2022

The Caregiver’s Experience of Post-Treatment Lyme Disease Syndrome

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Recommended Citation

Deschene, J. (2022). The Caregiver’s Experience of Post-Treatment Lyme Disease Syndrome. https://aura.antioch.edu/etds/874

THE CAREGIVER’S EXPERIENCE OF POST-TREATMENT LYME DISEASE SYNDROME

A Dissertation

Presented to the Faculty of

Antioch University New England

In partial fulfillment for the degree of

DOCTOR OF PSYCHOLOGY

by

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October 2021

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This dissertation, by Jordyn Graves Deschene, has
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Antioch University New England
in partial fulfillment of requirements for the degree of

DOCTOR OF PSYCHOLOGY

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ABSTRACT

THE CAREGIVER'S EXPERIENCE OF POST-TREATMENT LYME DISEASE SYNDROME

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As the rate of Lyme disease diagnoses increases in the United States, it can be assumed that the frequency at which post-treatment Lyme disease syndrome (PTLDS) is diagnosed will also increase. While research has been published on the experience of caregivers of other chronic illnesses, no studies have examined the experience of the PTLDS caregiver. This quantitative study sought to discover the most significant burdens, mental health status (levels of anxiety and depression), and level of invalidation experienced by the PTLDS caregiver. Thirty individual participants took part in this study. This study found that mental burden is a significant area of concern for PTLDS caregivers, that increased PTLDS symptomology is associated with increased financial concern, and that PTLDS caregivers endorsed a high rate of anxiety and depression symptoms related to the diagnosis. Invalidation did not appear to be experienced by the PTLDS caregiver in this sample. This study has clinical implications for medical professionals as they should be aware of the potential impact of medical invalidation, financial concern, and the burdens and mental health of the PTLDS caregiver. This dissertation is available in open access at AURA (https://aura.antioch.edu) and OhioLINK ETD Center (https://etd.ohiolink.edu).

Keywords: Lyme disease, post-treatment Lyme disease, caregiving, quality of life, caregiver burden, invalidation, mental health

Dedication

This dissertation is dedicated to my parents, Bob and Lynne Graves. Your constant support, encouragement, and love have made it possible for me to pursue my dream of becoming a psychologist. Thank you for supporting me, Ben, and your grandchildren over the past five years. Knowing that I have you in my corner has empowered me more than I can ever express. This journey to becoming a doctor would not have been possible without the two of you. Thank you. Always.

This dissertation is also dedicated to my husband, Ben, and my children, Lincoln, Maya, and Sloane. Ben, your patience and love have gotten me through. This journey would not have been possible without you by my side, holding my hand and championing me every step of the way. To my children, I am eternally grateful. It is all for you.

Acknowledgements

I would like to express my gratitude to every participant who took part in my study. I am so grateful that every person was interested and kind enough to give me their time. I would also like to express my thanks to the primary Instagram accounts who took the time to spread the word about my survey.

I want to thank my dissertation chair, Dr. Karen Meteyer. Karen, thank you for all your support and encouragement throughout this program. Whether it was listening to me vent or empowering me as a woman and mother, you have played such a pivotal role in my success in this program. Thank you for your feedback and patience throughout this study. I would also like to thank my committee members Dr. Christina Tempesta and Dr. Nancy Ruddy. Tina, I am the psychologist I am today because of your support and mentorship over the past four years. Thank you for introducing me to this important topic and helping me design a study based around Lyme Disease. Nancy, you were not in your faculty role very long before I asked you to be part of my committee. Thank you for your eagerness and perspective throughout this process. I am so fortunate to have had such a lovely committee that provided me with amazing support in this study and through my academic career.

To all my friends, but especially Tessa, Rebecca, Sara, Janelle, and Tara, thank you. You all are the reason that I made it through this program, and it has been one of the greatest joys of my life to have gotten to know you. Thank you for your support and encouragement, but most importantly, thank you for the laughs. I love you all.

Finally, to my little brother, Logan. You have always been my north star and my guiding light. You motivated me to begin this journey and I carry your memory in my heart each day that I do this work.

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CHAPTER I: INTRODUCTION

The Centers for Disease Control and Prevention (CDC) estimates that roughly 300,000 people are diagnosed with Lyme disease each year (Johnson et al., 2014). This is 1.5 times the number of women diagnosed with breast cancer and six times the number of people diagnosed with HIV/AIDS. An infection from bacteria in black-legged ticks causes Lyme disease and, if left untreated, can produce a variety of pathological symptoms (Maloney, 2016). Interestingly, some individuals are treated for Lyme disease and experience long-term atypical manifestations of the disease. This condition, known as post-treatment Lyme disease syndrome (PTLDS), is estimated to affect as many as 5–30% of individuals diagnosed and treated for Lyme disease (Johnson et al., 2014). The symptoms of PTLDS affect a broad range of functional areas and can seriously disrupt the quality of life for the individual. Furthermore, due in part to the manifestation of symptoms resembling other autoimmune conditions, PTLDS is not widely accepted in the medical community, which has the potential to increase medical invalidation in the PTLDS patient. While there is some research on the experience of post-treatment Lyme disease syndrome, a survey of the literature has shown that there is very little written about the experience of the caregivers of individuals with PTLDS. The purpose of this study was to learn what the most significant caregiver burdens are for PTLDS caregivers, what their mental health status is, and how—if at all—invalidation from the medical community affects their overall burden and mental health.

CHAPTER II: LITERATURE REVIEW

Lyme Disease

Lyme disease (LD) is a multi-staged tick-borne illness which frequently produces multisystemic illness (Maloney, 2016). In the United States, patients diagnosed with LD have contracted the bacterial agent *Borrelia burgdorferi* from black-legged (deer) ticks. The early stage of LD is localized to the skin, with symptoms and signs usually appearing within 2 to 30 days of a bite. This stage's hallmark manifestation—showing up in 70% of cases—is the expanding erythema migrans (EM) rash, also known as the “bullseye” rash. In the United States, EM is frequently accompanied by flu-like symptoms, such as malaise and fatigue, headache, and fever (Steere et al., 2004). The late stage of LD is defined by the bacterial agent spreading to other body sites (Maloney, 2016). The dissemination of the bacteria can occur soon after the bite, yet the symptoms and signs indicating the later stage of LD may not appear for weeks, months, or years after the initial infection. Both early and late-stage LD are treated with antibiotics, but treatment outcomes are highly variable, and a patient’s response is impossible to predict. If left untreated, patients with this infection begin to experience intermittent arthritis, and United States studies have shown a rare late neurologic syndrome characterized by subtle cognitive disturbances and spinal radicular pain (Steere et al., 2004).

Post-treatment Lyme Disease Syndrome

PTLDS is often referred to and used interchangeably with the terms, *Chronic Lyme Disease*, *Persistent Lyme Disease*, and *Post-Lyme Syndrome*. This study will be using the term PTLDS to characterize participants who have been treated for Lyme Disease and are continuing to experience symptoms. While this term will continue to be used in this research paper as it is the appropriate medical term, it was discovered through the recruitment process that this term is not accepted among the PTLDS population due to the word “syndrome.” It was advised that the survey begin using the term Chronic Lyme Disease in the process of recruiting participants. Additionally, please note that when LD is used, it means explicitly Lyme Disease and not post-treatment Lyme Disease. This distinction is important because the term PTLDS indicates that the patient has been diagnosed *and* treated for Lyme disease and is still experiencing symptoms despite the treatment versus patients suffering from undiagnosed or untreated Lyme disease.

