiffness on the baseline SQ. Participant 8 was a 59-year-old female. Two themes emerged from their exertional symptom comments: strain and fatigue. Participant 8 reported the presence of sore soles of feet, knee pain, hip pain, back pain, and muscle pain on the baseline SQ.

Table 1. Exercise-centric exertional symptom themes experienced by participants with PSLD.

Leg Press	Seated Row	Chest Press	Standing Heel Raise	Supine Abdominal Crunch
Strain	Strain	Discomfort	Burning	Fatigue
Discomfort	Tightness	Fatigue	Tightness	Strain
Crepitus	Discomfort	Shaking	Discomfort	Shaking
Tightness	Other	Strain	Shaking	Tightness
Shaking	Shaking	Tightness	Control Loss	Discomfort
Control Loss	Control Loss	Burning	Other	Burning

Note: Coding units were listed in the order of their recurrence for each exercise

Table 2. Participant-centric exertional symptom themes experienced by participants with PSLD.

Part. 1	Part. 2	Part. 3	Part. 4	Part. 5	Part. 6	Part. 7	Part. 8
Control Loss	Discomfort	Control Loss	Crepitus	Discomfort	Shaking	Discomfort	Strain
Shaking	Tightness	Burning	Discomfort	Strain	Strain		Fatigue
Burning	Strain	Shaking	Tightness	Tightness	Burning		
				Control Loss			
				Shaking			

Note: Coding units were identified in the order of their recurrence for each participant

Discussion

This study provides novel insight into the PSLD patient's exertional symptoms during an RT intervention. The information gained from this study may help to inform the expectations of exercise professionals when supervising an RT program with PSLD patients. The presence of certain exertional symptoms (e.g., knee pain) were consistent with what might be expected to be reported by patients with PSLD ³⁵. However, the results of D'Adamo et al. ²⁸ suggest that neither the severity nor frequency of these symptoms increased during the RT intervention. Some PSLD patients, like Participant 1, show discomfort in daily life but not during RT. More importantly, the findings of this study combined with those of D'Adamo et al. ²⁸ make it clear that the presence of exertional symptoms reported prior to and during exercise do not impede the safety or feasibility of participating in a low-intensity RT intervention.

Other exertional symptoms (e.g., quadriceps strain) were consistent with what might be expected to be reported during progressive RT programs in general. The exertional symptoms were summarized from both an exercise-centric and a participant-centric framework. An interesting revelation yielded by the participant-centric framework data display indicates that a PSLD participant might exhibit homogeneity in the themes of exertional symptoms. This homogeneity suggests that a participant who exhibits shaking on one RT exercise might be expected to exhibit shaking during other RT exercises. All of the exertional symptoms reported were associated with changes in the RPE. This finding is especially useful for exercise professionals regarding exertional symptoms associated with motor behavior themes (e.g., shaking and control loss) that might be used to justify associations between an individual's exertional symptoms and changes in intensity level during RT.

Conclusions

The results of this study fill a void in the literature that exists as to what an exercise professional might expect when supervising RT with PSLD patients. The apparent lack of association between exertional symptom themes experienced during RT and symptoms experienced during everyday life should serve to remind exercise professionals to refrain from assuming the experience of PSLD patients especially as to how it might inform their choice in terms of RT exercise selection. If the exercise professional recognizes an exertional symptom appears to be consistent in an individual across exercises, its absence, presence, or increase might be used in coordination with the RPE to ensure safety and feasibility.

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