PTLDS describes the attribution of various atypical symptoms to the bacterial infection that causes LD (Lantos, 2015). These are categorized as atypical symptoms for LD in that they lack the clinical abnormalities that are well recognized in LD, and, in many cases, there is an absence of both serologic evidence and plausible exposure to the LD infection. The symptoms typically associated with a diagnosis of PTLDS include, but are not limited to, chronic pain, fatigue, neurocognitive and behavioral symptoms, as well as alternative medical diagnoses, which are the most common neurologic and rheumatologic diseases (Lantos, 2016). Patients with PTLDS may develop disabling musculoskeletal pain, neurocognitive difficulties, fatigue, or a combination of symptoms (Steere et al., 2004). These symptoms strongly resemble those experienced in chronic fatigue syndrome or fibromyalgia and can persist for months or years after standard antibiotic treatment. The critical distinction between LD and PTLDS is that patients with PTLDS have been treated with antibiotics unsuccessfully, which allows the disease to continue living in the body (CDC, 2019; Steere et al., 2004). Of those diagnosed and treated for LD promptly, studies have reported a wide range—5–30%—of the proportion that experience PTLDS (Johns Hopkins Medicine Newsroom, 2019).

Diagnosing PTLDS

The challenge in diagnosing PTLDS is real and legitimate as LD manifests as an autoimmune disorder. Autoimmune diseases encompass a wide variety of disorders, ranging from those that are acute and spontaneously regressive to those that are more chronic conditions (Bach, 2012). The etiology of autoimmune disease has not been well established, but there is overlap in the presentation of symptoms. These are most commonly joint and muscle pain, general muscle weakness, possible rashes and low-grade fever, numbness and tingling, shortness of breath, and heart palpitations. However, it is important to note that the combination of symptoms experienced by those with PTLDS is different from those seen in autoimmune diseases such as lupus, fibromyalgia, and other diseases, such as chronic fatigue syndrome, and depression.

A wide range of different symptoms can be found in PTLDS. Cairns and Godwin (2005) conducted a meta-analysis of the symptoms commonly associated with PTLDS. The five studies used in the meta-analysis looked at the occurrence of 10 symptoms persisting for 3–6 years after onset and initial treatment of the infection. The 10 symptoms included fatigue (one symptom), musculoskeletal pain (three symptoms: joint or muscle pain, muscle aches, and swollen joints), and neurocognitive difficulties (six symptoms: memory problems, poor concentration, difficulties in formulating ideas, difficulties in word finding, difficulties in judgment, and difficulties naming objects). The results showed that fatigue and all three musculoskeletal symptoms were significantly more frequent in patients diagnosed and treated with LD than control subjects. Four neurocognitive difficulties were more frequent in patients with LD. As mentioned above, while there is some symptom overlap between LD and autoimmune diseases and other disorders, it can seem as though the PTLDS patient suffers from multiple of these diagnoses at once. This study shows a definitive connection between LD and a distinct set of persistent symptoms known as PTLDS which impact a person's life significantly.

Impact on Quality of Life

Given what is known about the symptomology of PTLDS, it becomes pertinent to consider what the quality of life is for those who are suffering from this chronic illness. Chronic medical conditions are characterized in various ways, and because these conditions come with varying levels of severity, it makes comparing the illnesses challenging (Johnson et al., 2014). Fortunately, the CDC developed a standardized 9-item survey known as the Health-Related Quality of Life (HRQoL) metric (as cited in Johnson et al., 2014). The results of a study comparing the HRQOL metrics of patients with PTLDS to those with other chronic illnesses (e.g., congestive heart failure, fibromyalgia, stroke, heartache, etc.) show that those with PTLDS have a significantly worse quality of life. When looking at how patients with PTLDS are affected throughout 30 days, it has been found that they experience the most severe symptoms for upwards of 55% of the days and experience overall symptoms nearly every day. Patients with PTLDS reported experiencing healthy days with vitality a mere three days of the 30 days (Johnson et al., 2014).

Children With PTLDS

PTLDS has also been known to manifest in children as well as adults. A controlled study done by Tager et al. (2001) compared 20 children with PTLDS to 20 healthy control subjects and found that the Lyme sample had significantly more psychopathology and more objective cognitive deficits than the control group. Children with PTLDS had higher rates of anxiety, mood, and behavioral disorders than children without PTLDS, and they also had more difficulty learning and focusing attention. On caregiver-report forms, parents indicated that their PTLDS child had learning and attention problems, feelings of ineffectiveness, and mood problems. This is of particular importance because children with PTLDS who present with psychiatric problems may be misdiagnosed with having a primary psychological condition such as affective disorder, attention-deficit/hyperactivity disorder, or oppositional defiant disorder. Compared to the control group, children with PTLDS had cognitive deficits (e.g., visual and auditory attention, working memory, and mental tracking) as defined by both objective measures of cognitive functioning and self-report measures.

As outlined above, PTLDS is a significant disorder that brings about a variety of debilitating symptoms in both children and adults. What compounds the severity of this disorder is that it is not widely acknowledged in the medical community, and patients are often told that another disorder causes their symptoms. There is more information regarding this in the invalidation section, but it is important to note that feelings of invalidation can intensify the experience of these symptoms and have the potential to increase the burden of the PTLDS caregiver (Rebman et al., 2015).

Controversy

On top of dealing with the physical and emotional suffering that comes with PTLDS, patients are also faced with several controversies surrounding the diagnosis (Maloney, 2016). First and foremost is that the existence of PTLDS is not agreed upon unanimously in the medical field. While some medical professionals believe in PTLDS, there is a significant gray area when discussing PTLDS. Some doctors believe that the post-treatment symptoms reported after an early diagnosis of LD are people reporting symptoms that are commonly seen in the general population or those of a secondary condition such as chronic fatigue syndrome or fibromyalgia. Other doctors believe that the post-treatment symptoms represent a failure in earlier treatment. Another element of controversy stems from pseudoscientific and alternative treatment practitioners spurring legislative efforts to subvert evidence-based medicine and peer-reviewed science (Auwaerter et al., 2011; Soucheray, 2017; Sun, 2019). These medical providers may be viewed as taking advantage of Lyme patients who are desperate to find symptom relief and charge them massive amounts of money for non-evidence-based treatments. As Auwaerter and colleagues (2015) outlined in their review, anti-science LD treatments have included the use of UV rays, essential oils, hyperbaric oxygen, chelation therapy, photon therapy, and many others. Furthermore, several deaths have been linked to LD patients being injected with toxic substances (Auwaerter et al., 2011).

Adding to the confusion is that, until recently, none of the clinically available tests for LD could determine whether a patient has an ongoing infection after treatment (Maloney, 2016). There is no evidence in any of the areas associated with LD—including blood, joints, etc.—that an individual is still infected. This leads many professionals to conclude that the patient’s symptoms are therefore attributable to another medical condition, even though studies have shown that there are no diseases that encapsulate all the symptoms experienced by patients with PTLDS (Cairns & Godwin, 2005). Mechanisms that can explain the symptoms of PTLDS include the presence of other untreated infections, permanent or temporary tissue damage, and persistent bacterial infection (Maloney, 2016). Regardless of the cause of their symptoms, patients with PTLDS experience great personal suffering and often feel as though the medical community has failed to effectively explain or treat their illness (Lantos, 2016).

However, promising research coming out of Johns Hopkins University (2019) may indicate emerging diagnostic capabilities for PTLDS. In a small study, researchers compared 12 patients with documented PTLDS, and they all showed widespread brain inflammation compared to 19 healthy control subjects. These results have been interpreted to suggest that brain inflammation from LD may continue in the brain after treatment. This may explain why it has been impossible to detect markers of Lyme in the joints and blood (not including endorsing joint pain) and why PTLDS patients suffer a wide variety of cognitive and physiological symptoms. This technique is still in its infancy, and as such, it is not widely available as a diagnostic tool yet. Diagnostic tools notwithstanding, patients with PTLDS and their caregivers continue to experience invalidation from the medical community for various reasons.

Invalidation

When considering how a disease can be debilitating mentally and physically, it is easy to take for granted what it means to have a confirmed diagnosis. A PTLDS diagnosis proves to be a complex challenge for physicians (Rebman & Aucott, 2020). Meanwhile, the lived experience of the PTLDS patient is marked by uncertainty and often illness invalidation. The PTLDS patient may be forced to re-negotiate physical and social identities to the “new normal” of chronic illness, often without the same level of medical support and certainty afforded to patients with conditions that are not contested (Rebman et al., 2015). There is debate about why this phenomenon occurs, but leading theories state that patients often over-endorse symptom experience when they feel they are not believed (Merckelbach et al., 2019). As devastating as PTLDS is for the person who has the diagnosis, it also can affect the physical and mental health of the person caring for them. There is scant research that focuses on the invalidation experienced by PTLDS patients and their caregivers.

Caregivers

The term *caregiver* refers to an unpaid family member, friend, or neighbor who provides care to an individual with an acute or chronic condition and needs assistance to manage different tasks (Reinhard et al., 2008)**.** Caring for individuals with chronic illnesses can lead to various pathological symptoms, including stress, depression, anxiety, and compassion fatigue (del-Pino-Casado et al., 2019; Pinquart & Sorensen, 2003). The psychological well-being and physical health of caregivers have been noted to be worse than individuals who are not responsible for taking care of another person (del-Pino-Casado et al., 2019). There are also many positive impacts of caregiving including feeling a sense of meaning and purpose in caring for a loved one (Semiatin & O'Connor, 2012). There is limited research available on caregivers' experiences with PTLDS, and much of the reported information comes from support websites and articles rather than peer-reviewed sources. However, given what is known about the quality of life of individuals with PTLDS, it is hypothesized that the burdens experienced by PTLDS caregivers are similar to caregivers of patients with other chronic illnesses.

Caregiver Burden

Individuals caring for others with chronic illnesses experience a variety of symptoms. Day and Alston (1988) looked at the overall stress and stress levels experienced in different areas for caregivers of adults with physically disabling chronic illness (Bevans & Sternberg, 2012;

del-Pino-Casado et al., 2019). They found a trend for caregivers of adults to have increased overall stress and more significant stress related to lack of personal reward, terminal illness stress, physical limitations, and preference for institutional care. Another study found that some caregivers experience exacerbation of their own physical and mental health concerns while caring for the ill individual and endorse negative experiences of support and describe the uncertainty of how to obtain said support (Noonan et al., 2018). These factors are crucial when considering the impact PTLDS has on caregivers due to the lack of support that is generally associated with a PTLDS diagnosis. Furthermore, many of the symptoms associated with PTLDS (cognitive fog, joint pain, lethargy, etc.) are often associated with aging; and as such, caregivers can expect similar outcomes to caregiving for the elderly when tending to PTLDS patients.

Emphasizing the results mentioned in the previous paragraph is a 2017 study conducted by the American Association of Retired Persons (AARP) in which they published data highlighting the adult caregiver's experience of tending to an older adult (age 50+) family member (Skufca, 2017). While family caregivers reported that positive emotions far outweigh the negative, they also reported feeling unprepared to take on the caregiver role and being stressed, worried, and overwhelmed. In addition to mental challenges, caregivers also described personal challenges surrounding caring for their household, tending to their health, and a reduction in the amount of money they can save (Gardiner et al., 2020; Schulz & Eden, 2016). In addition to experiencing several negative emotions, about a quarter of the caregivers expressed regrets or wish they had done something different regarding caring for their family member. While caregiving is challenging across the board, tending to someone with a chronic illness yields its own set of concerns.

Caregivers of Individuals With Chronic Illness

In 2004, Lim and Zebrack published a meta-analysis of 19 studies on the quality of life for family caregivers helping those with chronic physical illness. The analysis found that family caregiving means increased financial, physical, and emotional responsibility. Caregivers deal with extensive coordination of care, including symptom management, disability, mobility, and dressings. Lim and Zebrack (2004) also found that caregivers often feel tired, isolated, and overwhelmed because they lack support, training, information, and a sympathetic ear. Additionally, caregivers who are employed report having to miss work, take personal days, or quit or retire early to provide care. Chronic illness affects the lives of those suffering from disease and those of the family members or loved ones who care for them. Family caregivers' physical and emotional health can influence the health-welfare and successful rehabilitation of persons with chronic illness. The effects on caregivers’ lives are physical, psychological, and social and may include worsened physical health, impaired social and family life, and increased stress, anxiety, and depression.

Caregivers of Children With Chronic Illness

Childhood chronic illness often impacts the entire family system (Cousino & Hazen, 2013). For parents, the devastating news of their child’s diagnosis, the associated medical risks and cost, and the potential for a shortened life expectancy can impact their mental and physical well-being. Adding to the jarring nature of a chronic diagnosis are the demanding treatment regimens, shifts in roles, responsibilities, and resources, all of which can negatively impact family functioning. Caregivers of children with chronic illnesses endorse more significant general parenting stress than caregivers of healthy children (Cohn et al., 2020; Cousino & Hazen, 2013; Day & Alston, 1988).

Additionally, while advances in medical care have improved the survival of children with chronic and critical illnesses, it also increases the financial strain experienced by the family (Thomson et al., 2016). Caregivers of children with chronic illnesses can spend thousands of dollars on out-of-pocket costs. This, coupled with the fact that many caregivers must stop working, tends to increase financial burden. Chronic, multisystemic diseases are associated with functional limitations as well as a need for care provided across multiple clinical specialties (Thomson et al., 2016). This is especially true for unidentified medical conditions and can lead to an increase in referrals and appointments. Often, caregivers spend time battling insurance companies as well because of the lack of a diagnosis that could explain the presenting symptoms (Thomson et al., 2016). There were no studies which showed if early onset of PTLDS leads to worse symptoms, but it does appear that it is the chronicity of symptoms in children that increases caregiver stress.

Caregivers and Invalidation

Research on the impacts of invalidation is still in the early stages compared to other external factors, but the available research shows just how vital validation can be in a patient's care, quality of life, and recovery (Lobo et al., 2014). Based on available literature, it is reasoned that invalidation of a condition will also impact the mental health and overall burden of caregivers because of how invalidation affects the person they are taking care of and how it impacts them directly.

Benefits of Caregiving

While the history of caregiver literature has focused around stressors, consequences, and the best methods to manage them, recent literature has shifted to focusing on the positive aspects of caregiving (Zarit, 2012). In research done by Folkman (1997, 2007), it was found that positive and negative emotions occur concurrently during periods of high stress. Folkman proposed that introducing meaning-focused coping strategies allowed caregivers to reframe the large and small events in their life, allowing them to look at their life in a more positive way. Furthermore, Fredrickson (2001) demonstrated that when people experience positive feelings, their perspective is broadened. During periods of chronic stress, narrowing their perspective may cause caregivers to overlook practical strategies for managing their situation, while experiencing positive emotions may lead to more adaptive coping skills.

Positive and negative emotions could occur simultaneously during periods of high stress (Folkman 1997, 2007), which could potentially allow caregivers to focus on the benefits of caregiving rather than adverse impacts. Among benefits are inner personal growth, increased beliefs about self-efficacy, strengthened relationships, feeling appreciated, and increased esteem (Contador et al., 2012; Semiatin & O’Connor, 2012). Increased beliefs about self-efficacy may lead to more positive views of one’s caregiving experience and less subjective stress (Semiatin & O’Connor, 2012). In 2012, research done by Mackenzie and Greenwood showed that positive experiences among caregivers were associated with coping strategies. While caregiving can be profoundly fulfilling, it can also be overwhelming, and caregivers should be given the resources to mitigate future issues (Sullivan & Miller, 2015).

Providing Caregiver Resources

Despite the possibility of positive impacts, past research suggests that the burden of caregiving has a significant impact on the individual caregivers and can also lead to a deterioration in family functioning (Toledano-Toledano & Dominguez-Guedea, 2019). By not mitigating caregiver burden, the likelihood of future mental and physical illness is increased (Schulz & Sherwood, 2008). Caregivers tend to experience depression and distress first, followed by physiologic changes and impaired habits that ultimately lead to further illness. This impairment of quality of life leads to high socioeconomic costs for healthcare systems and society (Oliva-Moreno et al., 2008), including, but not limited to, direct medical costs, direct non-medical costs, and loss of labor productivity. While caregivers are generally offered resources by medical providers, there may be some illnesses where providing resources may not be standard practice, which may be the case with PTLDS caregivers (Thomas, 2017).

Caregivers and Lyme

The literature on caregiving is extensive, and there have been numerous studies done on the impact of caregiving for the elderly, those with specific and general chronic conditions, etc. However, there is a significant gap in the literature on the experience of the PTLDS caregiver. It is unclear why this gap in the literature exists, but it seems likely that ambiguous testing/diagnosis and stigma of a PTLDS diagnosis have something to do with it. From what is known about the patients' experience of PTLDS, it is expected that the overall burden of the PTLDS caregiver is high. What remains unclear in the research are the areas in which PTLDS caregivers feel the most burdened and how this burden affects their overall mental health (i.e., anxiety and depression). Additionally, the research does not address the rate at which the medical community invalidates PTLDS, nor how invalidation affects caregiver burden and mental health.

The current study employed a quantitative survey of the experience of PTLDS caregivers. The questions assessed PTLDS patient symptomology, different caregiver burden areas (Burden, Disruptiveness, Positive Adaptation, Financial Concern, and Other), invalidation, quality of life, and the caregiver's mental health (i.e., anxiety and depression).

Research Questions

This study explored the relationship between caregiver quality of life, illness invalidation, and caregiver mental health with the goal of addressing the following questions:

1. What are the most significant burdens for caregivers of PTLDS?
2. What is the level of anxiety and depression of PTLDS caregivers?
3. What is the level of invalidation experienced by caregivers of PTLDS?
4. Is the level of invalidation experienced by caregivers associated with overall caregiver burden?
5. Is the level of invalidation experienced by caregivers associated with the level of anxiety and depression of caregivers?

This study ran descriptive statistics to determine the most significant burdens, as well as the level of overall burden, for this sample. Descriptive statistics were also run to determine the levels of anxiety, depression, and invalidation experienced by this sample. Pearson correlations were used to determine significant associations between scales and subscales. It was hypothesized that caregivers would experience a high level of burden, as well as a high level of anxiety, depression, and invalidation.

CHAPTER III: METHOD

This study used a quantitative survey to investigate PTLDS caregivers' experience in the areas of caregiver burden, mental health, and experiences with invalidation, and explore how these areas related to one another. The study recruited participants via snowball sampling and by contacting various LD groups, social media accounts, and research facilities. Emails were sent to three research organizations, seven Lyme caregiver support groups, and nine Lyme related accounts on Facebook and Instagram. All the participants in this study who ultimately completed this survey were recruited on Instagram.

Participants

A total of 30 individuals participated in this study. All participants were caregivers of PTLDS patients who had been previously diagnosed and treated for Lyme disease but who continue to experience Lyme symptoms. On average, participants were 48 years old (*SD* = 11.38) and ages ranged from 29–72 years (see Table B1). The sample consisted of 100% heterosexual women, 93% of whom identified as white or of European descent, 3.3% Hispanic or Latinx, and 3.3% would prefer not to say. Of the 30 participants, six individuals reported that they had no longer been able to work since becoming a caregiver for their loved one. In an open-ended question on why they were unable to work, answers included: “[I] cannot work while caring for three children and myself with Lyme,” “I am my daughter’s main caregiver. She has persistent neurologic Lyme disease,” “[I am a] full-time caregiver,” “I am my 28-year-old daughter’s fulltime caregiver. She has chronic neurologic Lyme and many co-infections,” “[I am a] fulltime caregiver to my son with Lyme/CFS/ME.” The average age of the PTLDS individual was 22 years (*SD* = 10.49) with ages ranging from 6–50. A majority (25) of the caregivers were parents to their loved one and the remaining (5) were either spouses, partners, or significant others. Sixty percent of the caregivers reported that they had caregiving help with 88.9% reporting that their spouse or co-parent provided the help. Of the 30 participants, 33.3% of them reported that they spend over 30 hours per week caregiving for their PTLDS loved one.

Measures

The study used a Google survey to collect the data. The survey included a demographic information questionnaire, the Horowitz Lyme Multiple Systemic Infectious Disease Syndrome (Horowitz Lyme-MSIDS) Questionnaire, the Caregiver Quality of Life Index-Lyme scale, the Illness Invalidity Inventory, and the Patient Health Questionnaire Anxiety and Depression Scale. Domain specific questionnaires for caregivers are nonexistent, and as such most of these surveys (except for the Lyme symptom questionnaire) needed to be adapted in language and some in content. While all measures listed below are valid and reliable, it is unclear if psychometrics holds after the necessary changes. However, Cronbach's alpha in the current sample was run for each adapted measure, and it appears as though liability and validity remained at acceptable levels despite the adaptations.

Horowitz Lyme Multiple Systemic Infectious Disease Syndrome Questionnaire

The Horowitz Lyme-MSIDS Questionnaire was used to assess the PTLDS patient's symptom frequency. Originally a self-report form, the questionnaire was modified to reflect the caregiver's experience of the PTLDS patient's symptoms. The Horowitz Lyme-MSIDS questionnaire has been proven to have internal reliability, as well as convergent and divergent validity (Citera et al., 2017). Cronbach's alpha was .911 in the current sample.

Studies have shown that the Horowitz Lyme-MSIDS questionnaire accurately differentiates between patients with LD and healthy individuals. It should be noted that this study added a Not Applicable (NA) option to items 7, 8, 9, and 11 as answering "None" may not reflect the age/sex of their loved one. Additionally, for the purposes of the current study the wording in Section 3 was changed from a self-report to a caregiver report form. For example, item one was changed from "You have had a tick bite with no rash or flu-like symptoms" to "Your loved one has had a tick bite with no rash or flu-like symptoms." Overall, participants reported a high frequency of Lyme symptoms in their loved ones (*mean* = 86.60; *SD* = 19.16) with the lowest possible score being 30 and the highest possible score being 120.

Caregiver Quality of Life Index–Lyme scale

In order to assess the quality of life of PTLDS caregivers, the Caregiver Quality of Life Index–Cancer (CQOLC) scale was adapted to target issues specific to caregivers of patients with PTLDS. The CQOLC is a well-established tool designed by Weitzner et al. (1999) to assess the distress experienced by cancer patients' caregivers. It is a 35 item self-report questionnaire that can be completed in approximately 10 minutes. Weitzner and team (1999) established that the CQOLC appears to possess adequate validity, retest reliability, and internal consistency and thus proves to be a solid foundation for adapting a caregiver Lyme scale. Cronbach's alpha was .901 in the current sample.

All the statements remained the same in the adapted Lyme scale, but an additional item about validation was added: "I feel validated by my loved one's health care provider." Subscales in the CQOLC include Burden (*M* = 32.90, *SD* = 8.49), Disruptiveness (*M* = 18.33, *SD* = 7.06, Positive Adaptation (*M* = 22.93, *SD* = 5.22), Financial Concern (*M* = 10.07, *SD* = 4.35), and

Other (*M* = 30.47, *SD* = 6.87). The other subscale includes items regarding sex life, sleep, feeling validated by their loved one's medical provider, and feeling adequately informed about their loved one's illness. Positive adaptation reverse scored and the added item was included in the "other" subscale. Participants had an average score of 109.37 (*SD* = 22.50) which indicates a poor quality of life associated with caregiving for a PTLDS loved one, with the lowest possible score being 35 and the maximum being 175. Higher scores reflect lower quality of life.

Illness Invalidity Inventory

The Illness Invalidity Inventory (3*I) is an eight-item self-report form that assesses validation levels across five environments: spouse, family, medical professionals, work environment, and social services (Kool et al., 2010). The 3*I has been established as a reliable and valid instrument for assessing patients' perceptions of invalidation from different sources. The study by Kool and team (2010) showed that patients with conditions that lack visual signs and laboratory findings (fibromyalgia) experience greater rates of invalidation than those with signs and findings (rheumatoid arthritis). This is particularly important as PTLDS lacks visual signs and laboratory findings and can often be mistakenly diagnosed as fibromyalgia.

While the original objective of the 3*I was to assess validation in patients, the scale has been adapted to target the PTLDS caregiver's experience. The wording has remained the same except for gearing it toward the experience of the caregiver. For example, item 3 was altered from "medical professionals give me unhelpful advice" to "medical professionals give my loved one unhelpful advice." Overall, participants averaged 26.2 on the 3*I which indicates a high level of invalidation from medical professionals (*SD* = 7.49). The 3*I is separated into discounting (*M* = 15.80, *SD* = 5.24) and lack of understanding subscales (*M* = 10.40, *SD* = 3.11), the latter of which was recoded for consistency of interpretation. Cronbach's alpha in the current sample was .878. Higher scores reflect greater frequency of invalidation.

Patient Health Questionnaire–Anxiety and Depression Scale

The Patient Health Questionnaire–Anxiety and Depression Scale (PHQ–ADS) combines the nine-item Patient Health Questionnaire depression scale and the seven-item Generalized Anxiety Disorder scale as a composite measure of depression and anxiety (Kroenke et al., 2016). The PHQ-ADS has been established as a valid and reliable tool for assessing two of the most common psychological conditions. Cronbach's alpha in the current sample was .934. The average level of anxiety and depression symptoms was 23.53 (*SD* = 11.66). Participants indicated a moderately severe experience with both anxiety and depression associated with their caregiving (*M* = 12.43, *SD* = 5.89, and *M* = 11.10, *SD* = 7.10, respectively).

Procedure

After being approved by the university's Institutional Review Board, the survey was disseminated via Google Forms to various Lyme caregiver support groups by email, through social media platforms including Facebook and Instagram, and by word-of-mouth. Participants were required to acknowledge informed consent before continuing to complete the survey. Participants could skip any questions or measures they did not feel comfortable answering. Upon completing the survey, results were saved anonymously in Google Forms. It should be noted that data was collected during the COVID pandemic.

Data Analysis

Data was available for all 30 participants. Across all responses there were four missing responses and a value of "0" was assigned to each of those items. Data collected in Google

Forms was downloaded to SPSS and analysis was conducted within the program. Cronbach's alpha was calculated to measure internal consistency with all items falling in the *Good* to *Excellent* range (.849–.936). Descriptive statistics were conducted to define and describe the sample and variables, which will be discussed further in following sections. Additionally, correlations between variables and measure subscales were run to determine significant associations.

CHAPTER IV: RESULTS

Thirty caregivers total participated in the survey. The data was checked for missing and incomplete responses, outliers, and to gather descriptive means and standard deviations. Two participants each had two missing responses, and a “0” was put in place of their missing responses for those items. All other items were complete. Sum values for each measure and subscale were calculated.

Caregiver Burden

Descriptive statistics were run on each item in the Caregiver Quality of Life-Lyme (CQOLL) scale to assess the most significant burdens for caregivers of PTLDS loved ones (Table B2). Total scores were computed by summing responses to the 35 items in the scale resulting in a minimum possible score of 35 and a maximum possible score of 175. Seventy-four percent of the items averaged at or above a 3 out of 5 suggesting that participants experienced a high level of burden in all areas. When weighted means were calculated for each subscale, Burden was rated highest, followed by Financial Concern, Other, recoded Positive Adaptation (which reflected more negative adaptation), and Disruptiveness.

A Pearson correlation (Table B3) examined the relationship between overall caregiver burden and each of the other measures and none were found to be statistically significant. A Pearson correlation was also run to determine the relationship between each subscale of the CQOLL and the other measures of the survey with only one significant finding. Financial concern was found to be moderately correlated with the Lyme Symptom Questionnaire (r (28) = .44, p = .02), suggesting that those who have loved ones with more symptom severity experience higher levels of financial concern.

Caregiver Mental Health

Descriptive statistics were run to determine the level of anxiety and depression experienced by caregivers. Sum scores were computed by totaling responses to the seven-item anxiety scale and the nine-item depression scale with a minimum number of 0 and a maximum number of 3 for each item. Collectively, participants averaged in the moderately severe range on both measures of anxiety and depression (*M* = 12.43 and 11.1, *SD* = 5.89 and 7.09, respectively). On the anxiety measure, 13.33% of participants were in the mild range (0–5), 23.33% were in the moderate range (6–10), 30% were in the moderately severe range (11–15), and 33.33% were in the severe range (16+). On the depression measure, 23.33% were in the mild range, 36.67% were in the moderate range, 13.33% were in the moderately severe range, and 26.67% were in the severe range.

A Pearson correlation examined the relationship between anxiety and all measures. There was a significant positive correlation between the caregiver quality of life and anxiety (r (28) = .58, $p < .001$, $R^2 = .37$), suggesting that 37% of the variance in quality of life is explained by anxiety. A Pearson correlation also examined the relationship between each subscale of the CQOLL and the anxiety scale. Caregiver Burden, Disruptiveness, and Other were found to be moderately correlated with anxiety (r (28) = .63, $p < .001$, r (28) = .44, $p = .02$, r (28) = .55, $p = .002$, respectively).

Additionally, a Pearson correlation examined the relationship between the depression scale and the CQOLL and there was a moderate correlation found (r (28) = .39, $p = .03$, $R^2 = .15$), suggesting that 15% of the variance in quality of life is explained by depression. Depression was also found to be moderately correlated with the Burden and Other subscales (r (28) = .38, *p*

= .04, and *r* (28) = .43, *p* = .02, respectively). No other significant correlations were found. Lower quality of life was associated with higher levels of depression in caregivers of individuals with PTLDS.

Invalidation

Descriptive statistics were run to determine the level of invalidation experienced by caregivers. Total scores were computed by summing responses to the eight-item invalidation measure with a minimum score of one and a maximum score of 5 for each item. Overall, caregivers experienced a moderate level of invalidation (*M* = 26.2, *SD* = 7.49). Additionally, caregivers experienced discounting and lack of understanding at approximately the same level. Pearson correlations were run to determine if the level of invalidation experienced was associated with caregiver burden and there were no significant findings shown for the overall measure or subscales. Pearson correlations were also run to determine if the level of invalidation experienced by caregivers impacted their levels of anxiety and depression and no statistical significance was found.

CHAPTER V: DISCUSSION

The aim of this study was to discover the most significant burdens for PTLDS caregivers, their mental health status, and the level of invalidation they experienced. This study administered a survey that examined Lyme symptomology in the PTLDS loved one, as well as overall caregiver burden, anxiety and depression symptoms in caregivers, and illness invalidation experienced surrounding the diagnosis. The main findings of this study were that mental burden is a significant area of concern for PTLDS caregivers. Additionally, PTLDS caregivers endorsed a high rate of anxiety and depression symptoms related to the diagnosis. While invalidation was experienced among caregivers, there were no correlations found between invalidation and other variables.

Caregiver Burden and Mental Health

One of the aims of the survey was to better understand what the most significant burdens are for PTLDS caregivers. Given the mean scores on each item in the survey, the most significant burden for PTLDS caregivers in this sample appears to be the mental toll the diagnosis takes on the caregiver. This includes feeling upset seeing their loved one deteriorate, increased stress, worry, frustration, mental strain, and fear of adverse treatment effects. With the caregiver focusing on the individual with PTLDS (most commonly in this study, mothers with children suffering from PTLDS) it limits the time they can tend to other relationships in the family and tasks around the house, as well as participating in self-care. Furthermore, as evidenced by the results in this survey, caregiver employment status is also affected by the long-term nature of caregiving for PTLDS. This, coupled with diagnostic uncertainty, can lead to significant financial concern. As mentioned above, providing caregivers with appropriate resources for managing their burden and stress will allow them to mitigate future issues, as well as allow them to focus more on the positive aspects of caregiving.

Caregiver Burden and Financial Concern

One significant finding from the current study was that the financial concern subscale was strongly correlated with the Lyme Symptom Questionnaire. This result may appear to indicate that increased symptomology increases financial concern or that caregivers are unable to hold jobs when caring for individuals with severe illness, for example. It should be acknowledged that causality can go in either direction and that the results could be the result of another factor(s). Given the set of symptoms that is typically associated with PTLDS, individuals may need to go to a variety of doctors before the diagnosis of PTLDS is identified, if it gets identified at all. Additionally, people with PTLDS may often try homeopathic remedies for symptoms to find relief. These treatments are not backed by research and are often not covered by insurance (Soucheray, 2017). As such, individuals are required to pay out-of-pocket. Following this path also leads to the potential for caregivers and PTLDS individuals to be taken advantage of and they may lose money due to a scheme, which inherently leads to increased financial burden and concern.

Caregiver Mental Health

As outlined above, previous research has demonstrated that caregivers of all kinds experience mental health issues at a greater rate than those who are not caregiving for someone. One of the primary goals of this research study was to explore how caregivers of PTLDS were experiencing their mental health. While the participants’ responses varied across ranges on the anxiety and depression measure, the average of the study sample was in the moderately severe range. Given the correlations between lower quality of life and anxiety and depression, the results suggest that lower quality of life is associated with more symptoms of anxiety and depression. This may also be explained by the fact that their loved one has been diagnosed with a chronic illness. However, it should be stated that there is a high degree of overlap between the CQOLL and the PHQ-ADS. They were both highly correlated and tap similar constructs. Lower quality of life was more significantly associated with depression versus anxiety symptoms

The results of this lend support to the findings of Pinquart and Sorensen (2003) in confirming that caregivers experience a variety of pathological symptoms in response to their caregiving duties. Given the small sample size in this study, it proves challenging to generalize the results. However, the results seem to suggest that caregiver burden is experienced at a high rate for PTLDS caregivers and as such, future studies should focus on large sampling and comparing the results to caregivers of other chronic illnesses. Additionally, further research is needed to establish appropriate interventions (psychoeducation, personal therapy, etc.) surrounding the burdens for the PTLDS caregiver.

Invalidation

There are significant repercussions for individuals experiencing medical invalidation. As Lobo and colleagues (2014) highlighted, validation proves to be significantly vital to the patient experience, quality of life, and recovery. It was reasoned that invalidation of a condition would also extend to the caregiver mental health and burden. Overall, caregivers of the survey reported experiencing a moderate level of invalidation and experienced both discounting and lack of understanding at similar levels. However, contrary to the hypothesized association, invalidation was not found to be associated with overall caregiver burden or mental health. One of the explanations—discussed in the limitations section—for this might be lack of clarity regarding when in the history of the diagnosis they experienced invalidation. Additionally, given that the vast majority of participants were white women from middle-upper socioeconomic means, it may be that they were more likely to be believed and supported (referred to specialists, medical labs, etc.), and thus not invalidated by their medical provider. Another possibility is that the low variability of invalidation in this small sample limited the ability to detect any correlation that might exist. Finally, another reason for this outcome could be due to the general geographic profile of the participants. Lyme disease originated in Connecticut and the primary Instagram account used to recruit participants was also based out of Connecticut. This could indicate that the location in which the participants live make it more likely that the symptoms of PTLDS would be identified, thus resulting in a diagnosis and consequently less likelihood of invalidation.

As mentioned above, another possibility is that the results were muddied by a lack of clarity in the wording of the survey. The instructions for the 3*I asked participants to “rate the frequency (‘Never’ to ‘Very Often’) of their experience with the statements provided.” Upon reflection, it would have been prudent to specify at which point in their experience from which they should be responding to the statements. For example, the level of invalidation experienced before a PTLDS diagnosis would most likely be greater than after receiving the PTLDS diagnosis as having the diagnosis is validation. As a result, the responses to this section may not reflect that rate at which PTLDS caregivers experienced invalidation and whether that invalidation contributed to their overall burden and mental health. Finally, it should be noted that it was hypothesized that invalidation by medical providers would be an issue for PTLDS caregivers, and these results may reflect that diagnosis mitigates invalidation, or that invalidation is not experienced by PTLDS caregivers in this sample.

Implications

The primary clinical implications of this study include expanded knowledge on the most significant burdens for PTLDS caregivers. In the past, studies have looked at the experience of caregivers of other chronic illnesses, but no studies have looked at the experience of the PTLDS caregivers specifically as in the current study. Knowing that the most significant burdens regard the mental toll of caregiving PTLDS individuals will aid medical professionals in recommending resources such as therapy and support groups to the caregivers. Further support for mental health treatment is evidenced by the anxiety and depression reported.

While the results of the invalidation inventory were not correlated with other measures as hypothesized, caregivers still reported invalidation surrounding the diagnosis of their loved one. Medical professionals must be aware of the impact of illness invalidation on patients and the potential impact it could have on caregivers. Medical professionals must choose their language carefully as to not imply lack of belief or discount information being given to them by the PTLDS patient and their caregiver. This study continues to emphasize the importance of considering the needs of caregivers, their burden and mental health. However, despite these implications, the study was not without limitations.

Limitations

This study was subject to limiting factors that were both sociocultural due to the timing of data collection, as well as specific limitations of study design and dissemination. The size of the sample was also a limiting factor as it was too small and homogeneous to be generalizable to other populations. Additionally, the household income for the sample was above average and as such, the results may not fully represent how finances affect burden, mental health, access to care, and invalidation. Furthermore, the lack of diversity in this study made it difficult to highlight specific struggles minorities may face when seeking access to healthcare. Research has shown that when visiting doctors, racial minorities are met more frequently with disbelief and passiveness than white patients (Armstrong et al., 2007). As mentioned above, the various symptoms of PTLDS may require patients to see a variety of specialists before the diagnosis is identified. This not only limits the care they receive, but also has the potential to increase experiences of invalidation.

Another limitation was the wording in the illness invalidation inventory made it unclear as to which time frame the participants were responding. More specific language regarding the timing of the experience of invalidation could have had an impact on the results. After several weeks of trying to recruit participants, it was brought to my attention that the term PTLDS was looked upon negatively in the Lyme community and it was suggested that I use the term “chronic Lyme disease” instead. This oversight caused the survey to be rejected by some accounts that have thousands of followers and may have caused the study to lose otherwise willing participants. Furthermore, dozens of support groups, online message boards, and other such groups were contacted using the term PTLDS and there were no responses to the study. It is unclear if using the term “chronic Lyme disease” instead would have had different results or garnered additional participation. Taking this note and making the appropriate edits in the survey opened the door for participants to feel safe completing the survey.

As mentioned above, while the original measures were proven to have reliability and validity, another limitation within this study lies in having to adapt them. Given this information, the degree to which adaptation invalidated the measures in this study is unclear. While Cronbach's alpha on the current sample showed a high internal consistency, the measures were not intended for or normed on PTLDS caregivers. An additional limitation of this study occurred in the way the data was analyzed. Multiple correlations between major variables and subscales were run, which increased the likelihood of family-wise errors and error rates may have been inflated.

Finally, data collection occurred during the COVID-19 pandemic and may have had an impact the results. First, the conditions of the pandemic made it challenging to use any other methods of collecting data other than the internet. The isolated networking could have resulted in the homogenous sample. Secondly, the collective trauma experienced during the pandemic may have increased levels of anxiety and depression that was reflected in the participants. While the survey did ask them about their mental health symptoms in relation to caregiving, it perhaps could have been challenging for parents to identify the origin of their symptoms. Similarly, parents across the country were experiencing harrowing caregiver burdens and increased financial strain in response to schools closing and not being able to work. As such, the levels of burden and financial concern being reported may have been influenced by this increased demand. Additionally, the original dissemination process for this survey was affected by the pandemic and therefore limited the already marginal population even more.

Future Directions

Future directions for research include continuing to explore the specific burdens of the PTLDS caregiver and the impact that caregiving has on their mental health. Further exploration of specific interventions to target improving caregiver mental health and quality of life is warranted. While this study was quantitative in nature, a future qualitative study would allow for the identification of common burden themes of PTLDS caregivers. Future directions for research should also include exploring the differences between various caregiver relationships (parent–child, spouse–spouse, etc.) and how the experience among those relationships is similar or different. This research could also examine the gender differences in the experience of caregiving for PTLDS. This would help differentiate those burdens that are significant to PTLDS caregivers in general and those that are significant to the specific caregiving relationship.

Future research should also include more detailed examinations about invalidation before the PTLDS diagnosis and how that impacts caregiver burden and mental health and how, if at all, the diagnosis improved functioning in those areas. Additionally, the groundbreaking project coming out of Johns Hopkins may make PTLDS invalidation a thing of the past and future research could look at caregiver mental health and burden before and after the diagnostic procedure. Finally, future studies should include larger sample sizes and include more diversity in areas of gender, ethnicity, and income.

Conclusion

With Lyme disease on the rise in the United States, it seems likely that incidences of PTLDS will increase as well. Given the debilitating symptoms of PTLDS on the individual, it is imperative that we consider the implications of the symptoms on the PTLDS caregiver. The results from this small sample seem to indicate that there is significant caregiver burden as well as intense anxiety and depression symptoms experienced by the PTLDS caregiver. Given the future positive direction of diagnosing PTLDS coming out of Johns Hopkins University, it seems likely that invalidation will be experienced less among patients and caregivers. Implications of future research could include providing psychoeducation to PTLDS caregivers, as well as access to resources to ease burden and alleviate mental health symptoms. Caregiver burden involves a cost to society and the individual that could be mitigated if resources were available from the outset.

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Appendix A: Demographic Information

What is your current age? __________

What is your racial/ethnic background? (check all that apply)

☐American Indian/Alaska Native ☐East Asian ☐South Asian ☐Black or African American ☐Hispanic or Latinx ☐Native Hawaiian or other Pacific Islander ☐ White/European Descent ☐Middle Eastern/North African ☐Biracial ☐Multiracial ☐Another:__________

What is your gender identity? (check all that apply)

☐Male ☐Female ☐Genderqueer ☐Non-Binary ☐Genderfluid ☐Two-spirit ☐Pangender ☐Queer ☐Trans ☐Prefer not to say ☐Another:__________

What is your sexual identity/sexual orientation?

☐Heterosexual ☐Gay ☐Lesbian ☐Bisexual ☐Pansexual ☐Queer ☐Asexual/Ace Spectrum ☐Unsure/Prefer Not to say ☐Another:___________

What is your marital status?

☐Married ☐Single (never married) ☐Divorced or Separated ☐In a domestic partnership ☐Widowed

What is your highest level of education?

☐Less than a high school diploma ☐High school degree or equivalent ☐Bachelor’s degree (BA, BS) ☐Master’s degree (e.g. MA, MS, Med, etc.) ☐Doctorate (e.g. PhD, EdD, etc.) ☐Another:__________

What was your employment status before Lyme diagnosis?

☐Employed full-time (40+ hours a week) ☐Employed part-time (less than 40 hours a week) ☐Unemployed (was looking for work) ☐Unemployed (was not looking for work) ☐Student ☐Retired ☐Self-employed ☐Unable to work: Explain___________________

What is your current employment status?

☐Employed full-time (40+ hours a week) ☐Employed part-time (less than 40 hours a week) ☐Unemployed (was looking for work) ☐Unemployed (was not looking for work) ☐Student ☐Retired ☐Self-employed ☐Unable to work: Explain___________________

What is your household income? ___________

What is the current age of the person you are caring for? __________

What is your relationship to the patient? __________

Do you have caregiving help?

☐No ☐Yes

If yes, who is helping you?

☐Spouse ☐Co-parent ☐Grandparent ☐Other family member: __________ ☐Domestic worker ☐Healthcare professional ☐Another:__________

On average, how many hours per week do you spend caregiving?

☐Less than 5 ☐5-10 ☐10-15 ☐15-20 ☐20-25 ☐25-30 ☐Over 30

Appendix B: Tables

Table B1

Demographic Characteristics

Gender	**Percent (%)**	**Count**
Female	100%	30
Sexuality		
Heterosexual	100%	30
Racial/Ethnic Background		
White/European Descent	93.3%	28
Hispanic/Latinx	3.3%	1
Prefer not to say	3.3%	1
Marital Status		
Married	73.3%	22
Single (never married)	3.3%	1
Divorced or separated	16.7%	5
In a domestic partnership	6.7%	2
Age		
20-29	3%	1
30-49	57%	17
50-72	40%	12
Yearly Household Income		
Less than $20,000	7.1%	2
$20,000-$34,999	3.6%	1
$35,000-$49,999	7.1%	2
$50,000-$74,999	14.3%	4
$75,000-$99,999	14.3%	4
$100,000-$149,999	32.1%	9
$150,000-$199,999	10.7	3
$200,000 or more	10.7	3
Employment Status Before Caregiving		
Employed full-time (40+)	36.7%	11
Employed part-time (<40)	20%	6

Unemployed (not looking for work)	10%	3
Retired	6.7%	2
Self-employed	23.3%	7
Unable to work	3.3%	1
Employment Status Before Caregiving		
Employed full-time (40+)	26.7%	8
Employed part-time (<40)	20%	6
Unemployed (not looking for work)	6.7%	2
Retired	10%	3
Self-employed	16.6%	5
Unable to work	20%	6
Average Hours Spent Caregiving		
Less than 5	20%	6
5-10	6.7%	2
11-15	10%	3
16-20	13.3%	4
21-25	6.7%	2
25-30	10%	3
Over 30	33.3%	10
Total	100%	30

Table B2

Descriptive Statistics for CQOLL Item Averages in Descending Order

	N	Minimum	Maximum	Mean	Std. Deviation
1. It upsets me to see my loved one deteriorate.	30	2	5	4.53	.82
2. My level of stress and worries has increased.	30	1	5	4.27	1.20
3. REI have more of a positive outlook on life since my loved one's illness.	30	1	5	4.07	1.44
4. I feel frustrated.	30	1	5	3.80	1.35
5. REI am satisfied with the support I get from my family.	30	2	5	3.80	1.06
6. I feel under increased mental strain.	30	1	5	3.70	1.34
7. I fear the adverse effects of treatment on my loved one.	30	1	5	3.70	1.34
8. REI am satisfied with my sex life.	30	1	5	3.63	1.49
9. The need to manage my loved one's pain is overwhelming.	30	1	5	3.53	1.36
10. REFamily communication has increased.	30	1	5	3.53	1.43
11. I worry about the impact my loved one's illness has had on my children or other family members.	30	1	5	3.50	1.36
12. I am under a financial strain.	30	1	5	3.47	1.57
13. REI get support from my friends and neighbors.	30	1	5	3.47	1.31
14. I feel sad.	30	1	5	3.47	1.28
15. I feel nervous.	30	1	5	3.43	1.35
16. It is challenging to maintain my outside interests.	30	1	5	3.40	1.19

	N	Minimum	Maximum	Mean	Std. Deviation
17. I am concerned about our insurance coverage.	30	1	5	3.37	1.69
18. REMy sense of spirituality has increased.	30	1	5	3.33	1.67
19. My economic future is uncertain.	30	1	5	3.23	1.65
20. The responsibility I have for my loved one’s care at home is overwhelming.	30	1	5	3.23	1.48
21. REI feel validated by my loved one’s healthcare provider.	30	1	5	3.23	1.63
22. I am discouraged about the future.	30	1	5	3.13	1.33
23. My sleep is less restful.	30	1	5	3.13	1.25
24. I feel guilty.	30	1	5	3.07	1.53
25. It bothers me, limiting my focus to day-to-day.	30	1	5	3.07	1.23
26. My daily life is imposed upon.	30	1	5	3.00	1.46
27. REI feel adequately informed about my loved one’s illness.	30	1	5	2.87	1.58
28. It bothers me that other family members have not shown interest in taking care of my loved one.	30	1	5	2.77	1.52
29. I have difficulty dealing with my loved one’s changing eating habits.	30	1	5	2.53	1.36
30. It bothers me that my daily routine is altered.	30	1	5	2.53	1.17
31. REI have developed a close relationship with my loved one.	30	1	5	2.47	1.33
32. REI am glad that my focus is on getting my loved one well.	30	1	5	2.27	1.28
33. It bothers me that my priorities have changed.	30	1	5	2.17	1.34
34. The need to protect my loved one bothers me.	30	1	5	1.47	1.29

	N	Minimum	Maximum	Mean	Std. Deviation
35. It bothers me that I need to be available to drive my loved one to appointments.	30	1	4	1.47	.900
Valid N (listwise)	30				

Note: This table lists the most significant burdens for PTLDS caregivers. RE items have been recoded

Table B3

Correlation Matrix Displaying Correlations Between all Major Variables

Variable	n	M	SD	1	2	3	4
1.Horowitz Lyme-MSIDS	30	86.60	19.16	-			
2.CQOLL	30	109.37	22.50	.255	-		
3.PHQ-ADS	30	23.53	11.66	.313	.531**	-	
4.3*I	30	26.20	7.49	.446	.376	.342	-

Note. ** significant at the 0.01 level